

**A DECONSTRUCTION OF DISABILITY DISCOURSE AMONGST CHRISTIANS IN  
LESOTHO**

**by**

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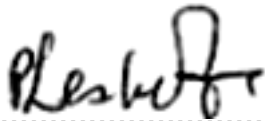
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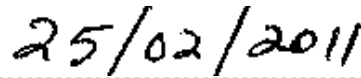
**FEBRUARY 2011**

I declare that ***A Deconstruction of Disability Discourse Amongst Christians in Lesotho*** is my own work and that all the sources I have used or quoted have been indicated or acknowledged by means of complete references.



.....  
Signature

(MR P L LESHOTA)



.....  
Date

Signed at Roma, Lesotho

## ACKNOWLEDGEMENTS

Thanking is part of the process that started with a request which is now granted. When this research journey started many requests were made and its now time to acknowledge and thank those who made their granting possible.

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## SUMMARY

The present research study is a deconstructive collaborative project situated within a postmodern paradigm. The research is premised on a notion that disability has been constructed by societies to reflect their values and norms. Despite various ancient and contemporary worldviews stabilising this normative paradigm, disability has remained a shifting and fleeting concept. For the most part, it has cast the disabled identity in more negative and alienating ways than positive.

The Christian cultural context of Lesotho within which the study is situated has not done any better in terms of portraying people with disabilities. Instead, it has inherited the legacy of the ancient Mediterranean world and further re-read it in the light of the demands of contemporary society on the disabled identity. For instance, people with disabilities are still constructed as 'sinners', 'monsters', 'add-ons', and pathological burdens who cannot by themselves survive the challenges of the contemporary world.

Using the ideas of Foucault and Derrida, the study examines ways in which such a notion of disability is not only linguistically unstable but also founded on the binary opposites. The participatory nature of the study brings the important voices of people with disabilities to further destabilise the notion of disability and to deconstruct the dominant disability story. The immersion of this study within the participatory ethics and consciousness of Kotzé and Heshusius respectively, has led to an ambitious proposing of the participatory model of disability. The latter has leanings towards metaphors of the church as communion founded on and nurtured by the theologies of embrace, interdependence, healing and *botho*. It also resonates with the metaphor of the church as expounded in I Corinthians 12. As members of the body of Christ, no member can suffer without the rest of the body feeling the same. If one member of the body is disabled all the body is disabled. Alienating and marginalising others has no place in such a metaphor of church as communion, since by its own definition, all belong to and participate within it.

**Key terms:** Deconstruction; participatory model of disability; communion; disability; social construction discourse; postmodern epistemology; contextual practical theology; Christian cultural narratives; participatory ethics; reflexivity.

## ABBREVIATIONS USED IN THIS THESIS

CBR	Community Based Rehabilitation
DNDRP	Draft National Disability and Rehabilitation Policy
DPOs	Disabled People's Organisation
EFA	Education for All
ICF	International Classification of Functioning
ITD	Institute for Therapeutic Development
LNFOOD	Lesotho National Federation of Organisations of Disabled
MOET	Ministry of Education and Training
MOHSW	Ministry of Health and Social welfare
NGOs	Non-Governmental Organisations
OVCs	Orphaned and Vulnerable Children
PWDs	People with Disabilities
SEU	Special Education Unit
SNE	Special Needs Education
UNESCO	United Nations educational Scientific and Cultural Organisation
WHO	World Health Organisation

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## CHAPTER 1

### STEPPING OUT INTO A JOURNEY WITH DISABILITIES

The hardest thing to do is to step out of what you are comfortable with. The unknown is always there once you step out. Then you have to take everything that comes at you. You have to answer for yourself and that's how you learn.

(Gerald Debbink)

#### 1.1 INTRODUCTION

This research is not *about* people. It is not *for* people. It is a research journey *with* people, with people whose bodies have been branded 'disabled'. Nor is this branding an innocent act. According to Galvin (2003:152), branding, labelling or naming connects the sense of self with society's definition. It is a political act which expresses strong views, in this case about what makes up a body, which bodies are valued and which ones are not (Berquist 2002:6). It is also a performance of language which informs and persuades people to read meanings into bodies, because societies attach meanings to bodies (Berquist 2002:18). They develop ideas around the body and each part of it, its appearance, weight and height, such that it eventually becomes a social product.

Though none of the meanings attached may be inherently part of the body's weight, height or appearance, societies are not deterred from attaching certain meanings to the said bodily qualities. This has been referred to as 'social or cultural construction' of the body (Berquist 2002:18; Viviers 2005a:799; 2005b:879), and it is a body that has been scripted, institutionalised and legitimated (Berger & Luckmann 1966:58-60) by adherents of that society to convey meaning. The adherents are in turn shaped by meanings attached to that body and its parts. It is in this sense that the body is understood as a social script onto and into which are written society's values (Viviers 2005:799; Vorster 2002:21). The societal values and meanings attached to the body are at the heart of the connection between discourse, language and power (Galvin 2003:156).

Some Hebrew Bible and New Testament texts, longstanding Christian traditions that have made inroads into laws and regulations governing Christian as well as secular societies and cultures, have connived to demonise disability and people with it (Wilke 2003:12-13). The result is an established hegemonic tradition that manifests itself, even today, in oppressive and marginalising tendencies against people with disabilities who are seen as objects of pity



and charity mission, or as accidents and cases for fixing or healing. Lane (1999:2) wrote candidly of this concern:

The normative tradition of our culture, and by extension much of the Church, is that one should be white, male, wealthy, educated, able-bodied, and able-minded. Consequently people without disabilities are not expected to accept the reality of disability in others, nor the possibility that it will probably affect them personally. Those within the Church who have attempted to do a ministry around the issues of disability are constantly inundated with reminders of more pressing needs of oppressed groups, and that disability is not an issue.

The theologians in the church, both male and female, educated, able-bodied, and able-minded, have found no urgency in addressing the issue of disability as seriously as they have addressed themselves to other issues of critical theological concern, such as sexism, racism and homophobia (Lane 1995:12). The presence of people with disability in Church and in society has, as a result, become a mocking counter-gaze (Ngwane 1994:118) to the portrait the church has carved for itself as voice of the voiceless and the place of inclusion. These observations are a clear indication of how, sometimes, discourse shapes relations between people in very profound but negative ways.

Even more problematic is that while state institutions are, in earnest, addressing themselves to the rights of people with disabilities, the church is seriously courting what Chitando (2008) refers to as 'ambulance theology', that is arriving after an accident has taken place to pick up casualties. In this analogy, the church responds energetically *after* a crisis, thus not only failing to become the voice of the voiceless but also neglecting to provide a platform to people with disabilities.

The above considerations together with what follows in the next section illustrate my motivation for becoming involved in this participatory project with people with disabilities,

## **1.2 INSPIRATION TO THE RESEARCH: A CALL TO GO**

In 2007, during the course of the practical component of the doctoral programme at the Institute for Therapeutic Development (ITD), in Pretoria, South Africa, other students and I had occasion to interact with learners with visual impairment at St. Catherine's High School in Lesotho. This occasion reconnected me to my earlier experiences with students with visual and mobility impairment at the National University of Lesotho, where I teach. With hindsight, I was able to recall how, during my brief sojourn as a Parish Priest at Mount Royal Church in Leribe, I had as regular attendants at Mass a group of learners with hearing and

speech impairment, and who would only miss Mass on Sundays for exceptional reasons. These experiences might have easily come and gone without leaving a mark.

### **1.3 THE MOMENT OF INSERTION**

It was not until one cold Sunday morning, when the church was half-empty and this congregation were the only group inside, with one identity marker of disability, that I became *aware*. It was indeed a 'moment of insertion', described by Cochrane, de Gruchy and Petersen (1991:17) as coming face-to-face with a critical issue which, though one encounters it every day, takes on a new dimension when related to oppression.

I became aware of the presence of people with disability in worship, and that I was not aware of my inability, or disability, to recognize their eloquent presence. I became aware that I, unawares, had become a bystander and a perpetrator of their marginalization, silence and invisibility (Weingarten 2000:55). In dialogue with myself I became aware of the different orders of silence that may have characterized our interactions. I needed what Maluleke (1997:330) refers to as 'silence and absence analysis', for I was "possibly going through a time of interesting, varied and pregnant silences and absences." Was my silence of the same order as that of the learners? Was mine a silence of power or silence of helplessness? Was theirs a silence of power or powerlessness? To what extent were these silences connected to our different social location and material conditions? (Maluleke 1997:331). This moment of insertion brought me face-to-face with discourses and practices that called for accountability and transformative relationships within my own ministry (Kotze & Kotze 2001:3).

At all these, I felt a sense of guilt and shame for having imposed on these learners, who were so eloquent by their presence, silence and absence through which they were, paradoxically, so present. Being a member of the board of the school and a parish priest could only help to compound my guilt. I thought to myself "I could have advised better the diocesan liturgical commission to earmark a Sunday or a month to raise awareness on disability and people with disabilities in church and in society." Still, I was caught up in the paradigm of disability as a mission for charity (Eiesland 1994:75; Lane 1995:31), grounded in modernist and positivistic tendencies and categorization of people as objects. Though people with disability were always there, they did not count for me a thing to be grasped. Though physically they were so eloquently present at Mass every Sunday, they were not present in my mind.

In dialogue with myself, I also became aware that I was a victim of the knowledge claims that I entertained, and their indispensability. These claims not only promoted self-other distinction but also, in very subtle ways, finalized both myself and the other. According to Bakhtin (1984:58), to finalize is to hopelessly determine and finish off a person, as if he or she were already dead. In dialogical relations finalisation of the other is an anomaly.

The particularity of this experience bade me to ask questions: How could I for so many years fail to see or witness a reality of disability and people with disabilities that looked at me so glaringly in the eyes? What conditions facilitated the thriving of this apathy? Could I also be classified among those who have eyes but do not see; those who have ears but cannot hear; those who have a mouth but cannot speak? Is there a sense, therefore, that I could also be called a person with disability? Is disability a loss of some function, a reference to some defect of the body or is it about the environment, attitudes and behaviours of the society one inhabits? How does the Church and society perceive people with disabilities? Are these perceptions incapacitating or life-giving? Are there ways in which one can re-author stories around disability and people with disabilities without excluding or marginalising the other voices? (Kotze 2002:ix).

It is in this context that a strong desire to undertake a journey with people with disabilities emerged, precipitating a break with my initial research topic, an exploration and deconstruction of hegemonic male headship, which I was on the verge of finalising. The desire was so strong that I could not resist it. It was indeed a call to go. Therefore, it was against the background of these meanings and connections, this research journey took place, seeking to understand the complex conditions within which bodies were and are constructed, institutionalised and legitimated by society as normal and abnormal; whole and unwhole; abled and disabled. In what Derrida (in Powell 1997:29-30) would call a play of binaries, the research interrogates the reasons for the marginalization of one term, usually the second, in the binary continuum. Within the same Derridaean paradigm, the research looks for ways of “good reading” which reveal and name the centres for what they are. They subvert the central terms, challenge the oppressive and dominant discourses and co-construct alternative discourses (Anderson 1995:31).

## 1.4 PILLAR OF CLOUD: RESEARCH QUESTION

Reflections on my ministerial practices and their context triggered in my mind the following questions:

- Under what conditions do we become witnesses of knowledge claims or ideologies that promote self-other distinctions?
- How do these knowledge claims assume truth status that privileges some voices and marginalise and oppress others?
- In what ways does language become an instrument of power and knowledge that serves to subjugate some voices that lie outside the realm of dominant discourse?
- How have traditional theologies and cultural narratives connived to alienate people with disabilities from participating meaningfully in society and in church?
- How can a participatory deconstruction of the dominant disability discourses be effected to bring healing to persons on both sides of the disability discourse divide?
- How can Christian and cultural stories facilitate alternative ways of re-storying and re-authoring relations with people with disabilities?

The initial response to these questions, which in turn forms the hypothesis of this research, was that discourses around the body are socially constructed in interaction with others. Through them the body becomes typified, institutionalised and legitimated. These discourses, within which and by which body is constructed, can therefore be evacuated without necessarily compromising either one's alleged identity or undermining the order which modernism tried to create. Guided by these questions and the resultant hypothesis, I formulated the following question that would guide this research:

*How can the participatory deconstruction of the dominant, constrictive and incapacitating Christian cultural stories on disability be effected to offer possibilities for re-storying and re-authoring ways of relating with people with disabilities in Lesotho?*

Guided by the metaphor of a journey of Israel from Egypt, I evoke the role and function of the cloud as explained in Ex 40:34-38 and Nm 9:15-23. It determined Israel's movement and moved in front of the people as a guide. Its presence, at day and at night, demanded Israel's constant attention. This presence would take the form of a cloud during the day and that of

fire during the night. These became the two different manifestations of the same presence. In a similar manner, this research question will guide every step of the journey, determining its direction, as without and outside its promptings there would be much aimless and purposeless wandering.

## **1.5 PILLAR OF FIRE: RESEARCH AIMS**

Informed by the above research question, the following aims will also give direction to the research.

Firstly, I aim to show how societies, including the Christian church, have always been responsible for the construction of the body in general and the disabled body in particular, and to expose the politics of power within the disability discourse. As discussed above, bodies are products of societies, which construct discourses about and around them (Berquist 2003:3) and attach meanings to them. The basic assumption is that these meanings can only make sense if read in the light of the discourses, which serve as their frame of reference (Burr 2003:66). As Webb-Mitchell (1996:38) observes, societies change in terms of what they value. Not only do they adopt different labels and categories, they also attach meanings to them. I argue that the body becomes a major focus of power relations, subjected by those who believe they have the right to decide how a person shall be labelled to often inferior classification and definition (Valentine 2002:215).

Secondly, through participation and collaboration with people with disabilities, I examine closely the machinations of the dominant disability discourses and their effects on people on both sides of the disability divide within the Christian and cultural context of Lesotho.

Thirdly, with the assistance of the research participants, I aim to deconstruct themes of oppression inherent in the dominant disability discourses, and propose an alternative pastoral disability narrative that is more inclusive, relational, responsible and accountable.

Just as the pillar of cloud and the pillar of fire guided the people – in their journey – during the day and during the night respectively, the research question and aims will guide and provide direction to this, our research journey.

## **1.6 MOTIVATION FOR THE STUDY**

The silence that defined my relationships with people with disabilities extended beyond the walls of the church to the academic field. Confounding my expectations, a search for literature on disabilities and people with them, with specific focus on Lesotho and the field of

theology in the country, revealed very little. My wish to close this gap in the research was reinforced by developments within the Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly in December 2006. Having opened for signatures on 30 March 2007, by 30 April 2008 the Convention had received its 20<sup>th</sup> ratification, whereupon it came into force. Signing the Convention was the first step to becoming a party to it, whilst ratification signalled the intention to undertake obligations enshrined in it, notably to promote and protect the rights of persons with disabilities. Lesotho's accession to the Convention on 2 December 2008 had the same legal effect as ratification, applicable from the beginning of 2009. However, at the time of writing, Lesotho is yet to sign the optional protocol, a separate document that enables individuals to seek redress after convention violations.

However, in the light of experiences recorded by Mandesi (2006:1), implementation of these convention is yet to improve the lives of the people for whom they were intended. It is also the case that in most developing countries intention has not always matched execution, due in part to a perceived lethargy that could be indicative of two things: a) the issue is not an urgent matter; b) the state's machinery is not geared to responding in time to issues of concern to its citizens. This has to be measured against the number of people with disabilities, opportunities available to them and the resultant quality of their lives. The Lesotho Demographic Survey of 2001 put the number of people with disabilities at approximately 4.2 percent of the total population of 2.2 million people. This, however, may not necessarily be a true reflection of the situation, given the subjective nature of the information provided by the respondents with respect to "their perception, understanding and reporting of what they thought constituted disability" (Lesotho Demographic Survey 2001:291).

The commitment of some Christian denominations in Lesotho to the plight of people with disabilities is strong in the area of care and education, and having been pioneers in this field they also boast the highest number of homes and schools for them in the country. However, reading this within the larger picture of the church's mission and nature, one realizes how far the churches still have to go before they become welcoming and inclusive churches. In many of the churches in Lesotho if not all, people with disabilities are not only physically excluded but they are also psychologically and spiritually alienated from participation in the fullness of life in the faith community (Steele 1994:40). In Lesotho, as elsewhere, the churches have adopted many or all of society's prejudices against people with disabilities.

These considerations have further intensified my resolve to journey with people with disabilities with a view to making our voice heard.

## 1.7 THE 'I' AND 'WE' IN THIS RESEARCH

How, then, do we write ourselves into our texts  
with intellectual and spiritual integrity? How do  
we nurture our own voices, our own  
individualities, and the same time lay claim to  
"knowing" something?

(Laurel Richardson, *Fields of Play*)

There is a deliberate use, in this research, of the first person, personal pronoun, 'I'. and its plural 'we'. The use of 'I' braves the long-standing marginalization of the researcher's voice, in research, with its 'baggage' of feelings, experiences as well as vulnerabilities. It is attuned to the participatory and relational nature of this research which bids us, author and readers, to take the voice of the researcher, 'my voice', as seriously as we take those of the co-researchers. In participatory and dialogic research, both researcher and participant 'come together in some shared time and space and have diverse effects on each other' (Frank 2005:968). This coming together is possible where bonds of given identities and rigid connections between bodies and subjectivities give way to relationality that blurs "the boundaries between self and other" (Heshusius & Ballard 1996:172).

The use of the 'I' allows for and points to "the immersion of the researcher in the research process, not as a separate researcher but as a fellow traveller along with other participants" (Hess 2006:25). The choice of the 'I' and 'we' also underlines what Wolgemuth and Donohue (2006:1033) call the 'ethic of friendship', which paradoxically achieves discomfort through comfort, and within which, "both participant and researcher feel comfortable to share their beliefs, assumptions, and vulnerabilities". This comfort in turn provides an opportunity to experience the discomfort of opening up one's soul to others and making oneself vulnerable publicly (Aglin 1996:22).

It is within this discomfort and the inhabiting of the ambiguous and flexible subjectivities that the familiar, the fixed beliefs and assumptions are interrogated. This interrogation leads to what Boler (1999:197) calls a "greater sense of connection, a fuller sense of meaning, and in the end a greater sense of 'comfort' with who we have chosen to be and how we act in our lives." Writing in the 3<sup>rd</sup> person hides the 'I' and the 'I' hides behind the 3<sup>rd</sup> person, the

researcher. The 3<sup>rd</sup> person says 'it is not me'. (Kotzé 2009). We know the 1<sup>st</sup> person is there but we cannot hear its voice.

In using the 'I' I am also taking up a political and ethical stance. The previously marginalized voice of the 'I' in the text is considered, while at the same time setting one's eyes on the dynamics of power at play in the context of this research. The questions of whose values are being served and who benefits from the interaction serve as a constant reminder of any commitment to the 'compassionate consciousness' of Harman (1988:15) and the 'passion' of Polanyi (1966:75-76), which bind and spur on, respectively, the researchers in their quest for the co-creation of embodied knowledge (Heshusius & Ballard 1996:3-9).

Doing participatory and dialogic research while keeping the participants locked up in their privacy would be an onslaught on what participatory consciousness stands for. The visibility of the researchers not only gives legitimacy to their voices, it also challenges us to take responsibility for the knowledge that such participation brings about (Kotze 2002:25-26). We know all too well that the creation of knowledge is fraught with political ramifications and practices of power. It evokes questions such as the following: Who decides what counts as knowledge? Who benefits from the creation of knowledge? Whose knowledge counts as knowledge? (Kotze 2002:6). I need to be constantly on my guard against privileging my voice over those of co-researchers. This is an ethical position on which this research is grounded.

The inclusion of the 'I' and 'we' further serves the purpose of making meaning of 'my stories' told in this chapter. Through these stories my identity that evades quantitative and objective measurements was shared and found resonance with other voices that will directly and indirectly inform struggles with my ambiguous and vulnerable identity. Through these stories, my journey, with its twists and turns, prepares me, albeit insufficiently, for the challenges of becoming a participant in another's story; a co-traveller in another's journey, which thus becomes "our" journey.

It is in this sense that I titled this part of the research 'A Journey within a Journey,' although since it is my journey within the journey *with* people with disability, perhaps it would be better to give it the title 'my journey within our journey.' As we journey together, the fault lines which previously characterised our relationship will hopefully give way to a fuller sense of meaning and a greater sense of comfort. This however can hardly be realised without a discomfort undergirding the ethic of friendship that should be a defining feature of our relationship and



collaboration throughout this journey. In this way, the tension between the use of 'I' and the 'we' becomes evident as a result of the journeying together.

The following sections relate the story of how I was recruited into the ideas espoused by the ITD. They also recount how inhabiting those ideas constantly challenged my previously held ideas of being and doing. It is to be noted that navigating through these possibilities has not been very smooth. The discomfort that went with this exercise is what living one's life with a measure of care, particularly the caring *with*, can be summarised as. It is embodied in that 'ethic of friendship' where comfort becomes a prerequisite for discomfort; where one's own vulnerabilities and weaknesses create space for a deeper and more articulated understanding of care, and which Heshusius and Ballard (1996:134) would describe as *awareness* of oneself "in the particulars of moment-to-moment living."

### **1.8 MY STORY: UNDER THE SPELL OF A FINALIZED INTELLECTUAL PERSON**

Any call presupposes a point from and to which one is called. My call came at a time when I thought I had made peace with the 'self' that I wished to inhabit. This self had become familiar and comfortable to relate with. Through this personal story I suggest with Boler (1999:197) that "to question the familiar may lead to greater sense of connection, a fuller sense of meaning, and in the end a greater sense of comfort with who we have chosen to be and how we act in our lives". This story also underlines the struggle and discomfort of having to relate, in different ways, with the 'baggage' that had for so long been part of my alleged identity. It further challenges me to "openness about the other's capacity to become someone other than whoever she or he already is" (Frank 2005:967).

After extended years of academic drilling and grilling I thought I was almost at the pinnacle of academic excellence. Reflecting on the books I had read and the conferences I had attended, I felt I was as good as the other participants. After four years of study in exegetical methods I thought I had all the tools for uncovering the truth, not only from the Biblical text but also from other texts. Two additional years of working for an MA in Practical Theology put me head and shoulders above the rest of my colleagues and prepared me well enough to deal with people's secrets and hurts. Over and above interpreting texts, I could also interpret people and their thoughts. After all these experiences I felt I was more than ready not only to teach but also to do counselling. I had certificates to display on the wall for those who wanted to know more about who I was and what I could do.

There was a glimmer of pride as I stood in front of a class to teach and to respond to almost every question without a grunt of doubt. I was the teacher, the one who knew and who had

control over what they should learn and how they should learn it. They, on the other hand, had a desire to know as much as I did, or so I thought. I taught them and conducted myself like the one who had authority. I had learned earlier that, at the university, instructors or teachers are called 'lecturers', that is, I was told, the one who lectures. It was impressed upon me that there was a difference between lecturing and teaching. It did not matter whether students understood or did not, my role was to lecture. I held the key to their becoming worthy students who could mix freely and rub shoulders with those who are learned. I was their point of reference for appropriate knowledge validation. Contrary to Bakhtin's unfinalized person (1984:58-59), I had been recruited into ways of thinking that there was a fixed academic person to which I and the students had to aspire.

The students' reward was to pass the end-of-year exam intended to determine their place in the official hierarchy of the school, occupation and community, and to help them to become part of the structure that had created them (Bauchspies 2000:246). In this way they were becoming, as Foucault (1977:28; 1982:221) would put it, the legacy of the technology of power/discipline. After some time they are configured to the teachers, through sharing in the teachers' corporate power and thus differentiated from others. The longer they stay within an educational system, the more recognition is conferred upon them. I was, unwittingly, still caught up in what Bakhtin (1984:59) calls a *monological* discourse. I had uttered the last word not only about myself but also about my students, who could not be more than representations of my academic voice.

## **1.9 STEPPING OUT OF MY PLACE OF COMFORT: A CALL AS *METANOIA***

This surety and certainty of being in almost total control was short lived. It was pronounced as only a shadow and a fleeting image of what I thought I knew by my association with the ITD and enrolment into its programme towards a PhD in Pastoral Therapy. My exposure to its epistemological, theological and narrative argument shook the foundations of knowledge which I had been building for the previous thirty years. My philosophical and theological training, which was predominantly scholastic, had been underpinned by a certain worldview and thought. I had been taught that the essence of being, with its properties of eternity, necessity, immutability, indivisibility and intelligibility, was the object of Ontology. Under Epistemology I was taught that truth was the correspondence between the mental idea and reality, and anything that fell outside the purview of this definition did not qualify as truth. The defining features of knowledge were certainty, objectivity, universality and unified system of knowledge. These were fixed and should be seen as common to all people. The dualistic tendencies, of matter – form, body – soul, light – darkness, heaven – hell, sin – righteous,

benign – malign, natural – supernatural, in keeping with the philosophical tendencies of the time, found their way, very subtly, into every theological discipline that I covered. This was to constitute the above-mentioned ‘baggage’ that I was to carry with me in my migration to a new land.

The idea of following a trend to embrace the ideas of Gergen, Heshusius, Ballard, Foucault and Derrida, among others, at the expense of the hard-earned scholastic knowledge claims, seemed to me an act of ‘intellectual suicide’. My mind was quickened by the attraction of social constructionism, post-structuralism and postmodernism, but my heart still submitted to the dictates of foundationalism. This transition was not very smooth, but rather was fraught with personal and intellectual conflicts that could be likened to a series of resistances that the people of Israel displayed in their journey out of Egypt (Ex 14:11-12; 15:24; 16:3; 17:1-2; 32:1-6). Arising largely from this analogy, the metaphor of a journey came to form a backdrop for the entire research. Smith and Winslade shared such sentiments regarding the complexities of journeying, and of shifting from one territory to another:

It also suggests the grief of separation, the company of fellow travelers, and the disorientation and confusion that can accompany being a stranger in a new land. As well as the performative aspects of making a journey, there are also the inner experiences that go with the journeying, the moments of reflection when we feel encouraged and full of enthusiasm or discouraged and tempted to turn back, or where we make sense of the episode we encounter along the way.

(Smith & Winslade 1997)

My journey or migration from either/or to both/and worlds, from positivist to interpretivist paradigms and beyond (Rhodes 1996:70; Heshusius & Ballard 1996) was an experience that can be explained in terms of an academic *metanoic* process, from the Greek word *Metanoia*, a change of mind and heart (see 7.4.1.3). This represents my experiences in evacuating the finalizability I had inhabited with consequences of sustaining Bakhtin’s (1984:59) *monological* discourse, and its claims to utter the last word about the person, in this case myself and others. The *metanoia* further evokes the metaphor of a journey, with its contingent nature, indecision, its liminality and uncertainty – of being caught between the point of separation and the point of incorporation. It is an experience that corroborates the words of Debbink (see 1.1) that underline the dilemma of stepping away from what one is comfortable with. Mine was an experience that could be likened to that of the conversion of Saul on his way to Damascus (Ac 9:1-22), in which he stepped out of his place of comfort and into the unknown, and which resembles in many ways the kind of feeling that overwhelmed me. It reflected a journey from one extreme to the other, from a herald of truth

of one kind to a herald of truth of another kind. It was a journey marked by tension, disappointment and uncertainty.

For Frank (2005:972), such a personal story “generates a sense of a social world, which, in turn, generates both typical conflicts that require dialogue and the conversational resources to engage in that dialogue”, and these conflicts constituted part of the ‘baggage’ that I once carried with pride. They have no way of escaping being part of the story that is, through relational dialogue, constructed anew, and therefore bid me to be continually conscious of my own struggles of becoming through this dialogical research process. Etherington (2004) argues cogently the “importance of ‘our awareness of the need to recognize and talk about the potential dilemmas raised by the research’ and our willingness to be transparent and to engage in dialogue.” These dilemmas bid me to assess what I have learned about myself in a dialogical relation with others.

#### **1.10 THE TITLE OF THIS RESEARCH**

A number of scholars influenced by the ‘narrative turn’ in social sciences, despite an assortment of perspectives, are generally agreed that the world is shaped by stories (Smith & Sparkes 2008:5). Not only are people constituted by stories but they in turn constitute those stories, relive and retell them in interaction with others. Shaped by the specific context of culture, place and time, the stories people inhabit hold sway over them and influence people to “ascribe certain meanings to particular life events and to treat others as relatively meaningless” (Freedman & Combs 1996:32). When these meanings represent or paint an event, a person or an object in a particular light, then they become a discourse (Burr 2003:64). Not only are these discourses produced by society but also the latter ascribes truth status to them. The discourses assume their role as instruments for the construction of norms around which persons are incited to shape or constitute their lives (White & Epston 1990:19).

Discourses assume the truth status and encourage people to see the world in a particular way. The world so represented produces knowledge which, according to Foucault (1977:27), cannot be separated from the power it produces and sustains. Knowledge and power then use language to further the aims of those who possess them, making it an instrument (Hall 1997:44) at the service of institutional and social practices. As Burr (2003:75) argued, discourses, power and knowledge go hand-in-hand, and are intimately connected to institutional and social practices. By determining what can and cannot be done or said; what is normal and what is abnormal; what is whole and what is unwhole, discourses assume the

truth status (Lowe 1991:41), the normalising effect (Parry & Doan 1994:56), the tyrannical nature (Gergen 1991:96) and the universalising tendencies (White 1997:222) which combine to marginalise and oppress.

The title of this research was phrased as *A Deconstruction of disability discourse Amongst Christians in Lesotho*. This title suggests a particular interest in how discourse around disability are socially scripted; how this discourse is sustained by institutional and social practices which feed on the prevailing knowledge that determines what disability is; who is disabled and who is not; and who determines who is disabled and who is not. I am particularly interested in how Christianity and culture shaped discourse around disability and under what conditions this discourse assumed truth status which privileged certain voices over others. Through Derrida's tool of deconstruction, I want to allow the emergence of the marginalised by subverting the original hierarchy of the privileged term 'able-bodied', over the marginalised term 'disabled'. I wish to allow the two terms of opposition to dance in a free play of non-hierarchical, non-stable meanings (Powell 1997:30). Together with the research participants, I attempted to subvert central terms in the dominant disability discourse so that alternative voices could emerge. A more detailed study of deconstruction will be made in Chapter 2.

### **1.11 THE CONTEXT OF THIS RESEARCH**

This research is situated within the Christian cultural context of Lesotho where a line of demarcation between what is Christian and what is cultural is blurred. It is in the light of this blurred boundary that I have titled this section a Christian cultural context. Ngwane (1994:114) explains that the missionary commission of Mt 28:19-20 was understood as a call for the church to give birth to a new humanity through conversion and formation of character. In many parts of Africa this would come to mean changes of name, and social and cultural identity, which were often attributed to ancient, heathen, evil and deficient ways (Schreier 1991:viii). In some cases it meant relocation to a mission station, which tallied with the *fuga mundi* (flight from the world). The missionary was at one with the colonisers in creating a new person in the image of Christian Europe (Ngwane 1994:116), but despite this assault on the African soul, African identity has stubbornly refused to disappear, resulting in what Homi Bhabha, following upon Lacan (quoted in Ngwane 1994:116), called the "emergence of native gentlemen and ladies, trapped in the expediency of 'mimicry'".

Both Christian and African identities have been carried with impunity by African Christians who, according to Ngwane (1994:116), find nothing wrong in "spraying the walls with treated

water while mumbling the names of the ancestors”, or “wearing Western designer clothes while the traditional ritualistic scars on their bodies are there for all to see”. More specifically, Lesotho was no exception to the efforts of the missionaries to “pull down the ancient scaffolding” on which the culture of the Basotho rested (Casalis 1861:302-303). The Basotho were, in their own way, able to negotiate and navigate with little trouble between these two realities, even at the expense of a temporary excommunication or penance imposed as a form of punishment for relapse into heathenism (Machobane 2001:127).

To date, the Basotho have embraced both Christianity and their own culture in a unique symbiotic relationship, such that there is hardly any Christian who is not in some way both a Christian and a Mosotho at the same time. This is, in a way understanding, interpreting and reinterpreting the message in a manner which, in very subtle ways, contradicts or even resists the colonising message of the church (Ngwane 1994:116). This reference to the Christian cultural context, therefore, is an attempt to underline the conflation between Christian and cultural narratives, which has resulted in what, for the purposes of this paper, I call ‘Lesotho Christian culture on disability’, with Christian and Sesotho discourses on disability interfacing with one another.

## **1.12 VOICES IN THE RESEARCH JOURNEY**

Any piece of work, whether oral or written, holds within it many voices and beliefs of people who have influenced the shape of that text in time and place. This research journey, too, holds within itself many voices, a brief synopsis of which I here outline. Firstly, there is the voice of the researcher, my voice, which represents my internal dialogue between what Martin (2007:53) calls different aspects of the self. My voice, like any other, carries contending voices, and in its every expression there is a crack. In every gesture that goes with it can be detected confidence and lack of confidence (Bakhtin 1984:30). Secondly, there are the voices of people with disabilities, and together we identify ways in which we become victims of disability knowledge claims with a view to seeking ways in which such claims can be deconstructed, such that they can bring healing to persons on both sides of the disability discourse divide. Alongside the participants is the Lesotho National Federation of Organisations of Disabled (LNFOD). Because of their immersion in the experiences of disability they continue to act as local informants, analogous in the metaphor to the travel agents or immigration consultants (Smith & Winslade 1997) in this journey.

Thirdly, I have, in consultation with the research participants, invited their parents and/or relatives/caregivers to story their experiences of living between Christian tradition and

culture on one side, and being a parent, caregiver or relative of a person with disability on the other. I have, in the same breadth, also invited pastors or priests who represent the voice of authority and the embodiment of disembodied theologies that tend to exclude and disempower, within their own churches. They have been invited to experience firsthand the conversations with research participants about their experiences of living with disability in the face of a Christian church that has for so long shared the negative perspective of disability. We are particularly interested in those pastors who minister to Congregations attended by the research participants. As Birch (2003:24) writes, people with disabilities live in every community where churches exercise ministry. Lastly, this research carries within it the voice of academia. It does not start from nothing, as much has been written on disability and theology, albeit not in Lesotho. The theoretical paradigms adopted in this research are a result of rigorous study and research, acknowledged and developed as framework throughout this research.

### **1.13 DISABILITY UNDER THE OPTIC OF POLITICS OF POWER AND KNOWLEDGE**

Foucault was *avant garde* in terms of exploring the previously unexplored and analyzing in new ways the dynamics of the relation between power and knowledge, and how these constitute truth claims that imprison, dehumanize and objectify people. His analysis of Western society revealed that people have been categorized into 'normal' and 'abnormal', and that such categorisation cuts the voices of those dubbed as 'abnormal' from the mainstream of polite discourse (Gutting 2005:84; Freedman and Combs 1996:38).

When in the late twentieth century, Michael White (1990; 1991; 1998) rose to prominence in the field of narrative therapy, he and others, particularly David Epston, integrated ideas of Foucault. In *Narrative Means to Therapeutic Ends* (1990) which White co-authored with Epston, they drew upon Foucault's analysis of history, developing ways of thinking and working that questioned the truth claims and power discourses that had long imprisoned people. A large number of people had, in the process of 'normalisation' of society, been disempowered and excluded from its discourses of power (Epston & White 1990:19). Through such discourses, what knowledge is held to be true, proper or right, is determined by society (Freedman & Combs 1996:38). Those who have leverage over the discourses that shape society have a control over power and knowledge, for in Foucault's (1980) view power is knowledge and vice versa. Language becomes an instrument of power and knowledge that serves to subjugate some voices that lie outside the realm of dominant discourses (Epston & White 1990:27).

The insurrection of these subjugated forms of knowledge (Foucault 1980:80) was of particular interest to Epston and White (1990), in that language, in the service of power and knowledge, shapes, expresses and represents the particular aspect of lives and relationships. These are fraught with “techniques of social control, ‘of subjugation’, ‘objectification’ or ‘thingification’ of bodies of persons”, and the authors’ therapeutic orientation was not only on guard against them but also encouraged the critique of their own practices (Epston & White 1990:24-29).

The above techniques of social control are clearly evident amongst in how people with disabilities are labelled, treated and constructed. Because labelling is not a neutral act it is sometimes used, particularly with people with disabilities, to separate, sequester and oppress (Freedman & Combs 1996:37), more so that the self is primarily a social construction crafted through linguistic exchanges with others (Harter 1999:677). Thus, the language of disability, like any other language, is constructed for purposes of representing and perpetuating certain systems of meaning (Galvin 2003a:160).

The last quarter of the twentieth century also saw what Foucault (1980:81-82) would call “an insurrection of subjugated knowledges”, reflected in the amount of literature written on a subject across a spectrum of disciplines (Pfeiffer et al. 2003:133). It is indeed within these subjugated knowledges that the potential for providing a voice resides (Galvin 2003:159), and it is within and through this insurrection that the dominant medical model which had, hitherto, been unchallenged, paved the way for more appealing perspectives of disability. This insurrection has further revealed the alternative histories which have in turn subverted the truth claims and allowed new discourses, which have been suppressed, to emerge.

The dominant histories had deified the medical model of disability that saw rehabilitation of the individual as the only solution to what was perceived as the physiological state of being incapacitated. They placed the blame on the individual rather than on society, the latter being responsible for the constructions of language and discourse through which disability had been typified, institutionalized, legitimated and reified (Berger & Luckmann 1966:58-89). In this, they connived with traditional theologies and cultural narratives to alienate people with disabilities from participation in the community and in the church (Lane 1992:9). One of the aims of this research is to expose and examine the politics of power within the disability discourse. As White (1990:15) would put it, “the examination of power politics amounts to preparing ground for the emergence of lived experience that lies outside the domain of the dominant stories that have marginalized and disempowered those lives”. These alternative histories point away from the individual to the society in need of rehabilitation.



## **1.14 RESEARCH PROCESS**

The moment of insertion brought me face-to-face with a critical issue which, though I encountered it every day, took on a new dimension when related to oppression. It made me aware, in a new way, of the presence and eloquence of people with disability in society and in church, in what Arthur Janos, (quoted in Brueggemann 1978:21) would have called “a primal scream that permits the beginning of history”.

From here this research journey was set in motion, as this ‘primal scream’ brought me into contact with six people who formed the basic participatory research group, together with their significant others and their pastors. I engaged with them through semi-structured interviews and reflexive conversations. The significant others and pastors were invited to experience firsthand conversations with research participants about their experience of living with disability in the face of a society that shares a negative perspective about disability. The process that ran the gamut from invitation to contract with research participants will be discussed in detail in Chapter 2.

## **1.15 RESEARCH PARADIGMS**

The research paradigm adopted here is a qualitative, participatory and dialogic inquiry into disability and people with disabilities. It is predisposed to the ideals of reflection, transformation, empowerment and emancipation, with a view to improving the social situation (Baker 1999:241). Together with all participants, new knowledge, experience and meaning, which opened space for new, preferred ways of relating with disability, were created. Consistent with this paradigm and adopted as a theological working paradigm is contextual practical theology (see 2.3.2.1), which not only acknowledges that every life is lived within a particular context, but is also well placed to engage critically, to expose and to call to account the harmful effects of ways of relating that were founded on exclusion and objectification of people (Graham 1999:193).

The social constructionist paradigm has been adopted because of the associations it evokes between language and social processes (Kotzé 1994:107). It views knowledge as a result of social processes and interactions, and therefore is a social construct which can be renegotiated and deconstructed for inherent meanings that may be unstable and subject to cultural and historical determinations (Cromby & Nightingale 1999:4). Social construction bids one be suspicious of the manner in which the world and surrounding reality have been portrayed (Gergen 1985:266). As such, it allows for a rethinking and renegotiation of ways in

which people have been relating to disabilities and those with them. In particular, it invites one to imagine alternative ways of relating with people, especially people with disabilities.

### **1.16 METAPHOR OF A JOURNEY**

Since the transformation envisaged by this research is not an event but a process, for both the proponents of able-bodied theology and persons with disabilities, I have adopted a metaphor of a 'journey' because of its spatial connotations, its usefulness in challenging and disrupting dominant discourses and because of its associations with narrative metaphor (Smith & Winslade 1997). As a spatial metaphor, a journey underlines the complexities of moving from a familiar territory (departure), which entails the grief of separation; the betwixt (liminal), which often goes with confusion and disorientation; and lastly, the incorporation into the new situation (arrival), which features novel understanding of life and identity and a modified sense of self (White 1997:39; 2004:51-52). This metaphor will be developed by mapping and graphing the migration journey people take, of the dominant disability story, as they migrate from its familiar locus of habitation (White 1995:100). My story, like that of the research participants, is as Mikkonen (2007) suggests, "... a journey, it is a travel story". As in a story, our encounters, pauses, and struggles in evacuating familiar territories of the dominant disability story are taken note of.

The metaphor of a journey is further grounded in the shifting of inhabited status quo and the fresh identity found in the new relationship with disability. Those who benefit from the status quo, as well as those on the receiving end of able-bodied theology who may have been colonised into accepting the situation as normal, are challenged to set off out of the familiar and routine world into the unknown (Smith & Winslade 1997).

The Bible is replete with metaphors of a journey, both of individuals and of a people, Israel. This metaphor of a journey, where not only journeys of individuals such as Abraham, Moses, Jesus and others are recounted, but also the journey of liberation of a people, Israel, is marked by long and hard struggles.

A similar metaphor is used in the cultural narratives of the Basotho, in the rites of passage, especially death, which is seen in terms of a journey marked by separation, transition and incorporation (Leshota 2004:34-35). I wish to explore this metaphor of a journey and possibly allow it to inform this study, especially in engaging both perpetrators and victims of disembodied theologies that emphasizes able-bodiedness as a more acceptable theological metaphor than disable-bodiedness. Even as we (the researchers) commit ourselves, we need to be conscious that journeys that lead to evacuation of such familiar ideologies are,

like many other journeys, marked by resistance that is reminiscent of Israel's struggle with the fear of the unknown, expressed in a series of complaints (Ex14:10-14; 15:24; 16:2-3; 17:2-3).

A journey, because of its uncertainty, open-endedness and precariousness, offers a metaphor consistent with the ethical and positioning of participatory consciousness adopted in this research. As a research team, we are not out hunting for the truth. The most suitable and appropriate destination can only be negotiated between ourselves in a "purposeless" conversation. I take particular interest in how all of us, on both sides of the disability divide, experience the journey that, in different ways, moves us out of the colonizing influence of disability.

### 1.17 CHAPTER OUTLINE

My journey is intricately intertwined with the journey of people with disabilities, not only in terms of how I became engrossed in this journey but also in terms of its ability to effect change in all who participate in it. The interest is not in who liberates whom, rather it is on the liberating effects of the journey on people on both sides of the disability divide. This, our journey underlines the struggles, challenges and responses in having to live with the dominant disability story. But this journey is not about struggles and challenges posed by having to live with the dominant disability story alone. It is also about the flip-side of the dominant disability story. The latter is achieved by looking deconstructively into the past and identifying the unique outcomes in the dominant disability story. I also look into the future to underline the emerging alternative stories and renegotiate their place in our significant relationships.

In terms of individual chapters, **Chapter 1** serves as an introduction to the whole research. **Chapter 2** provides the epistemological and methodological lenses through which knowledge shared will be read and interpreted. **Chapter 3** is concerned with how the body, particularly the disabled body, has been scripted and constructed by society throughout history. It goes on to argue that attitudes towards and perceptions around disability and people with disabilities in church and in society have evolved from the ancient Mediterranean region to the present contemporary world. It further exposes the politics of power inherent in the disability discourse throughout the years. The Christian church inherited a deep-seated legacy of marginalisation and alienation of people with disabilities from the antecedent ancient Mediterranean worldview. The Western world, which has been largely influenced by Christianity, continues to pass on attitudes from that legacy.

**Chapter 4** situates the issue of disability within the larger context of literature on disability studies and research, as well as its competing and shifting features. It focuses on ways in which society, through the adoption of different models, in an effort to describe the dynamics of disability, carried further the agenda of the Christian church of constructing disabled bodies through the process of normalisation. The Christian cultural context of Lesotho also played a role in the shaping and production of disabled identities in Lesotho.

**Chapter 5** looks at the evolving scenes in Lesotho regarding the shaping of disabled identities within public modern institutions. Reference is made here to the different government ministries whose focus has a bearing on issues of disability. Through the application of social construction and post-structural paradigms the power valences underlying the relationship between people with disabilities and the public modern institutions became visible. Voices of people with disabilities are incorporated into the body of the research to challenge, deconstruct or commend strides made by the public institutions towards levelling of ground for a relational and interdependent interaction between all God's people.

**Chapters Six** takes the deconstructive process to another level. It starts by identifying the binary opposites on which the dominant disability story is founded and the effects such systems have on people on both sides of the disability divide. This chapter further underlines the unique outcomes as they emerge from our conversations with research participants. The ethical positioning adopted in this research requires that voices of participants who are often marginalised to be privileged over that of the researcher or of literature. The chapter further underlines the intricacies of evacuating the familiar and colonising effects of disability. The voices of participants reflecting these tensions were captured. The above four chapters (3-6), as in a scaffold, logically lead to the conclusion that disabled bodies, like all other bodies, are socially scripted and their meanings determined by society. Some constructions and meanings of disability, despite the shifting and unstable nature of disability throughout time, have stood the test of time and have been identified by participants as texts of terror (Trible 1984), haunting, as it were, both perpetrators and victims of dominant disability story alike. If they are social products they can therefore be deconstructed and reconstructed.

**Chapter 7** goes to the heart of this research, focussing on the deconstruction of dominant disability discourse and co-construction of alternative stories of disability respectively. Not only does it subvert truth claims, taken-for-granted stories around disability, internal contradictions and binary oppositions sustaining dominant disability discourses, but it also

underlines and thickens the emerging alternative stories around them. Even as I do that, I am very careful to privilege the voices of the research participants.

**Chapter 8** is both evaluative and reflective in nature, looking back over the ground covered in this research journey. As participatory action research it was geared towards social and personal change informed by reflection with the participation of stakeholders. A reflection on how we (the participants and I) were transformed through involvement in this research journey is made and reported. The writing in bold of an emerging pastoral narrative, that is more relational, responsible, and accountable, and with the ability to proffer healing to all of us, is envisaged by this research.

## CHAPTER 2

### INTRODUCING THE FRAMEWORKS OF THIS STUDY

#### 2.1 INTRODUCTION

This chapter outlines and discusses the frameworks which undergird this research journey, group into two interrelated categories namely, epistemological and theological. Thayser (2005:54) observes that “traditionally, many dissertations are silent on the epistemology in which research is located”, however in contemporary research an epistemological framework is now commonplace, including within it the postmodern, social constructionist and post-structuralist paradigms, with the narrative metaphor as a preferred tool. I also situate myself within postmodern theology and a contextual practical theology of transformation, working within a pastoral care model that is liberative, ethical, relational and accountable. These constitute the lenses through which the stories emerging from our (the participants’, co-researchers’ and my) conversations will be read.

#### 2.2 EPISTEMOLOGICAL FRAMEWORKS

Epistemology is defined by van Rensburg (2000:2) as a method of gaining knowledge and arranging information, while for Moon, Dillon and Sprenkle (1991:174) it refers to assumptions that inform and shape the process of knowing. It seeks to respond to the question: ‘how do we come to know?’ (Laubscher 2001:12). A framework or paradigm is a point of departure from which one thinks and acts (van Rensburg 2000:1), therefore an epistemological framework is one that guides and defines the content and determines the end-result of research (van Rensburg 2000:2). Postmodernism, social constructionism and post-structuralism have been adopted in this research as epistemological frameworks through which conversations will be organised and read.

##### 2.2.1 Postmodernist epistemology

Butler (1995:35) contends that postmodernism is often invoked as a catch-all-term for approaches that subvert important modernist concerns, such as “the effort to shore up primary processes, to establish in advance that any theory of politics requires a subject”. Emerging as a reaction to modernism, it represents a challenge to the worldview characterized by objective facts, grand-narratives, absolute and universally applicable truths and principles (Kotzé 2002:8). It represents a critiquing and questioning of the assumptions of modernists (Burr 2003:10), whose fixed structures and grand-narratives, privileged

discourses and universal truths should be discarded on the grounds of their totalizing tendencies (Anderson 1997:36).

Postmodernism not only celebrates the difference, context and pluriformity of knowledge (Burr 2003:12), but also forms, as Kotzé (2002:11) suggests, “an ethical-political resistance – against the injustices resulting from the scientific and technological power regimes of modernity itself.” The uniformity, the harmony and the homogeneity that modernism craved for and proposed melts in the face of a postmodern paradigm. The latter’s penchant for the different, the multiplicity and the contextually situated ways of life (Burr 2003:12) has opened space for the dissipation and liberation of the fixed identity of modernism.

Some scholars have expressed their discomfort with the relativism that postmodernism seems to entail (Benson 2002:2; van Rensburg 2000:11), as they argue that relativism leads to a situation where ‘anything goes.’ By contrast, others believe that it provides a multiplicity of interpretations and perspectives, recognition and acknowledgement of which provides scope to look critically at knowledge claims that had previously occupied privileged positions. As Kotzé (2002:30) observes, such an acknowledgement leads to the realisation that

.no one has a privileged position of knowing, be it scientific, religious or any other way. We are in this together. The more we participate in such a way that the voices of all, especially those who have been previously silenced, can be heard, the more we can research and co-construct, in an ethical manner, an ethical, just and ecologically sound world to live in.

My preference for a postmodern epistemology derives from its capacity to provide opening and space for the different, the ‘other’, the local and the particular to emerge (Tracy 1994:109). Despite the tendency to traditionally categorise PWDs as a homogeneous group, that there are different forms of disabilities and that within each form of disability there are different individual experiences, lends credence to the claim that the ‘other’ is a permanent feature. Because of its tendency to “move toward *knowledge as a discursive practice*, toward a *plurality of narratives that are more local, contextual, and fluid*” (Anderson 1997:36), postmodernism makes it possible to engage possibilities for new ways of being and living with disabilities.

In this way, postmodernism provides the latitude to engage a disability reality in a different way, for within and as a result of it, different disability voices have equal opportunity and space to build a more humane world in which all can live in ethical, just and ecological ways. Denzin and Lincoln (1994:15) argue that “post-modernism privileges no single authority, method or paradigm.” Not only are the institutionalized forms of disability that have remained

the same throughout history challenged by the postmodern paradigm, they are also opposed to it.

The postmodernist paradigm has also been adopted because of its aptness towards critically questioning and subverting the dominant, constrictive and incapacitating Christian, cultural disability discourse embodied in the deficit model, the dualistic paradigms of disability (Ratliffe & Haley 2002:126), disembodied theologies (Newell 2007), and fixed linguistic and societal structures that serve to sustain certain practices over and against others (see 6.2.1.1; 6.2.1.2; 6.2.1.3). The postmodern paradigm further valorizes the oft-marginalised and silenced disability stories and facilitates their recognition in the process of building up the Body of Christ, the church.

Even whilst musing on the prospects of postmodernism, it is worth recalling the passion with which modernism challenged the dominant discourses of the time whilst itself also becoming some kind of dominant discourse and knowledge. This is the temptation to absolutism that Botha (1998:400) warns against, and it is necessary constantly to remember the questions raised by Kotzé (2002:8), or else will simply revert to the same complacency that docked religion and science under the modern garb:

- *Whose knowledge are these?*
- *For whose purposes?*
- *To whose benefit are these knowledges?*
- *Who is silenced or marginalized by these knowledges?*
- *Who suffers as a result of these knowledges?*

Social construction discourse and post-structuralism work in tandem and fit within the postmodern paradigm, not only supporting its tenets but also expanding them. In the sections that follow I discuss the two lenses in succession.

### **2.2.2 Social constructionism**

The conversations in this research journey will also be read through the lens of social constructionism, which in linking to postmodernism is seen by Gergen (2001:2) as a “page from the postmodern text.” Though its origins can be traced to a number of voices, social constructionism found its way into the sociological terminology through the work of Berger and Luckmann, namely *The Social Construction of Reality: A treatise in the sociology of Knowledge* (1966). It was later taken up by and expanded in the works of Kuhn (1970), Geertz (1973), Anderson (1990), Butler (1990), Bruner (1990) and Kenneth Gergen



(1985,1994,1998,1999), all of whose authorship and commitment to social constructionist ideas, especially in psychology, spanned almost four decades.

An assortment of terms have been used to describe the reality represented by social constructionism (Kotzé & Kotzé 1997:28; Stam 2001:294), including a movement, a position, a theory, an approach and a theoretical orientation. Others prefer to call it a discourse, and while it is not the aim here to name an exclusive preference, a *discourse* is in line with the spirit and orientation of this research. The term, other than being key to postmodern and Foucauldian thought (Kotzé & Kotzé 1997:28), is more fluid, open and amenable to change and evolution, as opposed to other designations that seem to suggest some fixity common to modernism. It evokes associations with postmodernism, language and practice, with which social construction discourse has affinity (Burr 2003:63).

Social constructionism, as a term, is self-explanatory, combining 'construct' and 'social'. Construct stands for what people create in community through language. Social, which represents the communal aspect, with emphasis on interaction, sharing, agreements and negotiated creations, is the *locus* of construction. This is where construction of reality takes place. Through the use of language as a literary and rhetorical device, meaning, and thus knowledge, are created and rendered compelling (Gergen 1997).

At the heart of social constructionism, therefore, is a view that reality is constructed by people in social interaction with others and that language is a crucial factor (Burr 2003:8; Gergen 1985:266). More than just a way of connecting people, language becomes a *locus* within which people exist (Kotzé & Kotzé 1997:28). It is also constitutive of meaning, which in turn constitutes people's lives.

It is important to note here, however, that language does not make sense outside culture, and this chapter focuses on how disability has gone through different historical and cultural mouldings. The regularisation of the disabled body through ritualisation within the Judeo-Christian context has evoked slightly nuanced meanings unheard of among the Greeks and Romans. This confirms Gergen's (1985:5) view that knowledge systems are not objective representations of reality but products of historically and culturally situated interactions between people. The body so constructed carried meanings produced within society to portray societal values and ideals. Such an idealised body often maintains the fabric of society, sometimes even to the point of tyranny (Viviers 2005:799).

The participants aired opinions derived from experiences of living under the tyranny of a constructed, idealised, regulatory body which treated them as the 'other', as the 'different' or

the so-called 'impaired', 'maimed' and 'disabled' body (Chapters 3-5). The continuum of these labels from the preceding generations has impacted on how today's generations understand and construct meanings around disabled bodies (Stiker 1999:viii). I followed through this continuum to argue that disability remains a social construct that reflects the values and ideals of a society which such a body inhabits.

Social construction, however, carries with it some political overtones. For a long time, both church and society have been under the spell of a dominant disability discourse that saw disabled people as sinners, unwhole and representative of the evil one. The latter discourse tended to view disability as a fixed and an inflexible reality. Social construction discourse bade people to be suspicious of this manner in which the world and surrounding reality had been portrayed. It urges one to make "connections between the world we live in and the meanings we use and that use us as well" (McLean 1996:x). Social construction discourse challenges us to accept and respect the alternative forms of knowledge, and bids us find ways to participate with people living differently from us, co-creating with them ethical ways of living (Kotzé 2002:20).

Social construction discourse helps in this research journey in a number of ways. Firstly, it allows us, co-researchers, to understand and describe the machinations of social construction discourse, in the construction of the body as a social script, within the context of the Christian cultural narratives. It shows how, over time, such societal constructions adopted a reality and truth status. Our use, therefore, of the term 'disabled' is not an innocent act, but is, especially when used of an individual, the product of relations of power exercised over bodies. (Foucault 1980:32).

Secondly, if bodies in general, and disabled bodies in particular, are products of societies, and discourses and meanings are created and attached to them respectively (Berquist 2002:3), then such discourses and meanings can be deconstructed. Social construction, because of its suspicion towards the taken-for-granted knowledge claims, bids us question the disabled identity that is linked essentially to an inferior or sinful status. Because of its interest in the performative function of language, social construction discourse becomes, as Burr (2003:8) suggests, a form of social action. As such, it has the ability to effect construction of the body and its meaning and their deconstruction thereof. Social constructionism allows us to challenge the constrictive meanings attached to disability and people with disabilities, and to offer new possibilities for the emergence of new meanings that are more life-giving.

Post-structuralism constitutes the second lens through which this research study was viewed.

### **2.2.3 Post-structuralism**

Post-structuralism constitutes another postmodern lens through which the conversations within this research journey were read. Often equated with postmodernism, largely because of the theoretical affinity that exists between the two, there is nevertheless a sense in which a clear distinction between the two can be clearly drawn, as argued by Haber (1994). This section does not purport to be a comprehensive exposition on the origins and development of post-structuralism but rather serves to present its features as a foreground to the research journey, particularly through the writings of Foucault and Derrida.

Foucault's ideas on power and knowledge, and the subjugated knowledge systems, have helped scholars appreciate the machinations of power within socially constructed knowledge systems, particularly in the creation of a disabled identity. Social construction emphasises the communal and relational aspects of knowledge and meanings constructed within the context of a particular language and culture (Sears 1992:147). Post-structuralism, on the other hand, posits that meanings carried by words are not fixed but always temporary (Burr 2003:53), and that such meanings are dependent on words as used in context of time and place. Weadon (as quoted in Jones, 1996:23), suggests that post-structuralism "allow[s] for the conflicting frames of knowledge; discursive productions of historical effects through language and a series of enquiries into the constructions and constitutions of subjects/individuals". A term for such an exercise in reading was coined almost four decades ago by Jacques Derrida, as deconstruction.

### **2.2.4 Deconstruction**

Compatible with the above research lenses is deconstruction, adopted in this research journey as an analytical tool. A defining concept in both postmodern and post-structuralist discourse, it continues to generate intense and heated debate among academics. For its critics, it is a fad, a nihilistic, anti-institutional and anarchist piece of relativism where 'anything goes' (Caputo 1997:37). For its proponents, however, it functions to open and 'loosen things up', by giving us the right and the means to ask any question about anything, including deconstruction itself (Caputo 1997:55).

Deconstruction was seen by Gergen's (2001:2) as "a page from the postmodernist text", and further linking postmodernism, post-structuralism and deconstruction, Jones (1998) suggests

that the last two can be seen as the theoretical formulations of the first condition. For Hedges (1998): “Post-structuralism is a philosophical development which Derrida’s work is associated with, deconstruction is a term within his work.” Though defining it would certainly go against the Derridean style (Wolfreys 1998:13), deconstruction has been described as a “way of reading that concerns itself with decentering – with unmasking the problematic nature of all centres” (Powell 1997:21). This was a reaction to the influence of Western metaphysics which saw the world as founded on a centre, an ideal form and a fixed point around which meaning is generated, and that is oriented toward spawning pairs of binary opposites defined hierarchically, with the first term having priority over the second.

Deconstruction has an important role to play in this research as it makes possible an appreciation of the complexity of texts, discourses and meanings. Disability, like many other terms, is complex and fraught with tensions and contradictions, but takes its meaning through its difference from those other terms (Hall 1997:33). Through employing the tool of deconstruction, not only have the tensions and instabilities inherent in the disability discourse been explored, but the privileged notion of able-bodied “is constantly haunted by the liminal presence of the disabled and impaired others ‘against which it defines itself and into which it continually threatens to collapse’” Redman (2000:12).

The fluidity and plurality of meanings in postmodern epistemology, within which deconstruction operates, offer a fertile ground for inhabiting other ways of relating to disability. The taken-for-granted assumptions about disability’s meanings collapse in the face of their refusal to remain linguistically stable. Deconstruction allows for a questioning of these taken-for-granted knowledge claims and common generalisations, and renders their subversion possible. History bears testimony to the assertion that the body, especially the disabled body, has historically been subjected to a variety of socially generated interpretations. The binary oppositions that defined these different perspectives around the body should be subjected to scrutiny, and deconstruction affords the scope and the means to do so.

### **2.3 IDEAS FROM THE NARRATIVE METAPHOR**

Ideas from the narrative metaphor incorporated into this research represent a shift in a series of developments in the realm of therapy. While this metaphor surpassed the then in vogue ‘interpretive method’ of Gregory Bateson, it also carried over from Bateson some ideas and insights to enhance and broaden its therapeutic base (Freedman & Combs 1996:15). The underlying theoretical tenet of the narrative metaphor, which resonates with

the postmodern, social constructionist paradigms discussed above, is that the world, knowledge and reality are not 'out there' to be discovered, but are created and negotiated through continuous interaction. As Gergen and Gergen (2003:159) argued, the world is not created by stories but even the understanding of selves is cast in life stories. By telling and re-telling these stories, life is given to them, which in turn creates the world that people inhabit. Through the stories that they tell, people create their own worlds, over which they become experts.

Not all stories that people identify with are positive, but some are suffused with problems, known as 'problem-saturated stories'. They affect people in adverse ways and are the result of the ways people inhabit and interpret their life experiences. The narrative metaphor, because of its use of the multiplicity of perspectives and stories (Morgan 2000:8), provides the latitude not only to examine the ideas that support the problem story but also to re-tell and re-author the problem disability stories. It facilitates the opening of an array of possibilities that could, to employ a Biblical image, be inhabited in ways that promise life in a valley of bones (Ez 37:1-14).

The question now arises as to how the narrative metaphor links up with the epistemological frameworks adopted in this research.

### **2.3.1 Epistemological grounding of the narrative metaphor**

In linking up and draws on the ideas of postmodernism, social constructionism and post-structuralism, the narrative metaphor adopts and utilizes concepts taken from social constructionism and post-structuralism, thus situating it within the postmodern paradigm. It is for this reason that it has been called in some circles a 'postmodern worldview' or 'social constructionist worldview' (Freedman & Combs 1996:22). In keeping with and informed by postmodern and post-structuralist philosophies, the narrative metaphor subscribes to what Freedman and Combs (1996:29) called "one word, one language but many meanings". Postmodernism, with its influence on the narrative metaphor, has exposed that realities are socially constructed, constituted through language and organized and maintained through narrative (Ibid.:22). It has confirmed the notion that people live more than one story at the time.

If reality is socially constructed and maintained through "stories of the culture in which we live" (Morgan 2000:9), it follows that some stories are then problem-saturated, and perhaps "anchored and supported by cultural discourses or taken-for-granted cultural prescriptions about how we should act" (Madsen 1999:171). Morgan (2000:45) adds that these cultural

beliefs and prescriptions that “serve to assist the problem story” should be questioned and challenged.

This questioning lays ground for the discovery of stories that were marginalised and subjugated as a result of society giving focus only to dominant ones. In this way, through their own participation, people are able to view their problem-saturated stories in a different light. Derrida challenges us to see that the term ‘problem-saturated story’ contains both itself and its other (problem-free story). It subverts its own logic and thereby opens up possibilities for a different relationship and meaning to emerge, through deconstruction. I concur with Appelt (2006:40) that deconstruction serves the narrative metaphor through questioning and putting under erasure the taken-for-granted meanings so that alternative stories emerge.

The narrative metaphor is at one with the postmodern worldview that stresses the social embeddedness of reality, constituted through language and maintained and organized through narrative (Freedman & Combs 1996:22). This postmodern emphasis on reality as social construct and context-dependent, with language as a medium (Anderson & Goolishian 1992; Boston 2000:451), converges well with narrative ideas. In the narrative metaphor, language and narrative have been used in ways that create possibilities for meaning and interaction (Kogan & Gale 1997:102).

Ways in which the narrative metaphor will serve to achieve the aims of this research journey, particularly the deconstruction of the dominant story and the co-construction of the alternative, preferred disability story are now discussed.

### **2.3.2 Narrative metaphor and disability**

With respect to disability, the scope thus provided by the ideas of a narrative metaphor facilitated the creation of alternative ways of perceiving the disability story, which has until now supported the discourse that denies persons with disability the liberty to pursue their preferred directions in life. Knowledge and power, as noted above, have been used in oppressive ways against people with disability, a practice, therefore, that has ethical and political implications (Kotzé 2002:6). While others profited from their exercise of power and knowledge, others suffered the consequences. This, in itself, suggests that social relationships are political in nature and taking a political stance against oppression and injustice is an integral part of the narrative metaphor. In that connection, the narrative metaphor offers not only the means to destabilise the dominant disability discourse, but also provides a stage on which healing and transformation, with respect to the effects of dominant disability discourse, can be played out.

Though this research entails an element of healing and transformation, it is not, *per se*, an exercise in narrative therapy. Some ideas of narrative therapy that link up well with deconstruction (Chapters Six and Seven) have been integrated into this research to enhance its capacity to heal and transform at personal, social and ecclesial levels. Because of the interest in the dominant disability discourse that this research shows, it could not shun the question of how we get caught up in such a discourse; what its effects are on identities on both sides of the disability divide and what binaries sustain such a discourse (Chapter 6). Our aim was also to look beyond the dominant disability discourse to the narratives or stories that lie outside the plot of the dominant disability storyline and to expand on such narratives (Chapter 7). These are what we call, in narrative therapy terms, ‘unique outcomes’ (Morgan 2000:51; McLeod 2003:238). These elements have been integrated into this research (Chapters Six and Seven) because of the possibilities they offer all of us, on both sides of the disability divide, to relate to disability, otherness and difference in more life-giving ways.

By way of summary, the narrative metaphor with its belief in people as meaning makers and interpretive beings connects well with the postmodern paradigm as well as social constructionist and post-structural lenses. The latter two subscribe to the communal and relational construction of reality through language, eschewing fixed meanings and tending toward multiplicity of meanings and perspectives. They make possible the realisation of the aims of this research, while in combination they offer latitude and a means to achieve them.

If disability is a social construct, its meaning(s) is (are) dependent on the society which constructs it (them). Constrictive and incapacitating dominant disability stories can therefore be deconstructed and a new disability story collaboratively co-constructed. In addition to the epistemological frameworks outlined above, this research is also an undertaking in theology which combines with the above epistemological paradigms to question the taken-for-granted knowledge claims that have marginalised all other theological positions that tend to diverge from the dominant truths (Kotzé 2002:14). These are discussed in the section below.

## **2.4 THEOLOGICAL POSITIONING**

Different theologies form the background to the reflection undertaken in this research journey, with particular attention paid to theologies that are aligned in their purpose with the epistemological frameworks adopted, as well as those that would facilitate the giving of voice to the previously silenced and subjugated knowledge claims.

### 2.4.1 Postmodern theology

The theological perspective to this research is informed mainly by postmodern theology, which according to Wallace (2001:94) marks an important break with Western theological tendencies that are grounded on metaphysical foundations. It was within the latter tradition that God could only be adequately seen through the eyes of what came to be known as 'ontotheology'. In this context, it would make sense to think of God as "the metaphysically certain God of supreme causality who mechanically functions as the cosmological ground and unity of all beings in the world." (Wallace 2001:96).

Heidegger (1969:72), meanwhile, proposed an engagement in "god-less thinking which must abandon the god of philosophy in order to approach the God of biblical faith." Heidegger's view here is reminiscent of the *kenotic* (from *kenosis*, which means self-emptying) act of Jesus who

....*had the nature of God*, but he did not think that by force he should try to become equal with God. Instead of this, of his own free will *he gave up all he had*, and took the nature of a servant he became like man and appeared in human likeness. He was humble and walked the path of obedience all the way to death – his death on the cross. For this reason God raised him *to the highest place above and gave him the name that is greater than any other name* (my own emphasis).

(Philippians 2:6-9)

This text further recalls the paradoxical, though suggestive, statement of Jesus in Luke 9:24, "whoever wants to save his life will lose it, but whoever loses his life for my sake will save it", which similarly evokes the biblical images of self-emptying through self-giving in Philippians 2:6-9. Jesus's openness to the 'uncertain other' led to genuine discovery of the self, if in Derridean style *such a thing exists*. Through embracing discomfort, which finds expression in the uncertain, ambiguous and flexible subjectivity, "a greater sense of connection, a fuller sense of meaning and in the end a greater sense of 'comfort' with who we have chosen to be and how we act in our lives", is achieved (Boler 1999:197; Aglin 1996:22; Wolgemuth & Donohue 2006:1033). The discomfort of losing one's life and privileged status and embracing the uncertain other self, as was the case with Jesus, led to possibilities for both Jesus and others in ways that would never have been imagined.

Postmodern theology is further premised on the importance of personal assumptions, participation and life experience of a theologian. The analysis and fragmentation in an effort to search for the truth, that was part and parcel of a positivist approach has, with postmodern



theology, been overtaken by relationality and blurring of the boundaries between the subjective self and the external world; the subject and the object; the knower and the known; the researcher and the researched.

In the postmodern theological condition, no truth is 'out there' for the taking by all generations *ad eternum*, but rather every generation has the metaphors, the language and a postmodern imagination which "must work its way in the presence of other, rival, and competing acts of imagination, none of which can claim any formal advantage or privilege" (Brueggemann 1993:19). Such a way of doing theology calls for a commitment to participation because it is necessary for both the discovery and the creation of truth that is open for further determination.

Herholdt (1998: 217) sums up the thrust of a postmodern theology:

The will of God is thus not a predetermined decision that Christians need to discover in a passive mode of obedience. Christians, and for that matter all people, are afforded the right to some human input that co-determines the "plan" for their lives. Many choices are possible, but in the variety of options we are guided by God as creative participant of our lives. Humans need not plug in to a blueprint that renders their own efforts and creative potential sterile, but are co-creators.

Such a theology would allow us, therefore, to break free from the shackles of disembodied theology, masquerading as the revealed will of God, which created binaries that saw disability demarcated "from the body and mind within which it resides" (Newell 2007:325). It comes in to provide the space for the voice of disability that has been suppressed under the pretext that it represents an unusually flawed, imperfect and un-whole relationship with God. Postmodern theology further allows us to embrace an alternative theology of disability that is rooted in "radical discontinuity with foundational assumptions" (Neuger & Poling 1997:23) which have seen people with disability, disabled not by their physical condition but by the Christian cultural tradition.

#### **2.4.2 Practical theology**

This research journey is a practical theological undertaking. In its origins, practical theology has always been associated with theory and action, seen by Gerkin (1991:13) to straddle theological concerns on one side and practical considerations on the other. It is therefore involved with living, communicating and practising the life of faith (Ackermann & Bons-Storm 1998:1), and brings theological reflections to bear on the real experiences in such a manner

that praxis and theory are both constantly brought into critical dialogue with one another (Bons-Storm 1998:16).

Of particular interest to this research is the political-critical current for the possibilities it offers in relating the methodology of practical theology, namely, understanding, explanation and change (Heitink 1999:165), with its leanings toward the epistemological and methodological thrusts adopted here. Höfte (quoted in Heitink 1999:175) observes that the political-critical current has leanings towards a “qualitative action research from the perspective of the participant.” In this connection, practical theology is provided “with a finely-honed scalpel to analyze and excise oppressive ideologies and structures” (Ackermann 1993:26). With a political-critical current, practical theology is also better placed to facilitate the changing of the situation of people on both sides of the disability divide.

This research actually went beyond examination and analysis of ideologies and structures to working together in the discovery of an alternative pastoral disability narrative. The oft-missing voice of people living with disabilities in social and theological discourses was recognised and given space to articulate the hurts, concerns and aspirations of people with disabilities from their social and faith perspectives.

I am not embracing a practical theology with leanings only toward political-critical currency, but also a practical theology that is contextually situated to give voice to the local knowledge systems of people with disabilities that have been hitherto silenced.

#### **2.4.2.1 Contextual practical theology**

Bosch (1991:422-423) gives a stern but pertinent warning that:

...all theology was influenced, if not determined, by the context in which it had evolved. There never was a “pure” message, supracultural and suprahistorical... One therefore has to concede that all theology (or sociology, political theory, etc) is by its very nature, contextual.

On that basis, therefore, if practical theology is to remain true to its qualification as theology it has to fuse two horizons, that of the text and that of the person to whom the text speaks (context) (Gadamer 1975:358). I therefore position myself within a practical theology which takes context seriously.

The insights of Pieterse (1998:180), though written within a South African context, are pertinent:

Justice and peace are theological concepts in the struggle for liberation that motivates contextual theologies to embark on a liberating praxis. Our view of practical theology is that of a contextual... studying religious praxis with the goal of enhancing a liberating praxis in establishing and building faith in Jesus Christ, and justice and peace for all in church and society.

Within the context of disability, this means acknowledging the cultural specificity and individual uniqueness of every experience of disability. As Eiesland (1994:31) notes:

The corporeal is for people with disabilities the most real. Unwilling and unable to take our bodies for granted, we attend to the kinesis of knowledge. That is, we become keenly aware that our physical selves determine our perceptions of the social and physical. These perceptions, like our bodies, are often nonconforming and disclose new categories and models of thinking and being. These new embodied categories arise from the concrete experiences of people with disabilities.

Even as Eiesland writes in terms of 'we', there is always the 'I' that is hidden in that 'we'. This is because, though the experience of disability comes to each according to stereotypes and prejudices created in society through interaction, their effect cannot be reduced only to a simple group feeling. That experience has an impact that will differ from one individual to the other and that need not be taken-for-granted. This view is articulated by Schutz (quoted in Eiesland 1994:31) as, "The place which my body occupies within the world, my actual Here is the starting point from which I take my bearings in space. It is, so to speak, the centre in my system of coordinates."

It is my contention that although disability is found in all cultures its expression and interpretation are determined by the context within which it is experienced. Contextual theology, therefore, with its critique of the universal and its propensity toward the insurrection of the marginalized knowledge systems, would be helpful in facilitating healing on both sides of the disability divide, at both social and personal levels. Every voice of the participants was listened to from within its own experiential context. Though there were always some common disability concerns, the unique features of every individual with disability were listened to and they were taken seriously.

Since the research was carried out in Lesotho the experiences of participants were shaped within the context of that country. This foregrounding is not only because it is demanded by our adoption of a participatory method but most importantly because it is ethical and godly to do so. The features of Trinitarian life are relationality, communion and participation, so should be the features of our life as members of the body of Christ.

#### 2.4.2.2 Doing practical theology as participation

“Theology from below” logically leads to participation by those who reflect on their faith experience and who act on its demands, therefore it is a theology that takes the voice of the “other” seriously. The “other” represents those who, under normal circumstances, “are disempowered and marginalised – those who seldom benefit from the ethics of discourses created and entertained by the powerful or knowledgeable” (Kotzé 2002:18). Doing theology, no longer the sole preserve of the educated elite, entails engaging in theological reflection that is rooted in real-life experience. Taking a cue from what Bosch (1991:425) calls “hermeneutic of the deed”, where doing counts more than knowing, only knowledge achieved through action is capable of transforming the world.

Within the postmodern context, where participation is a defining feature, there is very little room for handing out theological prescriptions. Instead, immersion in the process of knowledge creation becomes a *conditio sine qua non*. It is this way of doing theology that is preferred in this research because of its leanings towards the adopted epistemologies and research methods. My engagement, therefore with people with disability and the significant others, is a *doing* theology *with*. This engagement promotes positive and empowering research relationships, as was later confirmed by participants (Salmon 2007:986). It does not wield a creed with readymade answers to questions that have not been asked, or problems posed by none of those who are participating in this research journey. If it did, it would rightly invite resistance against its shaping unethical practices (Kotzé 2002:17).

The perception that has been, up to now, created in both church and society about people with disability is one in which they are seen as ‘misfits’, ‘sinners’, ‘abnormal’ and objects of pity who have no voice and cannot have a voice because of their alleged condition of impurity and sinfulness. Contextual practical theology of participation would bid us to restore the voice of people with disability so that they can reflect on their faith experience in ways that affirm their dignity (Eiesland 1994:21). In the attempt to facilitate such a restoration of the marginalised voices of people with disabilities, experiences of research participants have been included in almost every chapter of this research journey. A choice of a participatory approach was not only a commitment but also a responsibility to ensure that participation did not become merely tokenistic.

Our choice of a participatory method of research, therefore, facilitates this doing of theology from below, thus allowing the genuine reflections of people with disabilities to come to the fore. As Galvin (2003:159) asserts, within the context of a reflection on silencing and

invisibility of people with disability, it is within these subjugated knowledge systems that the potential for providing the voice resides. Without a voice, participatory deconstruction of dominant disability narratives envisaged by this research would be highly compromised. Participation is not an end but a means to an end, and it is intended to bring about change, beginning with everyday life struggles in the lives of participants (Conde-Frazier 2006:324), hence the practical theology of transformation which forms the matter for the next section.

The different chapters in this research represent the practical theological re-construction of a fixed disabled identity. Read through a postmodern lens such an endeavour opens up possibilities for alternative ways of understanding disabled identities. Not only should the theology be contextual but it should also lead to action that is oriented toward emancipation and transformation, particularly in the context of disability.

### **2.4.2.3 Practical theology of transformation**

To say that theology, and consequently practical theology, is contextual means that it not only reflects on the context in the light of the gospel, but it is also doing theology with view to changing the world for the better in the light of the gospel. Transformation has been called by other names, such as 'liberation' (Cochrane et al. 1991:10) and 'emancipation' (Cochrane 1994:26-34), but common to the different perspectives is concern for and commitment to the cause of the marginalised and those suffering from their relative weakness in power relations.

Reflection on and understanding of the dynamics of the context is not the goal of practical theology of transformation, rather it lies in improving the conditions and the social situation of those who suffer. Such a pastoral praxis, in the words of Cochrane, de Gruchy and Petersen (1991:25), is not

ad hoc, a crisis reaction only, a spontaneous attempt to help without any clear ideas on how best to go about this, or a fixed set of ideas learned at seminary or from books or from "bitter experience" (which usually means that one did not succeed before in finding the liberative way through something). It is a dynamic spiral of planned, reflected activity.

However, a caveat is that commitment to the poor and the marginalised, without their involvement, is as inadequate as the erstwhile ways of doing theology with emphasis on doing *for* instead of doing *with*. Indeed, that would amount, in a way, to sharing in the shaping of the theology that we seek to resist and to evacuate. Barth (quoted in Bosch 1991:424) was right to exorcise "a lonely bird on the rooftop" sort-of-theologian who only

surveys and evaluates the world and its sufferings, with no engagement with those who suffer.

Within the context of disability and people with disability, Christian cultural narratives, for the most part, have connived to oppress, silence, and render invisible the suffering of people with disability. Practical theology of transformation, especially because of its association with the “hermeneutic of suspicion”, is best suited to expose the oppression and its harmful effects that occurred in the guise of Christianity (Kotzé & Kotzé 2001:4) on one side, and that of the ancestors and society on the other.

Practical theology of transformation not only facilitates the discovery of the history of the dominated groups, it also facilitates the re-writing and articulation of their concept of themselves and their vision of a just society (Welch 1990:157). Stories of intense pain and accounts of journeys towards conversion, recounted in Chapters Six and Seven, have been embraced because of the potentiality for change they promise. They should be taken seriously because they are recounted by people who have withstood the worst of injustice.

To understand what disability means entails listening to meanings that people with disabilities give to their experiences. They experience, first-hand, the pain from the Christian and cultural stories of disability, therefore “they know exactly what they lost” (Tamasese & Waldegrave 2003:92). A practical theology of transformation, with a participatory thrust, would be better suited to engage the painful experiences of people with disabilities with more “humility, respect, sacredness and love” (Ibid.:93). Chapter 7 (2.1.4, a) recounts some of the narratives of conversion (transformation) as narrated by the research participants.

Because transformation is not an event but a journey, this research intends to have an impact beyond the limits of what its content could say. It also goes beyond the completion of this thesis and the reception of the DTh degree.

### **2.4.3 Pastoral care as co-journeying**

In light of McLaren’s call to learn “to be Christians in a new way” (2001:x), I depart from the traditional approach to pastoral care and embrace one in the postmodern paradigm, involving participatory action research and informed by the metaphor of a journey. I therefore work not with definitions of fixity, but with values that undergird and are consistent with the kind of care adopted in this research. Rather than view care as maintaining the hierarchy and political distance between the caregiver and the cared for, I am prompted by the witness of pain and suffering in society (Kotzé & Kotzé 2001:2). This is characterized by “the power

of empathy and compassion, of delight in otherness, and the strength in the solidarity of listening to others, bearing *together* stories of pain and resistance” (Welch 1990:135) (my emphasis). It is a model of pastoral care that is liberative, ethical, relational (participatory) and accountable (see Chapter 7.6.1).

The insights from the theologies adopted in this research journey have been useful not only in grounding this research in the lived experience of people with disabilities but also in providing the space and the means to transform in more positive ways the lives of all who took part in it. The methodology is consistent with the epistemological frameworks and has a predilection for the theologies espoused in achieving the aim of deconstructing the dominant disability story and construction of a preferred one through participation.

## **2.5 RESEARCH METHODOLOGY**

Any research work depends on the researcher’s way of thinking on the matter being researched. The manner of gathering data, as well as its interpretation towards a specific outcome, has to conform to the philosophical assumptions that guide the researcher’s way of thinking towards an intended goal. This constitutes a research methodology, which for purposes of this research is qualitative, participatory action research, whose nature, modalities and goals form the subject matter of the next sections.

### **2.5.1 Qualitative research**

Qualitative research is a naturalistic and interpretive approach that draws from various disciplines and fields. It is in this sense that some authors prefer to talk of it in terms of ‘qualitative methods’, a term that covers different methodologies with different theoretical underpinnings and ways of thinking about knowledge (Kuper, Reeves & Levinson 2008:404).

Patton (2001:39) adds that qualitative research, as opposed to quantitative, does not rely on statistical figures and other means of quantification to arrive at conclusions, but rather proceeds by interaction with the real and context-specific settings where events unfold naturally. At the heart of qualitative research is a belief that perceived reality is created, negotiated and interpreted by people in their social historical and individual contexts (Kuper, Reeves & Levinson 2008:405). Reality, therefore, becomes a text which is endlessly interpretable and therefore able to be deconstructed (Heshusius & Ballard 1996:9; Griffith & Griffith 1990:13).

Qualitative research works through generating an in-depth understanding of human behaviour as well as lived experience, as it occurs in real-world settings with a view to

elucidate the deeper reasons behind various aspects of this experience. It is for this reason that it is said to focus more on answering the questions “how?” and “why?” (Kuper et al. 2008:337; Golafshani 2003:600). The choice of qualitative approach was a conscious decision to elucidate ways in which bodies in general and disabled bodies in particular become discursive productions (Butler 1999:240). They further support configurations of power resulting from specific historical contingencies. It is in this sense that “disabled bodies are defined to invent and privilege healthy bodies” (Ellingson 2006:300). Qualitative research also affords an opportunity to explore, share and understand how other people give meaning to their experiences of the effects of dominant disability discourses on their lives.

With a view to better grasping the matter of disability in its complexity, the qualitative method, together with a wide array of insights from epistemologies, metaphors and theological standpoints, will be employed to offer the scope and the means. The qualitative method has predilection for interpretation of reality with a view to gathering an in-depth understanding and meaning of the knowledge systems as produced through interaction within historical and individual contexts. Deconstruction presupposes that there are meanings that are marginalised through centring or privileging of some constrictive and dominant stories of disability. Working together with these frameworks, the qualitative method is appropriate for achieving the aims and responding to the research question.

## **2.5.2 Participatory action research**

The next two sections look into the two defining aspects of participatory action research and argue for my choice of this methodology.

### **2.5.2.1 Participatory**

According to McTaggart (1997:6), research becomes participatory and truly so when the “entire process, from conceptualisation, through improvement of practice, is shared and co-produced by research participants”, and as such it becomes democratic with grounding in a participatory worldview (Reason & Bradbury 2001:1).

Central to participatory research is dialogue through which a social space is forged, containing shared experiences and information, common meanings and concerted actions (Park 2001:81). The same sentiment is described by Frank (2005:968):

... the dialogical research report offers an account of how researcher and participant came together in some shared time and space and had diverse effects on each other. The mutual



effects that each has on the other continue to reverberate to readers of research reports, who become part of the dialogue; readers' participation causes further reverberations.

Frank's words resonate with those of Bakhtin (1984:58) that "two is the minimum number, because life requires dialogue." Dialogue therefore must of necessity involve participants in mutual interplay as opposed to a one-way imposition of one upon the other. Not only is dialogue reciprocal in nature but both participants are affected by the other and are able to affect it in turn.

Participatory research, with its core of a dialogue, has a number of benefits to it and all who take part in it. As Salmon (2007:982-988) suggests, it:

- supports responsible agency in knowledge production
- democratizes the research process
- mitigates the potential for misrepresentation and appropriation of people's experiences
- allows for incorporation of participants' lived experiences, which causes a different picture to emerge
- reduces risk of co-optation and exploitation of people in the realization of the plans of others
- calls for an ethical consciousness situated in the participation of all, especially those who are usually marginalised and silenced (see also Kotzé 2002:18).

The history of research on disability has been belaboured with practices bordering on objectifying, disempowering and oppressive relations common to standard traditional research methods. Radermacher (2006:22) concurs that "traditionally disability research has often been done 'on' or 'to' people with disabilities" and that it has been alienating and exploitative. Participatory research, because of its involvement-oriented and relationship-building values, would go a long way to facilitating active agency, hitherto lacking in most researches on people with disability. Its propensity towards collaboration allows people with disability to take ownership and become experts of their lives (Turmusani 2004:5).

Research participants have, therefore, been invited and informed about the aims, the process as well as the requirements for being involved. They were invited throughout to take ownership of the research process and to contribute to its creation and re-creation. A form of participation adopted in this research recognises the value of including others as essential generators of useful knowledge (Conde-Frazier 2006:324). Even as we negotiated these terms, I was conscious of my privileged stance on the construction and content of the text. I had to remind myself of my commitment to a participatory research and to continually consult and hold dialogue with the research participants (Park 2001:81). In this way I was able to find a balance between including the self of the principal researcher and the voice of

the co-researchers (Tootell 2004:59) a stance that recognised their right to be part of activity that impacts on their lives (Radermacher 2006:23).

The choice of the topic, the research question as well as the aims of the research, were prepared by myself and communicated to the research participants, who were invited to join me in responding to the research questions and in realising the aims of the research (see Section 2.4.3, below). Operating in this way matched participatory research with the epistemological and theological frameworks.

### **2.5.2.2 Action research**

Action research is associated, in its origins, with Kurt Lewin within the context of community development projects. It has, with time, developed into perhaps the “most influential and almost certainly the fastest growing orientation...” (Webb 1996:139), profoundly effecting a wide variety of fields and disciplines and described as “the whole family of approaches to inquiry which are participative, grounded in experience and action-oriented (Reason & Bradbury 2001:xxiv).

It is seen by a number of researchers as seeking to bring together action and reflection, theory and practice in the pursuit of practical solutions to issues of pressing concern to people at both individual and community levels (Reason & Bradbury 2001:1; Kemmis 1988:87). Action research focuses on social change and change informed by reflection, with the participation of all stakeholders.

The focus of this study is not so much to understand as to improve the conditions of all the victims of the disembodied theology through examining their life stories as they experience them. There is no intention to exclude the perpetrators and the witnesses because the self-other relationships suggest that one’s liberation is tied to that of others. As Isherwood and McEwan, and Freire (as quoted in Kotzé & Kotzé 2001:4) suggest, liberation of the oppressed also liberates the oppressor.

The knowledge and power paradigms inherent in the disability discourse in terms of their effects, how they work, who benefits and who suffers, are questioned and interrogated with a view to co-construct new paradigms consistent with the new order in which inclusiveness is achieved through healing and liberation (Kotzé 2002:11). Participatory action research, with its ability to link participation, social action and knowledge generation, is better placed to realize the aims of this research of offering possibilities for re-storying ways of relating to disability and people with disability.

My methodological strategies are in keeping with the participatory approach as well as the transformative nature of the epistemological and theological paradigms adopted in this research. In a narrative metaphor there are no people as objects of research, but rather the research process is owned by all who are participating in it as subjects of the process. The deconstructive process was not an imposition from outside. It was something that emerged from our conversations with research participants. Discourses that lay outside the dominant storyline were identified and confirmed with research participants, not contrived elsewhere and imposed upon the participants.

According to McTaggart (1997:6), research becomes participatory and truly so when the process is shared and co-produced by research participants. Our reflection was based on the conversation we had together as co-researchers in this research journey. Kotzé (2002:25) calls this 'ethicizing research' in that realities and knowledge systems that shape the world we inhabit are constructed in this research through collaboration and participation of all stakeholders.

I chose semi-structured and active interviews, and reflexive conversations in engaging the issue of disability with research participants.

#### **a) Semi-structured Interview**

Called by some a 'focussed interview' (Merton & Kendall 1946), the semi-structured interview has a framework of themes that serve as guides rather than a format to be followed strictly (see Appendix D). The respondents do not have a very limited scope to how they answer the questions (Babbie & Mouton 2001) and there may be a conversational flow covering topics rather than focusing on specific questions. It thus increases the potential for narrative development (Anderson & Goolishian 1992:38).

Having discussed issues pertaining to the manner of interviewing, the participants opted for being interviewed individually. This was the most convenient arrangement for all of us, given that some were students while others were employed. To find the most suitable time for all would be difficult, however we remained open to the possibility of coming together in a group at a later stage. The participants suggested that knowing what the focus of the interview in general would be well in advance would facilitate smoother conversations. We all agreed that the conversations be audio-taped and transcribed for ease of reference and recollection. I made an effort in keeping with participatory ethics that research participants would be involved in almost every stage of the research as co-owners of the research (Kotzé 2002:28). After the initial interview I made at least four follow-up interviews with each of the

research participants, to seek their validation of the reporting as it unfolded, as well as to raise other pertinent issues.

### **b) Active interviews**

An active interview is described, by Wolgemuth and Donohue (2006:1026-1927) as “an interview strategy informed by postmodern and other critical stances which argue that interviewing is not about asking questions to elicit participant ‘truths’; it is a method for socially constructing knowledge.” The interview could, as Allen and Cloyes (2005:101-102) suggested, become the confessional, in which participants feel safe and comfortable to tell their stories.

The merits of active interviewing lie in its ability to bring about individual transformation. It is also amenable to a variety of subject positions (Weingarten 2003:22), which inform this research as well as activating repressed or marginalized knowledge (Wolgemuth & Donohue 2006:1026-1027). This ability to bring out the un-storied and the neglected, in the disability discourse, is at the heart of the aims of this research. Careful epistemological and theological positioning assisted us in achieving this goal, and in discovering the unique outcomes and the alternative ways that lie outside the dominant disability discourse.

### **c) Reflexive conversations**

Reflexive conversations were also a preferred approach of engaging with research participants. As described by Christian (quoted in Etherington 2007:601) reflexive conversations gives us the ability “to be aware of the personal, social, and cultural contexts in which we (and others) live and work and to understand how these affect our conduct, interpretations, and representations of research stories”. It not only exposed the lopsided nature of power relationships, but also helped sustain ethical research relationships (Etherington 2007:599), and facilitated self-examination and alertness to the values, assumptions, prejudices and influences (Etherington 2007:602). Reflexive conversations have the advantage of deconstructing the power/knowledge relation and expanding the interpretations of issues (Kotzé & Kotzé 1997:11), particularly if they are used within the postmodern discourse.

My positioning within a participatory action research bade me continue questioning my practice and the kind of a relationship that obtained between myself and the research participants. I had constantly to remind myself of the question as to whom the knowledge systems, actions and words generated were supposed to benefit (Kotzé 2002:8). Despite the

obvious challenges of maintaining oneself within this framework of responsibility and accountability, the results of this reflexivity were evident as our conversations became even more open and friendly. This way of inviting a conversation was, as the research participants confirmed, adapted to their style of thinking, and it enlivened the research (Pattison 2000:248).

### **2.5.3 The methodological process**

In this research journey we have positioned ourselves within an ethicising research where participation retains its value (Kotzé 2002:25). A search for new knowledge is not a unilateral undertaking but an endeavour negotiated by all who take part. In keeping with the participatory approach as well as the metaphor of a journey employed, I engaged all participants in it. I therefore found Reinharz (1992:211) informative, fitting and useful, when he wrote: "being a researcher-traveller means having a self and a body." Such a concept rejects a traditional embodied objectivity conceivable outside time and space, instead evoking notions of a process, map and steps. To call it a process is evocative of the change that it entails. The selves of all those who participated were expected to change and they did change. As Navone (1977:63-64) observes:

The travel stories assume that the essential condition of maturity is the capacity for growth. Although such growth is a movement in a direction, it knows no apparent limits in its open-endedness for both personal and social development. The refusal to grow, to cope with an open future, would effect the rejection of life as a process of maturation; it would result in a state of arrested development, remaining fixed at a given point and closed to further development.

This journey unfolded in different moments (steps), which were subject to negotiation with the research participants. Indeed, there is no final text as engagement with it constitutes its inhabitation, which through interaction generates new meaning (Muchimba 2004:6). The metaphor of a journey was kept alive throughout the research, as the stories of participants were explored and the reflection on the research process and its impact on them was carried out. The result was that our different selves changed during the journey (Reinharz 1992:212), fulfilling our hope that all of us would be transformed, not only in terms of acquiring new knowledge but also by the process of self-reflection that such journeys could initiate (Kvale 1996:5).

This participatory action research journey is motivated by a need for such change and that willingness for change is born in awareness (Ackermann 1998:90). That awareness,

embodied in the 'moment of insertion' which revealed a disparity in the balance of power between able-bodied and disability (see 1.2.1), set in motion this research journey. It bade me to invite participants from among people with disabilities to be my co-travellers in this research journey.

### **2.5.3.1 Step one: invitation to participants**

The participants consisted of five men and one woman, all living with a form of disability. Two persons were invited from each of the two categories, namely, mobility impairment and visual impairment; and one in each of the two categories, namely, mental handicap and hearing impairment. Although it would have been ideal to have two people in each of the four categories of disability, I was forced by circumstances to opt for one person for each of the two categories of mental handicap and hearing impairment. Acquiring the services of a translator who would be available for every interview, in the case of a person with hearing and speech impairment, posed a challenge. In the case of mental handicap, counsel was provided by someone who works with people with mental handicap to follow that route of one person to work with. Because of her experience in working with people with mental handicap, her advice was followed and her wisdom was evident when we started our conversations. We agreed with her (the person working with them) that a person with slight cognitive impairment who would be able to engage a conversation in more fruitful manner would be preferable (Turkett 2004:51).

The participants represented different denominational and educational backgrounds, and all gave written and informed consent to be interviewed (see Appendix A & B). The participants in the research conversations were Jack, Reg, Tsili, Maki, Sam and Ken<sup>1</sup>. I should also include Rev Frank, the only pastor who was ready to share his story, and 'Maki's mother, who was the only parent I could arrange with to tell her story. One of the participants, Jack, died in July 2010, after a short illness and only two months away from his graduation as a Pastoral Counsellor<sup>2</sup>.

My choice of participants was guided by pragmatic concerns of familiarity, size, availability of resources and time, as well as geographical accessibility not only for initial interviews but also for follow-up interviews (Turkett 2004:49-50). Most of the participants were known to me prior to the commencement of this research, making our agreement and conversation easier

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<sup>1</sup> These are not the real names but pseudonyms of the research participants.

<sup>2</sup> In the memorial service held in his honour we acknowledged the contributions he made in the development of this research. The depth with which he engaged issues will solely be missed.

than if we had we been strangers (Kitchin 2001; Hofmeyer & Scott 2007:72; Jaspal 2009:15) Our positioning within a social constructionist paradigm required me to look at invited participants not as a group representing segments of the population (Holstein & Gubrium 1995:74), but as individuals capable of the production of “representative horizons of meaning.” In recruiting participants, in some cases (mental handicap) I had to rely on leaders and co-ordinators of one or the other organisation of people with disability. This assisted me a great deal not only in using sensitive language but also in ensuring that the approach was such that it did not objectify those with whom research was conducted (Kitchin 2001).

In consultation with research participants, I invited their parents, caregivers and/or relatives, as well as their pastors or priests, where possible, to journey together with us in this research. I was particularly interested in those pastors who ministered to churches attended by the research participants. While it was possible to talk to some parents it was not possible to talk to others because of the distance factor. Even with pastors it was not as easy as I had expected, with only one showing a readiness to share his story.

The initial communication of my intentions to involve them in my research, the reasons thereof as well as their input in how the interviews could best be done, were not enough to assure their participation. While with some I could only afford one interview, with others I was not able to round up the envisaged meetings between the participants, myself and the pastors. In one case, unforeseen and sad circumstances that occurred in the parish made it particularly unhealthy to have such meetings. After consultation with research participants attending service in the parish, and in keeping with authentic participation adopted in this research, we resolved not to pursue the issue with the pastor as the tensions were still high. In keeping with authentic participation (McTaggart 1997:28) adopted in this research, the decision had to be reached in consultation with research participants.

Literature relevant to the issue under investigation also constituted an important partner in this research journey, in particular that pertaining to disability in its social and theological dimensions. The many interactions with my colleagues and supervisor proved indispensable and served to change the direction of our journey from time to time. This was to be expected as the needs and experiences of all the research participants were bound to change.

### **2.5.3.2 Step two: negotiating the journey**

The agreement with research partners was followed by detailed discussion of the project and its contents. The inspiration to the research as well as the aims of the project were laid out before the research participants, as a provisional indication of where we would like to go.

Care was taken to ethicise the research by not presenting the project in pre-packaged and finished form. I had to be careful about the privilege to power that my social location and material condition afforded me, and to use that power and knowledge “to ensure participation with the marginalised and silenced, to listen *to* them, but not to decide *for* them, and to engage in participatory solidarity *with* them” (Kotzé 2002:18). Having read the research question and aims the participants felt that they had nothing to change or to suggest, except that they marvelled at the participatory component of the research as something they did not know much about. One (Tsili) aligned it to the principle guiding disability movements: “nothing about us without us”.

### **2.5.3.3 Step three: sharing in our stories**

The participatory nature of this research required the nature and content of the interviews to be negotiated with the participants. This way of doing research presents a way to overcome and address the exclusion that disabled people have faced in the past (Radermacher & Sonn 2007:63). The participants had preference for individual interviews with a possibility of focused group interviews at a later stage if circumstances allowed. A description of what kind of issues would guide our conversation was given verbally and in writing (Appendix D) where applicable, in advance at the request of the participants. I, however, intimated to them that these issues were only ideas that would give impetus to starting our conversation and that our movement within and out of the conversation would be determined by their interests, experiences and needs. This was part of creating a space where participants could feel safe and comfortable to tell their stories (see also 2.5.2.2 a, b and c).

The conversation was expected to focus on the stories of participants with disabilities and what living with disability and the concomitant perception of significant others, the society and the community of faith, are like. The original plan was to give each participant a chance to be interviewed individually and then decide on the basis of that interview whether to meet together with pastors (i.e. participant, parent and pastor). However, circumstances did not allow this to happen. The conversations with research participants were audio-taped, transcribed and sections of them co-read with the participants, with a view to gleaning the cultural and Christian meanings carried in the language used.

### **2.5.3.4 Step four: deconstruction of Christian cultural discourses**

This research is an exercise on deconstruction and re-construction of stories around disability and people with disability. Ideas gleaned from social constructionism, post-structuralism as well as a narrative metaphor were employed to unravel the complexities of



the discourses around disability. Disability discourse is a social phenomenon cast in language and kept alive by social practices (Burr 2003:38), and its operations and meanings need to be understood. The power and knowledge claims they evoke, like the interests they serve, need to be discovered, acknowledged and 'taken apart' (Morgan 2000:45). The way language and practice work to maintain power and knowledge claims is discussed in Chapters Three, Four and Five, in which I trace how ancient and contemporary societies understood and through that understanding constructed disabilities and people with disabilities. I have started exploring ways in which disability within Christian and cultural discourses has, through constructions, acquired different meanings. I further listened to the voices of contemporary literature on disability. The meanings were tested and their ability to either hurt or heal explored together with the participants.

Through the analysis of technologies of power, inherent in language and practices, it became clear that power indeed produce discourses and knowledge. But because meanings carried by words, embedded in language, are never fixed they can be evacuated and inhabited in different and life giving ways. In light of the above, this research looked into the use of language in disability stories and how amenable to power storied-language could be.

Social constructionism, post-structuralism and deconstruction are well placed, through their association to language and its operations as a prime site of constructions, to assist in achieving the aims and objectives of this research. The result of our conversations was proof that language is never stable and continues changing (Freedman & Combs 1996:29). It can, therefore, be deconstructed and reconstructed. The application of the narrative technique of deconstruction, to achieve this end, unfolded in three main ways: 1) I sought to identify binary oppositions and the dualistic thinking on which dominant disability discourse is based, 2) to underline stories that lie outside the dominant disability story line, 3) and to expand on unique outcomes gleaned from conversations with research participants. The idea is collaboratively to create alternative, life-giving disability stories.

#### **2.5.3.5 Step five: Inviting participants in the creation of a practical theological model**

Participation in this research is not mere tokenism, and participants' ideas were taken seriously. Having positioned myself within a contextual practical theology which has leanings towards knowledge derived from lived experiences I was not, therefore, coming into this research as an elitist interlocutor. Rather, I was reflecting from the underside of history, together with the research participants (Bosch 1991:423), Notions rooted in real life

experience on what disability and living with disability means. I was not bringing the practical theological model developed elsewhere to the context, but the pastoral care model. This speaks to the experience of disability and people with disability, and was derived and emerged from the context of our conversations. As Stackhouse (quoted in Bosch 1991:430) wrote, that message is not something that we bring to context but something we derive from context. Themes were gleaned from conversations with research participants and were confirmed with them during the follow-up interviews. Stories of the research participants are recorded in italics throughout the entire research to give voice and visibility. On this I consulted with research participants and they agreed.

#### **2.5.3.6 Step six: reporting the research**

Care was taken that our commitment to this participatory research was not sidetracked by the enthusiasm that normally accompanies any research. We stated from the onset that this research journey would be co-owned by the participants (Kotzé 2002:28), and the report on this co-research was a two-way process between myself and the participants. My notes and the transcriptions were shared with research participants for validation and further expansions, as was the draft report of the chapters. Stories not only carry meanings from collective and individual experiences, they also have their own language deriving from contextual and cultural as well as individual experiences. The research report was, therefore, a by-product of all research participants and its validity was a negotiated settlement. A report written within a context of a dialogical research, as Frank (2005:968) suggests, should offer

...an account of how researcher and participant came together in some shared time and space and had diverse effects *on each other*. The mutual effects that each has on the other continue to reverberate to readers of research reports, who become part of the dialogue; readers' participation causes further reverberations.

#### **2.5.3.7 Step seven: reflection on a research journey**

The last step of this journey is a looking back and a reflection on the journey. It is a recollection of the experiences thus far, for both myself and the participants in this research journey. It is a musing on the transformations the journey has achieved for all of us on the personal, relational and intellectual levels. I came into this research already under the spell of the promptings of the ethic of friendship, where my discomfort is a prerequisite for the comfort of all of us. My positioning within the postmodern, social constructionist and poststructuralist paradigms allowed for the unfixed and unchanging sense of self. This allowed me to evacuate promptings that were not consistent with a greater sense of

connection with the other (Heshusius 1994). It also reminded me of my vulnerability, which makes possible the emerging of stories and selves that would not have emerged and which enabled all of us to experience ourselves differently (Etherington 2007:602). This positioning imposed upon me from the onset:

- a) awareness to make transparent the values and beliefs we hold
- b) sensitivity to display in our conversation and writing the interaction between all of us taking part in this research journey, so that our work could be understood not only in terms of *what* we have discovered, but also *how* we have discovered it
- c) awareness and sensitivity to cultural and dogmatic differences (Etherington 2007:602).

This reflection on the research journey was made in Chapter 8.

## **2.6 CONCLUSION**

My situation within the postmodern context brought to the fore important associations with social constructionism, post-structuralism and deconstruction. The methodological approaches adopted in this research were not only consistent with the above frameworks but also promised to be sensitive to the ethical positioning adopted in this research journey. They will be employed in the course of this journey to tease out the dynamics of the disability story.

## CHAPTER 3

### CONSTRUCTIONS OF DISABILITY IN CHRISTIAN HISTORICAL NARRATIVES

#### 3.1 INTRODUCTION

In this chapter I set out on a journey to converse with the Christian historical voices of disability, in particular the social construction of disabilities within Christian narratives. The basic assumption that underpins not only this chapter, but also this research, is that the notion of disability has assumed different meanings throughout the years (Stiker 1999:ix). Meanings, because of their discursive nature, cannot be finalised but continue changing and acquiring new significance, depending on the context. As a discursive product, disability is a creation of specific and historical conditions (Ballard 1992:28) with its meaning is dependent on the context. While I admit that disability discourse has been and continues to be a contextual and, therefore, shifting category, it is also sustained in existence by an ideal, a fixed point of reference and a centre around which everything evolves. That centre is a regulatory body that normalises the meanings and value of bodies. In its quest to normalise it works through binaries (Powell 1997:23), which we (myself, the participants and co-researchers), shall identify and expose.

#### 3.2 JOURNEYING WITH CHRISTIAN DISABILITY NARRATIVES

The Christian story, as was, on disability has a bearing on how different Christian communities today behave towards people with disabilities. In this section I therefore pay particular attention to how the Christian perceptions on disability evolved from an ancient Mediterranean environment to present day status. As Barnes (1997:4) suggests, we cannot fully understand the present effects of the Western culture unless the central value systems around which such a culture is clustered are fully appreciated. However, the “contemporary attitudes toward people with perceived impairment have their roots in the ancient world of the Greeks and Romans” (Barnes 1997:4), as well as Jewish religion which is “seen as the principal source of contemporary Western moral values” (Barnes 1997:14; Berquist 2002:10, 182-183). I cite some writers, particularly Berquist, Covey, Stiker, Hartsock and Barnes, to show how values on the body throughout Christian history shaped perceptions and attitudes on disability and people with disabilities. Points of intersection on these perceptions and attitudes between different historical epochs will be underlined and pursued, insofar as they contribute toward understanding the fluidity of constructions and meanings of disability.

### **3.2.1 Politics of disabilities in the ancient Mediterranean world**

The Christian tradition grew out of a cluster of traditions that formed part of what I refer to as the ancient Mediterranean worldview (Barnes 1997:4). These are the Greco-Roman world, the Jewish culture embodied in the Hebrew Bible writings and other extra-testamental writings, as well as the New Testament and its environment. Christianity grew up within these traditions and in conversation with these worldviews (Stiker 1999:39; Berquist 2002:181-196). It is for this reason that we trace the presence and meaning of disability within these traditions. Through this exercise, I hope to glean different meanings assumed by the disabled body throughout the years.

The basic assumption is that, underlying these meanings are different philosophical and cultural ideals that are central to the understanding of these meanings. As Webb-Mitchell (1996:38) observes, societies change in terms of what they value. Not only do they adopt different labels and categories but they also attach meanings to these changed and newly adopted labels and categories. I have adopted the notion of a regulatory body for use as a germane interpretive tool in the analysis of the meanings of the body in the ancient Mediterranean world.

#### **3.2.1.1 The regulatory body**

Societies attach meanings to the body (Berquist 2002:3), developing ideas around it and each part of the it, its appearance, weight and height, such that the body eventually, becomes a social product (Berquist 2002:18; Viviers 2005:880). Though none of the meanings attached may be inherently part of the body's weight, height or appearance, societies are not deterred from placing certain meanings on the said bodily qualities. This may be referred to as social or cultural construction of the body (Berquist 2002:5), and it has been scripted, institutionalised and legitimated (Berger & Luckmann 1966:58-60) by adherents of that society to convey meaning. The adherents are in turn shaped by meanings attached to that body and its parts, and in this sense it is understood as a social script onto and into which are written society's values. Viviers (2005:880) writes:

'Body' as social script refers to the symbolic body of a society or the ideas that a particular society holds about body. These body ideologies do not necessarily coincide with real flesh and blood ones but are ideal constructs.....The symbolizations of the body become part of a society's ideological world, expose its deepest convictions and values and provide a tangible avenue (therefore 'body') to the heart of culture.

When such a body becomes a yardstick against which all other bodies within a culture, are measured, it becomes a regulatory body. A regulatory body is defined as a corporeal, natural body turned, through social scripting, into a symbol that represents the ideas that a particular society has about that corporeal body (Viviers 2005:880). As a symbolic body it is not only a product of a culture that gave life to it, it in turn gives shape to that very same culture. In the words of Vorster (2005:575), it functions as the social yardstick in the construction of meaning as well as a site of power relations. As such, it embodies the ultimate values of society. Though brought into existence by social negotiation, it acquires qualities of durability and objectivity within a particular historical context (Vorster 2005:577).

The notion of a regulatory body, in terms of its functions, comes closer to, if not representing what Bourdieu (1972; 1990) called *habitus*. In Bourdieu's view a *habitus* embodies systems predisposed to function as principles that not only generate but also organize practices (Bourdieu 1972:18). The *habitus* functions to structure structures. As an embodiment of principles generated and sedimented over a long period of time, the regulatory body attains the status of the "common sense" that regulates and directs thoughts, practices and behaviours of society (Bourdieu 1990:53; Vorster 2005:578). Consequently, every culture has its constructed ideal body against which all other bodies within the same culture or period are defined and regulated.

The regulatory body embodies the features of normativity or naturalness, generating "what is seen as normalcy and natural" (Vorster 2005:577). It becomes a norm and a criterion against which all normality, naturalness, perfection and wholeness of a body are measured. Through it all other bodies are constituted, and it further serves as the context within which these other bodies re-constitute and reproduce themselves. Its non-negotiable and objective status adorns a regulatory body with a durable and generative capacity.

In the process of generating, constructing and reproducing bodies it also defines the non-normative. The very process of creating the normative, constructs at the same time its opposite, non-normative, which in the logic of the binaries becomes the marginalized term. The regulatory body works through and evokes this binary logic which classifies, orders, polarizes and establishes fixed boundaries between natural and unnatural; normal and abnormal; perfect and imperfect; male and female; insiders and outsiders; whole and unwhole; pure and impure. It, therefore, represents imbalances in the relations of power between the two poles of the relationship continuum (Powell 1997:23-35; Galvin 2003:156; Vorster 2005:589).

Far from reading the notion of the regulatory body into the different traditions that are analyzed in this chapter, the notion emerges from the same traditions and worldviews. Each of these traditions, as I shall argue, had an ideal body that all other bodies had to match up to. Such a body served to embody all the values and beliefs the society had about how bodies should be (Berquist 2002:6). Using this notion of the regulatory body, the Christian perspective on disability, as well as its principal sources, the Greco-Roman worldview and the Judeo-Christian traditions, are analyzed. The idea is to identify the ideal and the binaries spawned thereof.

### **3.2.1.2 Disability in the Greco-Roman world**

To date, Robert Garland's seminal publication, *The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World* (1995), remains the most comprehensive historical treatise on that specific topic. Garland (1995:viii) observes that though there is a growing interest on the body as a cultural construct, publications on disability in the Greco-Roman world are proportionately quite scant. This is particularly surprising given that no culture has so consistently idealised bodily perfection and its opposite as the Greeks and the Romans. As Garland (1995:viii) argues:

By their own imperious reckoning, the Greeks and the Romans stood head and shoulders, culturally speaking, above all other races on earth in part because they alone exemplified the ideal human type. Any departure from that ideal type, however trivial, was therefore interpreted as a mark of the despised barbarian, whose attributed physiological defects were regarded as an expression of the latter's cultural limitations.

Given this unique idealisation of a perfect body among the Greeks and the Romans, it makes sense, therefore, to look for an ideal or regulatory body within these cultures, to which all other bodies had to conform. However, although both Greeks and Romans shared similar features in their conceptualization of a perfect and regulatory body, there were some notable differences.

### **3.2.1.3 Regulatory body in the Greco-Roman world**

The constitution of a perfect body in a Greco-Roman world can be reduced to the following criteria: 1) order/arrangement part in a whole; 2) gendered features; and 3) conformity to the divine features (Viviers 2005:881; Vorster 2002:40).

In terms of the first criteria, strength, endurance and beauty were constitutive of a perfect body according to the Greco-Roman worldview. An ideal body had to be perfectly balanced;

neither too thin nor too fat; neither too tall nor too short. The Greeks and the Romans placed great value on competition, war and sport, and their bodies had to be such that they could participate successfully in all these activities (Garland 1995:14). Physical and intellectual fitness were esteemed features in both worldviews, as they ensured triumph and conquest in any form of competition (Barnes 1997:13). Because of the violent and competitive nature of Greek society there was, therefore, little room for people with any type of physical bodily defect, or what Goldhill (2004) calls “a flabby citizen”.

Not only was bodily perfection measured in terms of strength and endurance, it was also expected to be

...perfect in all its parts, limbs and senses, and have passages that are not obstructed, including the ears, nose, throat, urethra and anus. Its natural movements should be neither slow nor feeble, its limbs should bend and stretch, its size and shape should be appropriate, and it should respond to external stimuli.

(Garland 1995:14)

Gender was also constitutive of a perfect body, which was not only expected to be muscular, symmetrical and strong, but also had to be male. Women, like the non-Greeks, were considered inferior (Barnes 1997:12), and the greatest threat or insult to a man was to have, or be told that he had, a body like that of a woman (Goldhill, 2004). In several of his writings, Aristotle as (quoted in Garland 1995:1) is reputed to have candidly stated:

Only in man are the natural parts in their natural position and that, in the zoological hierarchy, men were at the pinnacle with women one giant evolutionary step below – a step which, in his telling phrase, represented ‘the first step along the road to deformity.

The human male, therefore, represented the standard for measuring physical perfection. Competition, both individual and collective, constituted for the Greek males the necessary means for achieving physical and intellectual excellence (Barnes 1997:13).

The perfect body also drew inspiration from conformity to the image of the Greek gods, in which its artistic beauty and perfection could only find ultimate representation, especially Apollo, “the most Greek of all Greek gods” (Garland 1995:105), and when depicted as a young man at the acme of physical fitness was the most inspiring. In Malul’s (2002:175) view, such a god would represent an ultimate structural-principle, or as Dutton (1996:25) described it “a representation of perfected humanity”.



Because of its tendency towards what became known as 'physiognomics', the Greco-Roman worldviews espoused the position that there was a correlation between appearance and character, and that physical deformity was an index for characterization (Garland 1995:87-104; Hartsock 2007:67-68). According to the Greek mentality, a bad body meant a bad citizen, and the state of the body that was uncared for was a reflection of a debauched moral disposition. This is attested to by Socrates remarking on the poor physical condition of Epigenes' body as shameful, thus further imbuing it with moral overtones (Goldhill 2004).

Because a body was a public property it had to be taken good care of. A perfect male body with divine features and perfectly balanced embodied the ideals and values of Greco-Roman society, and all other bodies had to conform to it. Failure to maintain the standards brought about the shame of not being apt to participate in public life (Goldhill 2004). There was a normative or regulatory Greek body to which all other bodies had to conform. Not only competing bodies but also public and religious bodies, such as those of a priest and religious magistrate, were required to conform (Garland 1995:64). Already we can observe the implied binaries on which the discourse of the body, particularly in the Greek worldview, was founded. It had to be ordered and arranged as opposed to disordered; male as opposed to female; and possessed of divine features as opposed to human features. In all the above pairs the first is more privileged and the second is marginalised. Often those bodies that did not conform to the norm were either eliminated or treated with disdain.

#### **3.2.1.4 Disability in the Jewish world**

A regulatory body, as Douglas (1966:115) argues, serves as a microcosm of the social body, exposing a society's deepest conviction and values (Viviers 2005:879). The Jewish tradition is a case in point for the identification of these values and convictions. This section will explore how the adherents of this tradition were informed and persuaded by such values and convictions, and examine the nature and meaning of disability in the Jewish tradition, under the optic of the regulatory body. The role of the Jewish traditional discourses in the formation, maintenance, preservation and perpetuation of the regulatory body will also be addressed.

This section has two main parts, starting with the regulatory body politics within the Jewish tradition. Reference here extends beyond the Hebrew Bible to other Jewish extra-biblical sources. The second part will trace the regulatory body politics within the New Testament and its environment, as well as early Christian literature, with a view to identifying in them the regulatory body politics.

### **3.2.1.5 The Jewish regulatory body politics**

The focus of this section is on ancient Israel's notion of the regulatory or ideal body. Berquist (2002:18) notes that the ancient Israelites, like other societies, attributed meaning to bodies, what should constitute them, how they should be structured. The criteria under which they would be judged as normal, natural, perfect and whole, depended entirely on the cultural reckoning of ancient Israel. The combination of these different aspects would add up to the notion of the ideal or regulatory body.

While the Hebrew Bible constitutes an important text and resource, there is no intention on my part to equate Jewish tradition with the Hebrew Bible. My discussion on disability within Jewish tradition will rely heavily on biblical literature, however recourse will also be had to extra-biblical literature and other Jewish sources that would shed some light on the regulatory body politics, as well as scholarly works on the subject.

Berquist's (2002) presents a comprehensive and rigorous critique at the notion of the body within the context of household in ancient Israel, defining the ideal body according to ancient Israel, as the whole body (2002:19), while for Stiker (1999:24-27) ritual cleanliness and wholeness of body constituted an ideal body in ancient Israel. For the ancient Israelites, as for the Greeks, a regulatory body consisted of wholeness, maleness and godlike features (Viviers 2005:881). Firstly, for a body to be whole it ought to have all organs intact and function properly (Berquist 2002:19). Not only was a person expected to have all the members of the body, such as arms, legs, hands, eyes, genitals, he or she also had to be fully functional. A whole body is balanced body and as such loathes "too much" or "too little". Secondly, it ought to contain itself within fixed boundaries (Berquist 2002:19). A leaking or oozing body already violates the sense of fixed boundaries, which had to be construed against the background of the cultural map of social time and space (Stiker 1999:28-29). They determined the arrangement within space thus defined and the social lines that defined boundaries of exclusion and inclusion; who to touch and who not to touch; what was acceptable and what was not. This discourse, as with any worldview, should be read in the context of the core values of ancient Israel (Neyrey 1998:205), as they provide direction, clarity and consistency to a system (Neyrey 1988:68). Reference to Israel as a social and cultural body, therefore, implied embodiment of core values entrenched in and influencing norms in the life of this group. Such core values also defined membership, belonging and hierarchical structure (Malina 1981:122-134).

In Judaism, 'Holiness' was a core value around which everything evolved. It was defined by Douglas (1966:50) in terms of creation, which in essence represented God's power to classify, arrange and order. Through the premier act of creation, God put everything in its place and thus expressed God's holiness (Neyrey 1988:69). The Temple became the concrete symbol of God's holiness, while classification of persons, as whole and pure, was judged by their proximity to the temple, designated as the 'House of Yahweh.' The temple in Jerusalem was structured in such a manner that people, according to their classification, would know their special and temporal boundaries (Malina 1981:132).

There were limits, for example, in terms of time, within which the high priest could enter the Temple's most holy place, the Holy of Holies (Hb 9:7). This means that his presence in that space, outside regulated time, rendered both him and the space impure. There were also limits in terms of rank within the hierarchical structure. People with damaged bodies "were pushed to the margins of Israelite society" (Berquist 2002:30). That determined their purity, which could be gauged according to their location within the map of places, since ranking of people replicates the map of places (Neyrey 1988:69; Malina 1981:131-137). Holiness therefore meant wholeness.

People with too little or too much were classified as lacking in bodily wholeness, where 'too much' refers to something that extends beyond its boundaries, where it does not belong. Regarding the body, a hermaphrodite, for example, being both male and female, is considered as having 'too much', on account of some sexual feature which spills over into an area where it does not belong. 'Too little', meanwhile, suggests having less than normal, or as Malina (1981:61) phrased it, "incompletely in its place or unsettled in it". A eunuch, or a blind, deaf or lame person, was considered as having less than normal with respect to the regulatory body (Malina 1981:133). Such persons were therefore lacking in holiness, hence their distance from the centre of the temple.

Belonging or membership was not automatic, but had to be measured against considerations of wholeness and purity, which served as criteria for inclusion or exclusion. Full-blooded Israelites had to avoid, by all means, contact with gentiles, their territory and utensils. Similarly, gentiles' space was not marked, as they did not belong to God's people. They were completely outside the domain of purity scale, and could not be allowed to participate in the collective honour of the priests and other full-blooded Israelities, in the temple (Malina 1981:132). As far as the temple was concerned they were entirely out of place.

These considerations exacted much rigour in ensuring that the Jewish body's wholeness was by no means tarnished. They loathed an indiscriminate mingling with different other bodies as some hardly satisfied the culturally constructed norm of wholeness. They were, as a result, using Mishnah's language, 'fathers of uncleanness' (Danby 1933:137). They were by nature defiling, which rendered a body impure and therefore unwhole. Because purity referred to the ordering of the social body, with everybody and everything in their right place at the right time, one had to conduct oneself in a manner that would not compromise that purity and wholeness. The ability to distance oneself from anything that pollutes was not only an obligation but was also a concern for others who formed part of the social body (Berquist 2002:42). This social body, as embodied in the physical body, had to be protected at all costs, in what was referred to as 'self-control', a highly prized attribute in ancient Israel.

Maleness was also constitutive of wholeness, and according to degrees of purity and wholeness a woman's body was not as whole as that of a man, since amongst other factors it lacked an important ability to contain itself within fixed boundaries. Berquist (2002:80) cogently argues:

A man's body is more whole than a woman's. Although a man's body has openings to mediate between himself and the outside world, a woman's body is seen as more porous than that of the man, and therefore poses a far greater risk for her society when it comes to impurity.

A woman's bodily orifices, especially the vagina, threatened the boundaries of her body politic, for it served as an opening through which all impurities could enter. It also underwent continuous changes, unlike the relatively unchanging male equivalent (Viviers 2005:881). An inability to have control over menstrual flow was indicative of looseness. If wholeness implied control and self-control, then it made sense, in the Jewish purview, that women could not be the best representations of a perfect or ideal body. Wholeness therefore implied physical integrity or completeness, purity and the ability for self-control. The male body, with godlike attributes, presented a good candidate for a perfect, whole and, therefore, ideal body.

All the above features of physical integrity, purity and self-control matched up to the *persona* of God, who served as the ultimate embodiment of the values of society, the regulatory body *par excellence* (Viviers 2005:803). To God, holiness, wholeness and completeness were necessary attributes. For any Israelite to be able to participate fully in social and religious activities, physical wholeness and purity were necessary. The socially constructed notion of an ideal body, from a Jewish perspective, was therefore pure and whole. This ideal body

was founded on the implied binaries of pure/impure; whole/unwhole; male/female; holy/sinful, with the first member of the binary privileged and the second marginalised.

### **3.2.1.6 Disabled body and the Jewish tradition**

Reading the Jewish perception of a disabled body through the lens of a regulatory body, according to the socially constructed notion of wholeness, purity and the ability for self-control, the disabled body did not conform to standards, and so did not enjoy full rights in the ancient Israelite community. This constituted a further restriction to full community participation in ancient Israel. In the main, the Jewish tradition, alive in the Hebrew Bible and mentality, attributed disability to divine ordination resulting from the sin of people with disability or their parents. God was holy and God created the world without blemish, and so any type of disability was seen as an affront. It made sense, therefore, that only sin could account for the presence of perceived impairment. Deuteronomy 26-28 set out the terms for a treaty between Yahweh and Israel, in particular the blessings and curses that accrue respectively from observance and non-observance of the Lord's commandments.

Leviticus 21:16-22, with its list of imperfections, makes sense if read in the light of the regulatory body politics discussed above. It cites blindness, lameness, mutilated face, excessive length of limb, injured hand, hunched back, dwarfism, itching disease, scabs or crushed testicles as defects that precluded any priest from approaching the altar of Yahweh lest they profane it. These imperfections constituted incompleteness and impurity, which would constitute an affront to God who was holy and without blemish (Lv 21:8).

Disabled bodies, because of their perceived damage and defect, were ranked last on the purity scale, and therefore not only unwhole but also unholy. They, in many ways, failed to meet the qualities and features of a perfect, ideal and regulatory body. Judged as having too little or too much, they were therefore "out of place" and as such could not stand before the Holy God (Malina 1981:14). The disabled body, because of its inability to meet the demands of the regulatory body, was categorised as abnormal, unwhole and impure, and so was relegated to the liminal realm of anti-structure or dis-order (Viviers 2005:800). People with a form of impairment were therefore treated with contempt and their place at the temple was far removed from the Holy of Holies.

Priests, because of their special relation to God, in terms of holiness, were required to be more vigilant than the rest of society in maintaining wholeness and holiness. It also fell to them to declare people clean and whole, and so fit to stand before the holy God, or unclean, and so unworthy of inclusion in God's worship (Neyrey 1988:68).

Lest we be carried away by the generalisations we make, a caution is in order that there seems to be another tradition within Jewry that counters excluding people with disabilities from the life of Israel. Leviticus 19:14, represents such a tradition. It suggests that people with disabilities should not be cursed or obstructed. 2 Samuel 9:1-13 is another example where Mephibosheth, Jonathan's son was accorded great compassion. Though the reason for such compassion did not lie with his disability, at least his disability did not impose on David ritual strictures that would be demanded for people with physical impairments.

Discussion now turns to a disabled body in the New Testament and Western Christianity.

### **3.2.2 Disability in the New Testament and Western Christianity**

There is an assumption that the New Testament and the early Christians were deeply immersed in and part of both the Greco-Roman and Jewish worldviews (Stiker 1999:33). Discussion of a disabled body, in the New Testament and early Christian literature, will therefore refer to similar features in the Greco-Roman and Jewish traditions.

#### **3.2.2.1 Disability in the New Testament**

For the most part the New Testament continued much of the legacy of the Jewish and Greco-Roman worldview of a disabled body, mainly because the New Testament grew out of a precarious socio-political period, marked by unparalleled social, economic and religious transitions. Bosch (1991:25) describes it as

a time of sectarianism and fanaticism, of religious traffic between East and West, of merchants and soldiers carrying home new ideas, of experimenting with new faiths. Socio-politically the period was no less volatile. Palestine was under Roman occupation.

It is not surprising that the Jews at the time of Jesus were caught up in this cross-fertilization of cultures (Kee & Young 1957:18). Greek philosophy and culture had penetrated much of Asia Minor, before Rome, with its military might, began to exert hold on the entire region, including Palestine. Jesus' story, which constitutes the essence of the New Testament and Christianity, was one among several new ideas that emerged around this time, and was affected by this cross-fertilization of cultures (Kee & Young 1957:30, 47). It is within this historical context that the interface between the Greco-Roman, the Jewish worldview and the New Testament and Christianity has to be read and understood. Given this interface, the notion of a regulatory body would not, therefore, be extraneous to the New Testament's outlook, despite the cultural shift that would have left many aspects of Israelite society unaffected (Berquist 2002:182).

The Jewish mentality that sees disability as evidence of sin is evident in the Hebrew Bible, and was carried over into the New Testament. Examples of disability are not rare in the New Testament literature, within and beyond the canonical books, and they constitute a bulk of literature in the healing narratives. The Gospels in particular contain a number of references to people with disability, especially in the healing narratives, which although generally Christological in nature, conjure up elements of the cultural context within which they were written. This detail notwithstanding, some useful information, around disability and the perception of disability at the time of Jesus can be gleaned through interacting with the text. It is appropriate here to cite some examples to elucidate, in a more general way, the meaning and treatment attached to disability and people with disability in the first century Mediterranean world.

Critical to reference to any kind of disability in the New Testament is the Johannine story of the man born blind (John 9:1-7), since it raises a number of associations with the ancient Mediterranean worldview. The disciples, in John 9:2, are raising a pertinent Jewish theological question, evoking the sin–sickness association that was still pervasive in the first century. This question of “who sinned?” established a clear association between sin and sickness or disability, assuming in clear terms that somebody was guilty of transgression. They wished to know whether it was the man or the parents, and the disciples were evidently under the spell of popular ancient belief that the wrath of God manifested itself in disability (Ex 20:5; Dt 5:9; Tb 3:3). John 9:2, read together with the latter Hebrew Bible texts, reconnects to the idea that punishment for parents’ guilt was meted out on their children.

John 9:2 read together with synoptic texts (Mt 9:1-8; Mk 2:1-12; Lk 5:17-26) conjures up a sin and disability conflation quite common in the ancient Mediterranean world (Barnes 1997:14). The man was brought to Jesus not because he was a sinner but because he was paralyzed. The answer, “Your sins are forgiven” serves a theological purpose that through Jesus the messianic salvation-time has opened, in which God will forgive sins (Stock 1994:146). However, read together with John 9:1-7, what would have remained a simple conjecture of sin and sickness conflation becomes clearer.

Authors disagree on the position taken by Jesus in John 9:2-3. Is he intentionally going against the view widespread in Judaism (Schnackenburg 1979:240)? Is he disavowing the universalizing of particular connections in response to a specific question about a particular man and/or his parents (Carson 1991:362; Bultmann 1971:331)? Alternatively, is he simply considering it irrelevant (Wilde 2003:11)? Could this text be read as Jesus’ pronouncement or position on disability? Should it be seen as a specific answer, with universal overtones, to

a specific question with general overtones? Phrased differently, is the question about this man or his parents specific and not about any other person who shares in the same fate? Would that not, perhaps, be asking too much from the text, which was merely concerned with setting up a man born blind as a foil to religious leaders who, though bestowed with healthy eyes, fail to see (Harstock 2007:183)?

Whatever the answer to these questions, the language and the implications could not have been extraneous to the audience, which was, for all intents and purposes, Jewish. Whether or not Jesus' answer constitutes a rebuttal of the theology assumed by his disciples, the point is made that during the first century Mediterranean world, the sin–sickness/disability association was still very strong. Disability remained a sign of moral imperfection or divine retribution for sin (Eiesland 1994:71), and these New Testament passages were cited as proof of this.

However, this has to be read against the deconstructive position taken by Jesus in the New Testament, especially the gospels, with regard to disability. Jesus not only disrupted the Jewish religious prohibitions around which understanding of disability evolved, he also challenged the entire religious mentality (Stiker 1999:33). His perspective revealed that within the Jewish notion of disability, and indeed within the entire mentality, lay the potential for its destruction. Jesus' challenge of this Jewish perspective showed that there were more ways than one of conceptualising disability. The traditional binary view of pure/impure; proper/improper; holy/profane is subverted by his statement to the effect that pollution of a person does not depend on the exterior determinants but is self-inflicted.

Such a breaking of the old order does not make the notion of disability more stable than it was before, but rather it opens horizons unthinkable in the old order (Stiker 1999:35). Nor does the possibility of the new order guarantee the non-exclusionary treatment of people with disabilities. I will argue that, despite Jesus' muddling of the old order which rendered it possible for peoples with disabilities to partake in social and religious life, the Christian church after Jesus' death was still following a similar way of thinking (Stiker 1999:65-119).

### **3.2.2.2 Disability and Western Christianity**

The interaction between the Greco-Roman and Jewish cultures has gone a long way in shaping the Christian perception of disability up to the present day. Berquist (2002) dedicates a chapter of his seminal work, *Controlling Corporeality: The Body and the Household in Ancient Israel*, to the interface between Hellenism and Judaism (2002:181-196). The book is pertinent to issues under discussion here for two reasons. Firstly, it



highlights how the intercourse between the two influenced Western culture, with respect to the body and to which we are heirs; and secondly it traces the origins of the widespread concept of dualism around which the notion of hegemonic disability is organised (Berquist 2002:193). I now turn to the understanding of disability within the Western Christian tradition, greatly influenced as it was by the preceding worldviews.

Covey (2005) identifies two traditions that have characterized the Christian church over time. The older tradition, which connects to the previous section, continued the legacy of the Hebrew Bible tradition and viewed disability as resulting from sin. Alongside the latter tradition emerged another, which saw people with disability treated more with sympathy and compassion. Rather than the latter attitude supplanting the former, both existed alongside each other for centuries and continued to influence societies' perceptions of disability in different ways. A survey of trends, paradigms and meanings of disability throughout the years, following the death of Jesus, is therefore pertinent here.

#### **a) Christian treatment of disability as evidence of sin**

From the time of the early Christians, through the Middle Ages to modern times, disability and disabled people have continued “to surface as that which must be assimilated or made to disappear” (Stiker 1999:xi). These expressions manifested themselves in different ways and in varying degrees of inhumane treatment, stemming from an entrenched belief that disability was a sign of God’s punishment or displeasure for sinful behaviour. As Covey (2005:108-109) observes, throughout much of history illness and disability have been seen as consequences of transgressions against God, and this view lasted for centuries.

With time, the Christian Church became less tolerant and increasingly took to seizing every opportunity to blame the disabled for mishaps that overtook society. It was during this time that the events around “Malleus Maleficarum”, with its propensity towards hunting, persecuting and eliminating those suspected of witchcraft, surfaced and reached a peak (Sprenger & Kramer 1487). Disabled people were seen as providing “living proof of Satan’s existence and of his power over humans. Thus visibly impaired children were seen as ‘changelings’ – the Devil’s substitute for human children” (Barnes 1997:17). It was believed that such children were the result of the parents’ (especially the mother’s) involvement in witchcraft and sorcery. Their trial and elimination, which the Church fully supported, was thus seen as the solution.

Around the nineteenth century, and alongside a noticeable upsurge of Christian charities, was a new development which Barnes (1997:18) calls “the systematic individualisation and

medicalisation of the body and the mind". People with disabilities were excluded from mainstream society and confined into institutions (Stiker 1999:99,106). In time, the eugenic ideals took over and expressed themselves in the callous exterminations of the Nazi camps, part of a plan to achieve a "Utopian society", rid of the disabled, the 'abnormal' and the different 'other' who did not meet the requirements of an ideal and perfect body.

The Enlightenment paradigm, with its insistence on the rational and the empirical, had far-reaching implications for the extent to which the Church could explain and dictate what should be believed (Barnes 1997:17). Spiritual-oriented paradigms gave way to more natural based views of reality, particularly of diseases and illnesses. Consequently, the view of disability resulting from sin and/or witchcraft gave way to more natural and scientific based explanations. The influence of the enlightenment thinkers, with their emphasis on the value of reason and science, left a lasting mark on the extent to which religion in general and Christianity in particular could reign unchallenged. They promoted the importance of individualism, scientific and social progress, and the capacity of the mind to draw conclusions through a process of reasoning (van Rensburg 2000:3).

Analysis of the above view points to a trend that saw people with disabilities as foils of the sacred, monstrous retributions from God, deserving of punishment and quarantine at best and elimination at worst. It seemingly carries over from the Jewish tradition, whose ideal body spawns binary opposites of holy/sinful and whole/unwhole. In the view of a Christian Church that inherited this legacy, institutionalisation was the best that could happen to the disabled, and extermination the worst.

However, there was also a more sympathetic tradition to the cause of people with disabilities in the Christian tradition.

#### **b) Disability and compassionate care in Christian tradition**

The Book of the Acts of the Apostles offers a prime example of how early Christians lived among themselves after the death and resurrection of Jesus, depicted as living in fellowship and service to one another. Characteristic of them was mutual aid, in the form of feeding the hungry, clothing the needy and caring for the sick (Kee & Young 1957:49, 189). Taking a cue from this tradition and practice, and informed by Jesus' attitude in the gospels, the Christian Church saw this as partaking in Jesus' ministry, and prolonging it (Ac 2:43-47; 4:32-37). After the example of Jesus, who had the plight of the marginalized, the poor and the disadvantaged at the centre of his ministry, the Church carved for itself a new role of protector and benefactor of the downtrodden (Covey 2005:108).

Influenced by this attitude, many people, under the auspices of Christianity, showed compassion towards people with disability. The burgeoning numbers of hospitals, asylums and hospices before, during and after the Middle Ages, marked a radical departure from the Greco-Roman and Jewish treatment of people with disabilities. Several personalities made significant contributions to improving the plight of people with disability, in particular St. Nicolas of Thaumaturgos, St. Basil of Caesarea and St. Lymnaeus, in keeping with Jesus' sympathetic stance towards the sick and destitute (Covey 2005:112). The Council of Carthage provided further impetus to the entire Church, especially the Bishops, to have services extended to those who were ill and to have hospices built in close proximity to churches.

The advent of the Protestant reformation and the Enlightenment marked, in many ways, an important shift in the church's thinking and practice. The long-standing symbiotic relationship between church and state that had continued undisturbed throughout the Middle Ages was affected by this new turn of events. The once united and strong Holy Roman Empire began to disintegrate into various nation states (Bosch 1991:275). Coupled with the wave of an enlightenment paradigm, which put pressure on the longstanding symbiosis, this disintegration weakened the church's influence on the public arena. Covey (2005:113) captures well the result of the tug-of-war between church and state over power and control:

Christianity lost much of its control and authority to the state. This struggle for control resulted in a reduction of funds available to care for the poor and consequently Christian sponsorship of facilities declined and people developed a greater sense of unworthiness of those seeking charity, such as those with severe disabilities. The state, due to centralization, was in a better position to maintain the social order and control people.

Despite the state's tendency toward centralization of services for people with disabilities, the Christian Church retained its influence in caring for such people, the difference being that what it now did could not in any way have been done on behalf of the state, as the two entities were now acting independently of each other. This new development did not however improve the plight of people with disability, but rather led to the proliferation of state-run confinements and 'insane asylums' across Europe (Webb-Mitchell 1994:67). The efforts of William Tuke, a Quaker in York – which represented a radical departure from the type of care provided by the state's segregated colonies – went a long way in assuaging what was developing into inhabitable human conditions of the lunatic asylums.

The treatment of people with disability within the Christian tradition was not homogeneous, for over the years people's perceptions about them continued to change, and meanings

attached to disabilities differed from one historical context and time to another. While the actions and attitudes of the compassionate church were not ideal by today's standards, they however represented a different and better discourse, as confirmed by Reg and Tsili, who argued that although it was a charity-like-compassion, it was better than what had been represented by the sin-disability discourse.

This chapter now turns to the different disability categories and how they were represented in Christian narratives.

### **3.3 JOURNEYING WITH DISABILITY CATEGORIES IN CHRISTIAN NARRATIVES**

Literature on the ancient Mediterranean world is replete with references to people with disabilities. The four categories, namely, mental illness, visual impairment, physical impairment, and hearing impairment, constitute the central focus of this section. The choice of terminology should not be taken to represent the position of the researcher or that of the Christian narrative, but rather it is guided by the need to balance proximity to the language of the text against current usage. I give a brief overview of the four categories, paying attention to salient features peculiar to each at different periods, from the Greco-Roman period to that of the Christian Church.

#### **3.3.1 Mental illness**

Mental illness was as much of an issue in the ancient Mediterranean world as it is today (Garland 1995:137). As a notion, it has gone through different stages of historical development, and it would be simplistic to conclude that a consistent picture emerges from an analysis of these, rather there were both positive and negative episodes.

##### **3.3.1.1 Mental illness in the Greco-Roman world**

Mental illness was a common phenomenon in the Greco-Roman period, manifesting itself in different ways and attributed to a number of causes, ranging from organic (physiological) to spiritual. In Greece, Hippocrates (460-377 B.C), the father of modern medicine, vigorously refuted claims for the intervention of demons in the development of disease, preferring to regard mental illness as having natural rather than metaphysical causes (Comer 1998:11). This physiological or organic explanation has survived to the present, though it gathered some sophistication, especially with the advent of rationalism (Eldam 2003:30).

Supernatural causes of mental illness have long been put forward, even among the Greeks. Kleomenes, a Spartan king, whose alleged mental illness posed a danger to society, was

believed to have been punished by gods for committing acts of sacrilege (Garland 1995:138). The human body and mind have been viewed as sites of struggle between forces of opposing realms, with normal and abnormal behaviour seen as an outcome of the prevailing of one upon the other (Eldam 2003:27). While some cases of mental illness were treatable through exorcism, magic, prayer and herbs, there were other forms such as starving, flogging and fettering. In extreme cases, some patients with mental illness were killed.

Discussion now turns to the Jewish milieu for an examination of mental illness and how it was understood.

### **3.3.1.2 Mental illness in Jewish world**

Though translating the notion of mental illness to the modern one is problematic, it was not unknown in the world of the Hebrew Bible, where the equivalent of madness *sga'on*, with its root *sg*, is suggestive of the various strange behaviours displayed by some individuals, and seen as a punishment. According to Deuteronomy 28:28, those who did not obey Yahweh were, among other things, struck down with madness (*sg*). Nebuchadnezzar (Dn 4:23-40), though punished with having to eat grass by Yahweh for his intransigence, the word used is not *sga'on*. His mental illness has been deduced from his unusual behaviour.

The Hebrew Bible is not helpful in tracing the origin and meaning of madness, perhaps because it was intended to be neither a medical treatise on madness, containing aetiology of different illnesses, their symptoms and treatment, nor an historical exposition about mad individuals. The conclusion that can be drawn from what sketchy information exists is that there is a reflection of a sin/madness in the Hebrew Bible. God was in certain cases a cause of madness and could make it disappear when proper amends had been made.

### **3.3.1.3 Mental illness in the New Testament**

In the New Testament, mental illness was not unknown, with references provided in several of the books (Lk 8:26-29; Mk 5:1-20; Ac 12:15). Though almost all make little or no mention of madness, the behaviour displayed, particularly by the man in chains, represents some violent form of madness known in the New Testament world. In Mark 5:3-5, Jesus' attitude and actions surpass in significant ways those of the inhabitants who had chained the man to protect themselves (Stock 1989:166). One could even argue that Jesus' action subverts the dominant discourse on madness by engaging a man in sane and fruitful conversation. While no connection between sin-madness can directly be deduced from the New Testament texts,

reference to sin as a cause of other forms of disability is suggestive of sin-disability conflation carried over from the Hebrew Bible environment. One cannot, therefore, on the basis of this little and scanty evidence, make a case for or against madness as a consequence of sin in the New Testament.

The next section discusses ways in which the Christian Church constructed people with mental illness.

#### **3.3.1.4 Mental illness in the Christian church**

Covey (2005:109) observes that sin-disability conflation lasted for centuries and to a large extent influenced the attitude of the Christian Church and society towards people with disability in general, and with mental illness in particular. Though episodes of tolerance can be traced in the church's treatment of mentally ill people, the Middle Ages will be remembered for their intolerance for mentally ill people. Foucault (1965) recounts the experiences people alleged to be mentally ill were subjected to through the history of Western civilization, often being made to perform as bizarre actors to satisfy the theatrical appetites of the public. Up to the beginning of the nineteenth century, people with mental illness "remained monsters", while those considered to be violent were chained to the walls and beds and sometimes exposed to swarms of huge rats which not only attacked them but also bit them to death (Foucault 1965:69-71).

According to Covey (2005:109), "societies increasingly blamed people who were mentally ill and Christianity provided a visible and convenient rationale for damming them". Both Protestants and Catholics during this time viewed mental illness as a sign of demonic possession and the mentally ill as witches. They were thus tortured, and the 'Inquisition' marked a low point in the persecution of people with disabilities, particularly mental illness. Eldam (2003:29) cites an example of how mentally ill people were executed: "In Kingbory in 1663, a man thought he was God, the Father. He claimed that all angels, the devils and the Son of God recognised his power. He was convicted. His tongue was cut, his head was cut off and his body was burned." However, alongside these negative attitudes were episodes of positive attitudes to people with mental illness, with some being likened to saints (Covey, 2005:111), and in some circles within medieval Europe earning the somewhat sarcastic name of "Holy Innocents" (Webb-Mitchel 1994:15).

The Christian Church has long been held in tension the two conflicting attitudes towards people with mental illness, yet despite this, the sin/madness conflation was always lurking on the side. With the passage of time the church's interpretation of mental illness was becoming

even more complex, and could not be reduced to one single interpretation or portrait. Overall, treatment through the church's history was negative, interspersed with positive episodes.

In keeping with the hypothesis of this chapter, that the Greco-Roman culture and philosophy had profound influence on the entire Western world, the church included (Barnes 1997:12), I now move on to examine how visual impairment was understood in the Greco-Roman, Jewish, New Testament worlds, as well as the Christian Church.

### **3.3.2 Visual impairment (Blindness) and the Christian church**

Visual impairment was a common condition in the ancient Mediterranean world from which the Christian Church originates, and as with all other forms of disability fell short of the ideal mark of wholeness and perfection set out by the society. It thus drew into question the physical and moral qualification of a disabled child or the parents (Hartsock 2007:68).

#### **3.3.2.1 Blindness in the Greco-Roman world**

Though the depiction of blindness in the Greco-Roman world was ambivalent (Hartsock 2006:78), on the whole it was viewed as a pitiable, shameful, helpless condition that rendered a person dependent on others. Examples of Teiresias and Oedipus, who were led around by their daughters, are offered as a proof of their dependence upon other people. Blindness was attributed to gods as a punishment for sins or crimes committed while intrusion into the divine realm and failure to offer worship properly both constituted serious violations punishable by gods. For instance, Teiresias was punished for accidentally glimpsing of goddess Athena's nakedness and Hermon of Thesus was re-blinded after being healed for failing to offer proper worship to the deity. His sight was restored after making amends for ingratitude (Hartsock 2006:82-88).

There were cases in the Greco-Roman world, albeit rare, where blindness was portrayed more positively, for example the blind seers or prophets who though physically blind, had the privilege of having insights into the spiritual world (Hartsock 2006:82). Their ability to decipher hidden meanings, often thought to be enhanced by their blindness, made them the envy of some, although blind seers were still dependent a great deal on charities. Perhaps more than many other forms of disabilities, they fared worst in economic terms.

### **3.3.2.2 Blindness in the Hebrew Bible**

Blind characters appear with relative frequency in the Hebrew Bible, the first five books of the Bible treat blindness in a manner similar to the Greco-Roman world, that is as a negative, pitiable and shameful condition. Measured against the Jewish notion of wholeness, blindness was judged as having too little, and further as a mark of uncleanness. Leviticus 21:18, which bars a blind priest from offering sacrifice, and Leviticus 22:22 (see also Dt 15:21) which disqualifies a blind animal as a candidate for a sacrifice, make sense if read in the light of the Jewish notion of wholeness of body. A whole body, as indicated above, has to have all organs intact and functioning properly, while blindness was also often associated with divine punishment, in Deuteronomy 28:28-29 as a curse for those who reject God. However, it was not all negative, with Leviticus 19:14 and Deuteronomy 27:18 forbidding misleading or placing of a stumbling block before a blind person. Even with respect to blindness there was no homogeneous view in the Hebrew Bible.

### **3.3.2.3 Blindness in the New Testament**

The New Testament is also replete with cases and examples of blindness, suggesting that it was a common phenomenon in the milieu. The significance here is not so much in the interpretation of these texts but in the pictorial background that illuminates the attitudes and perceptions of people in the New Testament world towards people with blindness. It is evident from the Gospel texts (Jn 9:1-41; Mk 8:22-26) and the parallel texts that the New Testament environment viewed blindness as helpless condition to be pitied and in need of charity. The question posed by the disciples to Jesus in John 9 evokes a sin/disability conflation, assuming it is a divine punishment (Hartsock 2007:184). Though Jesus' response has been interpreted as a rebuttal of this view, the point is that the perception of blind people as helpless and victims of God's wrath for their sinfulness, or that of their parents, was prevalent during New Testament times.

### **3.3.2.4 Blindness in the Christian church**

The Jewish religious conscience that linked blindness to sin was inherited by the Christian Church, in which its effects can still be felt to this day. Though Jesus' attitude, especially toward the man born blind, was unambiguous, the Christian Church was constantly tempted by the very thing that Jesus probably challenged. It is therefore not surprising that blindness was and still is interpreted in terms of God's retribution for people's sins. In different ways the Church relived the stereotypes of both the Greco-Roman world and Jewish society, and held the same fears that troubled the Greeks and the Romans (Stiker 1999:41). Christians



asked and are still asking the same questions that the Jews asked, believing through the years that blind children paid the price for their parents' sinfulness (Covey 2005:109). The similar pity that drove people to acts of compassion still drives Christians to acts of charity to blind people. Examples of this will be provided in the following chapters (4-6), particularly from people with visual impairment.

Despite this overly negative attitude toward people with blindness, there is evidence that the church throughout the years, following upon Jesus' example, showed compassion to people with visual impairment. I now turn to the understanding of physical immobility in the Greco-Roman, Jewish and Biblical world.

### **3.3.3 Physical immobility**

Lameness and being crippled were subjects of comment in the ancient Mediterranean world. In the Greco-Roman world, the Hebrew Bible, the New Testament and the history of the Christian Church they vacillate between objects of ridicule and cases for charity, leaving their treatment no better than other forms of disability. As with the other categories, I will follow through the evolution of constructions of mobility impairment in the history of Christianity and its antecedents.

#### **3.3.3.1 Mobility impairment in the Greco-Roman world**

Cases of physical impairment, congenital and acquired, were quite common in the Greco-Roman world, covering lameness, clubfoot and loss of limbs. An ideal body in a Greco-Roman world was expected to be perfect in all its parts, limbs and senses, and physical impairment of any form was therefore seen as a defect, imperfection and deficit, to be interpreted as a punishment inflicted by the gods (Garland 1995:13). According to physiognomic principles it pointed to a flaw in one's moral character, and in a world where competition, sport and war were the order of the day, there was little room, if any, for physically deformed people.

Oedipus, a famous cripple in Greek mythology, and Hephaestus, an unfortunate crippled god, were rejected as intolerable monstrosities by the Greeks (Garland 1995:13). Not only were their bodies lacking in physical wholeness but also they were inadequate in terms of strength and beauty. They were considered harmful and a cause of fear, with signs and reason of the gods' anger (Stiker 1999:40, 50). Despite this negative treatment, there were however rare cases of parents sparing such children (Garland 1995:15). Practical and religious considerations accounted for much of this negative perception of and treatment for

physically deformed persons in the Greco-Roman world. In this way, a physically deformed body was constructed through society's musings and shared to the rest of society for internalisation.

### **3.3.3.2 Mobility impairment in the Hebrew Bible**

In the view of ancient Israel, a complete body had to be whole with its parts intact and fully functional, whereas a body that did not meet these requirements was considered unwhole and could not participate in many of the socio-religious functions (Lv 21:18). Israel had many such bodies, some of which were unwhole through congenital causes and others the result of diseases or accidents (Berquist 2002:26). Lameness, though it cannot be equated with mobility impairment such that one is the other and vice versa, represented many of the deformities of a mobility impairment nature within the Hebrew Bible environment.

A careful reading of the Hebrew Bible literature divulges two contesting notions of the understanding of a deformed body. The first was a notion of a body created by God as good "in all its various forms" (Berquist 2002:27). Lameness was considered to be an act of God in that there was nothing one could do about it. The second notion was an understanding of a body that had to match the demands of an ideal body that was whole and complete. In the light of the foregoing observations, coming across conflicting expectations about the deformed body may not be surprising. Because lameness was sometimes seen as an act of God (Ex 4:11), Israel was required to accept such people (Lv 19:14; Dt 27:18) as they were also within the purview of God's healing. On the other hand, there is a perspective that saw all forms of deformity, including lameness, as a curse and punishment by God for a transgression. For this reason the lame were also pushed to the margins of society, to the victim of social assumptions about the whole body, the criteria of which they did not meet (Berquist 2002:30).

### **3.3.3.3 Mobility impairment in the New Testament**

The position of the New Testament on mobility impairment presents a new phenomenon, in the person of Jesus, which seems to disrupt the traditional Jewish perspective on disability. This perspective was founded on what Stiker (1999:33) calls 'religious prohibitions'. Jesus challenged this fulcrum on which the whole traditional Jewish system was based and thereby destabilized Jewish society. Jesus' healing of the lame and the crippled subverted the traditional Jewish patterns of pure/impure; normal/abnormal; what belongs/what does not belong. His healing of the disabled represented not only restoration to health but also to the community from which they had been alienated by their deformity (Lk 17:11-19). Peter and

John took a cue from Jesus and continued his healing ministry (Ac 3:2-13). It is interesting to note that people's perceptions about lame people, on the contrary, were such that they promised nothing more than acts of charity and alms, leaving them reliant on others for their survival.

Despite the extraordinary words and actions of Jesus in respect of people with disabilities, the predominant view of the time was more under the spell of demonic possession, with God's wrath and punishment for sinful behaviour expressing itself in a deformed body. This is the view that influenced the attitude of the Christian church to people with mobility impairment in very significant ways.

### **3.3.4 Hearing impairment**

Deafness, often associated with muteness, was a common occurrence in the ancient Mediterranean world. According to the three-zone make up of a man developed by De Geradon (as quoted in Malina 1981:60), the mouth and ears belonged to the zone of self-expressive speech. The ancient Israelites, Judeans and Christians gathered information through their ears, for digestion in the heart, and response through the mouth. It, therefore, mattered if people were ill in any part of the zone of self-expressive speech (Malina 1981:60-62). Under this category I trace the constructions of the hearing impaired (deaf/mute) in the Christian history and its antecedents.

#### **3.3.4.1 Hearing impairment in the Greco-Roman world**

Garland (1995:26) observed that deafness was, like blindness, prevalent in the ancient communities, particularly because the lifespan for men and women was on average between 30-40 years. As with other forms of disability, it was not treated with kindness as it constituted an affront to the beauty and perfection required of a body in the Greco-Roman world. Kroisos' treatment of his deaf and dumb son, by disowning him, is evidence that he was an embarrassment to both family and society (Garland 1995:96). Aristotle's conviction was that learning was an important component of human constitution, for without it, he maintained, there could not be any learning. This perception set a tone for later reflections on the amount of participation that deaf people could have in faith issues: "...as they had no way to learn about God and acquire faith" (Covey 2005:110). They were therefore excluded from participation in cultic events.

### **3.3.4.2 Hearing impairment in Hebrew Bible**

Deafness is one of the defects mentioned in the Hebrew Bible books, wherein its frequency, as in Talmudic literature, not only points to its existence but also to its sanction by God (Talmud Gittin 24A; Talmud Sanhedrin 34b; Talmud Megillah 4:6; Havat Yair 176). Deaf people could not act as principals in legal transactions, nor act as judges or witnesses in Jewish courts or recite certain prayers. Deafness represented a complex range of attitudes, from negative to positive (Ladd 2003:93), and under Talmudic law a deaf person could not assume full citizenship in a Jewish community (Stiker 1999:ix). Seen as defective, impure and unwhole, they were believed to be lacking in what made for the essential attribute of God, completeness and perfection.

On the other hand, the text of Leviticus 19:14 suggests that muteness and deafness, despite their differentness, were to be treated with compassion. There was a perception in the Hebrew Bible that God possessed the power to eliminate disabilities and restore health, especially to enable the revelation on Mount Sinai (Covey 2005:112).

### **3.3.4.3 Hearing impairment in the New Testament**

The New Testament literature is replete with incidences of deafness and deaf people (Mt 11:5; Mk 7:32-37; 9:25; Lk 7:22). Other than Jesus' exceptional treatment and care for disabled people in general and deaf people in particular, the New Testament environment tended to paint a negative perspective on deaf people (Ladd 2003:94). According to the New Testament worldview, deafness was also seen as an indication of demonic possession. From a man who was brought to Jesus allegedly for being possessed by a spirit of dumbness, Jesus rebuked the unclean spirit, and Mark 9:14-25 showed the pervasiveness of this belief at the time of Jesus. Deaf people were portrayed as requiring healing and/or exorcism, and were seen as defective, lacking in something and as impure. In Paul's letters, faith is depicted as coming by hearing, which excludes deaf people from the possibility of becoming Christians (Ladd 2003:94).

### **3.3.4.4 Hearing and speech impairment and the Christian church**

The following centuries saw the intensification of a central Christian view around deaf people, as one of isolated individuals, requiring healing (deficit model) or exorcism (demonological model) (Ladd 2003:94). With the spread of Christianity, the latter perspective succumbed to a multiple perspective with some exceptions to both the deficit and demonological models emerging. Unlike in other forms of disability, deafness enjoyed some

positive moments in the history of the Christian church, with traces of positive acceptance of deaf people in the mainstream community evident as early as the monastic times, there are (Ladd 2003:97).

In the subsequent years, their numbers grew dramatically, triggering recognition from a variety of circles. In church services, as Jackson (1990:5) observes, “their behaviour, gestures and zealous signs had procured and allowed admittance to sermons, prayers and Eucharist”. Their growth in numbers further excited debate among philosophers, whose reaction was mixed. Kant developed a negative portrait of deaf people while Leibniz and Descartes saw their sign language as a factor that distinguished men from animals (Ladd 2003:102).

Despite this positive wave, there was still bias in church, inherited from the New Testament milieu, which saw deaf people as living machines without souls (Ladd 2003:107). This has to be read against the role speech played in the Christian tradition of creation. God created through divine speech but speech separates humans from animals. As a result and because of the extent of the influence of this conviction, Christianity held very little hope for deaf people, especially within the church (Covey 2005:109-110).

### **3.4 CONCLUSION**

Emerging from this chapter is that, within Christian history, disability has remained a very fluid concept. Though it has also remained linguistically unstable (Stiker 1999:ix), its reference to the dominant and alienating story has been the most pronounced. Its close connection with the body has not however been lost. It is in that sense that Stiker (1999:vii) saw in disability a “window into the variability of the human body as a biological and historical entity”.

Measured against what was termed a regulatory body, through society’s ruminations, a body becomes normal or abnormal; pure or impure; able or disabled, with the second term, in the binary continuum, marginalised and kept on the boundary of human embodiment. Though the focus of this research is on the construction and deconstruction of the disabled body within Christian narratives, I have had to go further back into the ancient Mediterranean world. The aim was to show the extent to which that worldview has influenced Christian (especially Western Christianity’s) perceptions, conceptualisations and attitudes toward disability and people with disabilities (Rose 1997:396). It was also to show the shifting nature of the disability constructions throughout the years and the inherent power relationships resulting from such constructions, as per the first aim of this research.

People with disabilities were constructed as monsters; signs of God's punishment; a challenge to divine perfection; signs of incompetence and exemption from religious practice; pitiable; helpless and, an occasion, objects of charity and compassionate care by others (Rose 1997:397). This all depended on the societal values and criteria as to what constituted the perfect embodiment of the perfect God. This perfect body in turn spawned binaries that further rendered the disabled body an anomaly. Despite this overly negative perception toward people with disabilities there were traces, both in the Greco-Roman and Biblical world, of a positive attitude toward them.

The coming of Jesus represented a significant break with the patterns of the old covenant organised around prohibitions (Stiker 1999:33). His perspective represents an alternative and resistant discourse, as he disrupted the disability/sin conflation on which the entire Jewish religious system was founded, making him in the process a "master deconstructor". His free interaction with the impure and the sinners was an act of deconstructing the structure around which the Jewish religious system evolved (Stiker 1999:33). As he befriended sinners and the sick, for him purity and impurity did not come from outside, as the Jewish mentality suggested. Rather, it was something that emerged from one's relationship with others. It was no longer the time (Sabbath) or the place (Temple) that mattered, but one's relationship with God and fellow humans. Jesus' breaking of the Jewish mentality, however, opened possibilities for new ways of thinking about and relating with people with disabilities. He guaranteed recognition of disabled people's right to participate in religious and societal life. By his actions and words, he rendered further unstable and unfixed the notion of disability and made it more apt for further relational possibilities.

In the next chapter, I explore the shifting voices in disability research, the aim being to follow through constructions of disability in literature and to identify ways in which it has contributed to the construction and perhaps marginalisation of a disabled body. The definitions and models of disability that have been proposed are subjected to scrutiny in the light of the voices from the research participants.

## CHAPTER 4

### JOURNEYING WITH SHIFTING VOICES IN DISABILITY STUDIES AND RESEARCH

#### 4.1 INTRODUCTION

From the last chapter it was evident that the Christian story of disability was founded on a religious model of disability, with prohibitions sustained by the binaries of sinner vs. righteous and pure vs. impure. Jesus not only overturned the traditional system of the time but also provided for the emergence of further relational possibilities around disability. The aim of this chapter is to place the social construction of disability within a wider context of disability studies and research. I outline the shifts and competing voices in contemporary disability studies and examine how they contribute to the conceptualisation of disability in the contemporary times. In the process of discussing the implications such understanding has for the lives of people with disabilities, I identify and follow through the problematic structure on which the different models of disability, particularly the medical, the social and the integrationist, are founded. I then propose an alternative, participatory model of disability that I argue is better positioned to deal with issues of people with disabilities, while at the same time showing the limitations of other models. Christian cultural constructions of disability will also be explored.

#### 4.2 VOICES IN DISABILITY STUDIES

Issues around disability and people with it have gone through different phases of conceptualisation and re-conceptualisation by societies, from ancient to modern, in different ways and intensities. The 1970s, however, saw a growing interest in the subject, reflected in the number of research articles and books across the spectrum of disciplines (Tan 2004:14; Calderbank 2000:524). The inclusion of people with disabilities in the mainstream of social life and academia changed the landscape of research and ownership on issues of disability, accompanied not only by diversification in research and advocacy on disability but also campaigns and organisations spearheaded, run and controlled by people with disability (Shakespeare & Watson 1997:293; Gabel & Peters 2004:585). This has contributed to the dramatic change in perspectives on disability.

##### 4.2.1 Differing perspectives on disability

The complexities of disability have been well documented (Powell 2003:65; Barton (1992:15), with their definitions “continuously changing, culturally variable, and highly contested” (Devlieger, Rush & Pfeiffer 2003:132). Disability’s resistance to succumbing to

the modernist pressures of stability, fixity and objectivity is a sign of its variability “and its socially generated interpretations”, while its evolution has been held together by the “passion for sameness” at the expense of “love for difference” (Stiker (1999:ix). According to Stiker the former has occasioned segregation and marginalisation of people with disabilities and their exclusion from mainstream society. The conceptualisation of disability determines attitudes (Radermacher 2006:21), which along with perceptions in turn inform conceptualisation of disability models and definitions. This section traces attempts to define disability and how, within the postmodern context, they become both paradoxical and puzzling (Grönvik 2007:38).

#### **4.2.2 Defining disability**

Though it is not within the scope of this section to give a detailed exposition and evaluation of the various definitions of disability, views around some and their evolution are pertinent. Any attempt at standardization of the definition of disability would be to prioritise the fluidity of meaning over fixity, and thus run counter to the *modus operandi* of this research journey.

The International Classification of Functioning, Disability and Health (ICF) encapsulates a supposedly inclusive definition of disability adopted by the 191 member countries in defining disability in terms of impairment, activity limitations or restrictive participation (World Health Organisation {WHO} 2001:3). The definition that brings together the biological and environmental dimensions to the experience and reflects the ICF’s view of disability as a multidimensional phenomenon resulting from the interaction between people and their physical and social environment (WHO 2001:242). Though this definition was intended to be an improved version of an earlier one, it has been adversely criticised, especially from researchers within Disability Studies. The incorporation of social and economic considerations did not see the definition lose its association with the medical models (Scotch 2002:25.29).

Pfeiffer (2002) also challenged attempts at defining disability, writing that “disability has no scientific or even a commonly agreed upon definition.” and rejecting the possibility that it can be identified or measured (2002:4-7). The attempts by the World Bank and the WHO (ICF), therefore, will only “further the agenda of eugenics which eliminate people with disabilities” (ibid. 2002:8). Scotch (2002) echoes the sentiments of Pfeiffer, claiming that disability cannot be defined except with reference to public policy, as “whatever public laws and programs say it is”. (Scotch 2002:24). In a slightly nuanced position, French (1993:17) disputed an either/or definition, and opposed to those who describe impairment as a physical problem and



disability as a social problem, opted for a both/and position, suggesting that disability has both physical and social dimensions. Thus, a rounded up definition would include both of these dimensions. Grönvik (2007), meanwhile, dedicated his doctoral research to the examination of definitions of disability by different researchers, hypothesising that it is too complex and contentious to merit a standard definition and that context and purpose determine the content.

Nevertheless, it is useful here to identify four brief definitions of disability as they relate to different models. The first focuses on a person's *functional* limitations (Gronvik 2007:11), the second on *environmental* factors to which the individual cannot easily adapt. The third, within the *social* model, points to the physical and social environment, not the person him or herself, as creating barriers to participation in society. The fourth is largely *administrative*, assessing disability in terms of applicability for aid.

Despite, or perhaps because of these definitions, Grönvik's (2007:38), it is difficult not to conclude that disability is a fascinating, volatile and elusive concept that continues to baffle and puzzle researchers. In dealing with it, efforts should not be expended on finding a universal and 'correct' definition, but rather focus should be placed on describing how disability *has been* defined (Grönvik 2007:40). In this way, there is room for more subjective definitions that pay attention to individual experiences and that have been a missing link in Disability studies. Such individual experiences not only form an important component of this research but are also subversive to meanings of disability that strive for fixity and universality.

Three of the participants shared the following perspectives about what disability is all about.

Reg<sup>3</sup>, who is visually impaired, stated the following:

*For me disability is not a problem as other people would suggest. It is not inability. I would prefer to call it a state of dysfunction of a part of the body which, in my case, would be compensated by another. For example, my sense of hearing is much more powerful. I am able to follow two conversations at the same time without a confusion that normally accompanies people who claim to be abled.*

(Reg 2009)

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<sup>3</sup> As indicated in Chapter 2, pseudonyms have been used to preserve the anonymity of participants.

For Tsili, who has mobility impairment:

*As an activist on disability issues, I look at disability as something more about the environment and society than about people with disabilities. Disability is not about a person but about the environment and the prejudices and attitudes which prevent people with disabilities from living like all other people.*

(Tsili 2009)

Jack has visual impairment, and said:

*Though I respect the position of Disability People's Organisations (DPO), as far as I am concerned, respectable language is not necessarily convertible with respectable attitude. You may call me blind, handicapped, a person with disability. As long as I feel respected and my human dignity upheld, however you may want to call me, I do not really mind. Words have no meaning outside context.*

(Jack 2009)

Maki has mobility impairment and this is what she had to say about disability:

*Disability is not inability. Though I am on my wheel chair people should not think that I am incapable of doing things. With the environment well rehabilitated we can do things on our own without having to overly rely on others. I have gone to school and have graduated with diploma in business management. I am employed and can do things that people with the same qualification as myself can do.*

(Maki 2009)

*While both Jack and Reg take into account individual experiences that subvert attempts to globalise the disability experience, Tsili and Maki speak from a point of view of disability activists. Emphasis is often placed on the environment not being 'disability-friendly', and thus the source of problems for people with disabilities, but the above definitions tend to specify, harmonise, generalise and often exclude other subjective experiences, especially those of Jack and Reg. Definitions are also tied to models and contexts within which such models emerge, and failure to do so leads to exclusion.*

The focus of the next section is a discussion of the models of disability developed over almost three decades. A model is not a whole but part of a whole, and each therefore reflects part of the complexity of the whole (Wilson, quoted in Jacobs 2004:94) says. The discussion of the different disability models will provide a framework for a more expanded treatment and critique of the perspectives and conceptualisations of disability as represented

in contemporary literature. This discussion will put in perspective the complexity of attempts at arriving at a universal definition of disability.

### **4.2.3 Conversing with models of disability**

There is an interplay between models of disability and definitions or perceptions of it, with models not only shaping definitions but also influencing perceptions which inform policies and practices. The latter in turn reinforce further entrenchment of particular models and definitions of disability. In this section I focus on the evolution of disability models and ways in which they contributed to the constructions of disabled identities. Particular attention is paid to the dominant models, namely the medical and the social, because of the influence they still have on Disability studies. Voices of participants are used either to challenge or to buttress the findings.

#### **4.2.3.1 The medical model of disability**

Before the 18<sup>th</sup> century, at a time when the power and influence of the church were at their strongest, impairment and disability were mainly attributed to religious and/or traditional superstitious causes. Other than forgiving sins the church “asserted and retained authority by propagating and perpetuating fear – fear of the Devil and of his influence” (Barnes 1997:17). The ‘Malleus Maleficarum’ represented the highest point in its efforts to rid itself of the influence of the Devil and his angels. Disability was, therefore, seen as proof of Devil’s existence and power (Barnes 1997:17), a perception that further entrenched the oppression and marginalisation of people with disability. This represented what came to be known as a religious model of disability.

The emergence of the Enlightenment, with its critique of established religion, marked an important shift, not only in the church’s influence and power but also in the construction of disability (Barnes 2005:5). It marked both continuity and discontinuity of the seventeenth century’s ‘Great Confinement’, which revolved around segregation aimed at maintaining social order (Stiker 1999:105). The proliferation of hospices, asylums and other specialised institutions was a reflection of the society’s attitude, at that time, toward those who were perceived as dangerously different. Placing or interning people in such places was not for treatment or care purposes but, as Stiker (1999:99) argues, “in order to concentrate their numbers.” This new order legally sanctioned a form of segregation and exclusion based on fears, myths and stereotypes (Ntlatlapa 2007), some of which were carried over from the preceding periods.

One of the offshoots of the Enlightenment was what came to be known as the 'era of medical power.' Characterised by sharper scientific focus and more improved medical treatment of diseases, it marked the emergence of new power which continues to dominate to the present day. Stiker (1999:104) writes:

This is the realization of the medical profession's great dream to care for the ill and in so doing to become the adjudicators of a social norm that is defined on the basis of norms of life and of health. At the close of the eighteenth century this dream of medical power, which had the mandate to serve, or even to dominate, political power, was effectively made reality.

The medical model of disability, as it is known today, descended directly from this new dream of medical power, which with its focus on rehabilitation unfolded in two modes. The first aimed at rehabilitating people for employment and the best possible independence, while the second, which was eventually to take precedence over the first, was concerned with providing medical rehabilitation for people with disability (Finkelstein 1993:11-12). Having taken shape around the 1970s, and rooted in the functionalist paradigm, the medical model transcended and transformed the preceding ideas and perceptions of disability and illness embodied in the religious model in terms of sin.

The medical model of disability dominated disability research for a long time after, finding fertile ground in interpretations that viewed impairment as a cause of disability and disability as a personal tragedy. This view is still expressed in protest against the new emerging paradigms of disability (Pfeiffer 2002:4), under such different names as the biomedical model (Jacobs 2004), rehabilitation model (Scotch 2002; Ntlatlapa 2007), individual model (Oliver 1990), and deficit model (Pfeiffer 2002). All of these have one or other feature of the medical model of disability, as follows.

**a) Features of the medical model**

The medical model of disability was identified with binaries such as normal vs. abnormal, functional vs. dysfunctional, curable vs. incurable, the second of which were invariably associated with disability. Associated with or being a variation of a deficit model, the medical model assumes that a person with disability has a deficit, lack and a problem that must be corrected, these limitations being of a pathological nature and thus only to be corrected or fixed through medical intervention (Oliver 1990:3). Within a pathological framework, fixing and correcting could only mean bringing back to normalcy and functionality what was abnormal and dysfunctional. Where such interventions were not successful, people with

disabilities were viewed as “not whole, not normal and incapable of participating in and contributing to the everyday life of the community” (Barnes 2005:6).

Disability read through the lens of the medical model evoked negative connotations, and people with it came to be seen as incomplete, deviants, incurable, tragic and inferior (Radermacher 2006:19). Because they were not capable of coping for themselves they were seen as perpetual dependents and victims of fate deserving of feelings of pity and compassion. They became charity cases, thus creating an impression of passivity and objectivising from their side.

Within the medical profession, there is much evidence that vital specialised service and rehabilitation are both needed, however the point is not whether or not care is provided but how, why and in which manner (Jacobs 2004:103-104). The decision on the type and manner of service provision has been the sole prerogative of the medical profession, with people with disabilities treated as recipients. The medical model has not been able to avoid the creation of a dependence variable, but dependence, especially within the professional service, hinges on power and control (Oliver 1993:54), more often than not used in unethical ways. The perceptions and attitudes created, therefore, become sources of oppression for and dehumanisation of people with disabilities. For Jacobs (2004:110), the medical model also contributes to a fixed identity for people with disabilities. According to Bakhtin to fix is to finalise and to finalise a person is to finish him/her off as if he/she were already dead (1.2.1). Despite the benefits and gains to individuals and families that result from the development of the medical model, the stigmatisation, objectification and marginalisation suffered by people with disability as a result were and remain immense.

## **b) Experiences from research participants**

Reg related an experience with a high-ranking government official some years before, and who, when asked by people with disabilities about the accessibility of polling stations for all, replied that hospitals had not been equipped to assist them with the upcoming elections. This response betrayed an equating of disabilities with illness, and indicated that he was still steeped in the medical model of disability. Tsili suggested that it is wrong to equate disability with illness: *“though my disability results from polio I am now not sick or ill. I am healthy. It is true that I use crutches but I am mobile like anyone of you. I even drive my own car.”* The tendency within the medical model is that people with disabilities are perpetually ill.

Reg (2009) asked:

*What does it mean to rehabilitate a person with visual impairment or person with speech and hearing impairment? Is that rehabilitation meant to restore their sight or speech hearing? If that is the case how will that be achieved? If it is for purposes of employment then rehabilitation is good for everybody not only for people with disabilities.*

Sam, also, was adamant that he was not sick: *How can somebody who differs from other people by the language he speaks be called sick? I am deaf but I am not sick.* The medical model of disability is challenged by participants because it does not correspond to their lived experience.

In summary, I argue that the medical model has not been able to resolve the normal vs. abnormal or sick vs. healthy binaries, and the notion of rehabilitation so characteristic of this model betrays them. In both its vocational (rehabilitating people for employment) and its strictly medical dimensions, rehabilitation cannot dispense with the implied meaning of a return to the assumed prior, normal state (Stiker 1999:122). Given that 'normal' is associated with good, and its opposite, 'abnormal', with bad, reveals ways in which the medical model has become a source of oppression for people with disabilities. It promotes stigma and discrimination against people with disabilities (Jacobs 2004:99), and attaches a fixed identity to people with them. In light of these limitations of the medical model, the social model was proposed.

#### **4.2.3.2 The social model of disability**

Over the last twenty five years the social model of disability has established itself, especially among disability activists, as a launching pad to demand just treatment for people with disabilities (Albert 2004:4). It has also provided "the framework within which the experience of disability may be understood as a socially constructed phenomenon" (Lloyd 2001:715). Consequent upon the establishment of the disabled people's movement in the 1960s, its emergence became associated with a reaction to the adverse conditions that resulted from a biased treatment-wielding power against people with disabilities common in the preceding functionalist models (Dewsbury et al. 2004:147). First in Britain, then in the United States of America (USA) and other parts of the world, the social model in its different manifestations (Shakespeare & Watson 2002:9) came to enjoy wide acceptance among disability groups. It represents a radical departure from and resistance to what the medical model and what it stood for.

### **a) Features of the social model**

The social model is some form of subversion of oppression and exclusion manifest in economic, environmental and cultural barriers (Hutchinson 2006:2). The attempt to “normalise”, accounts for much of the societal oppressive attitudes against people with disabilities. Inaccessible education, poor working environments, and economic problems resulting from inaccessibility of equal employment opportunities and affordable and diversified health services, has compounded the economic problems of people with disabilities and denied them the most basic requirement for decent living (Jacobs 2004:116). Culture as a system that produces and communicates social order has the potential to both marginalise and liberate, but people with disabilities have often been victims to popular and dominant culture, which metes out oppressive attitudes against them. Their shared experiences of oppression have stirred up what Riddell and Watson (2003:1) call a ‘culture of resistance’, and it is these oppressive tendencies that the social model was meant to address.

The social model does not pretend there is no disability, but rather that problems around it should not be located in an individual but in society’s failure to accept people with disability as they are, not as society thinks they should be (Oliver 1990:5; Albert 2004:3). It does not suggest that the medical model of disability, as Oliver (1990; 2003) argued, is of no use, but that its disempowering thrust should give way to a ‘prescription for sharing of power’ (Oliver 1990:6). The prescription of power sharing has to be understood against the background of what Oliver perceives as the lopsided wielding of power in favour of medical professionals at the expense of people with disability.

### **b) Social model and the dissenting voices**

Despite its obvious successes, especially in countering discrimination and oppression against people with disability, the social model has not been immune to criticism (Gabel & Peters 2004:585). Some dissenting voices, demanding alternatives to the social model, began to emerge around the 1990s (Dewsbury et al. 2004; Lang 2001). Though these voices do not doubt the important contribution the model has proffered, they are in varying degrees striving for its reformulation and/or extension to include a variety of experiences. I add that the social model has not been able to avoid the “them” (society) and “us” (people with disabilities) dichotomy and language. The temptation that the social model faces is that of creating the “generalised other” (people with disabilities), which does not take into account “the individuality and concrete identity of the other” (Welch 1990:127). However, the

suggestion of Radermacher (2006:3) that the social model is better placed to facilitate participation of people with disabilities, its elitist decoy would prove an imposition on Africa rather than something that grew out of the continent. Some of the research participants had heard about the social model of disability but had no idea what the social model was. If they did not know about it, yet it is purported to be their model, then it cannot be amenable to their individual experiences.

I now explore alternative models that would be inclusive of the experiences of the other.

#### **4.2.3.3 An eclectic model of disability**

Within the disability movement, a new generation of scholars has emerged. Spurred on by what Slee and Allan (2001:180-181) call 'scholarly and cultural vigilantism', they are looking for how things could be improved. With the passage of time they believe anything needs to be subjected to some relevancy litmus test, and that the social model, despite its dominance in policy-making and service provision, and opening discursive opportunities within the disability context, was becoming a form of closure (Bailey & Hall 1992:15). It therefore needed to be saved from acquiring a status of a grand narrative.

Drawing from different contexts, theoretical frameworks and experiences, these scholars have challenged the all encompassing nature that the social model seemed to be developing. They are – in different ways – arguing for a model that is more holistic (Shakespeare & Watson 1997; Pinder 1997) such that it encompasses questions of individual experience of impairment, difference and culture (Barnes, Oliver & Barton 2002).

##### **a) Disability and individual experience**

Taking a cue from the feminist movement, which underlined the importance of individual experience, scholars such as Hughes and Paterson (1997), Crow (1996), and Morris (1991) began to question the taken-for-granted adequacy of the social model. They challenged the assumptions of the social model on two main fronts. Firstly, the Oliverian assumption that disability and impairment are distinct and that disablement has nothing to do with the body (Oliver 1995:4-5) was questioned. In their view, "an individual experience of living with an impairment, sometimes in a state of acute pain, has a valid role in the experience of disability" (Lang 2001:19). These scholars, many of whom are women, argued that the social model has not adequately accommodated the subjective experiences of pain and fatigue that disabled people go through as a result of their bodily impairment (Crow 1996:209). They



felt there was a need for a paradigm shift towards a model that would account for the individual experiences of people with disabilities.

Informed by the idea of the importance of the body and that of the individual experience, some feminist disability scholars have highlighted the plight of disabled women (Begum 1992, Cooper 1993, Lister 1997, Lloyd 1998, Meekosha & Dowse 1997). In the process they have also opened up the complexities of the disability movement's agenda or indeed of any other movement, showing that the liberation which the social model was striving for could have easily been claimed at the expense of women with disabilities. Margaret Lloyd, in her article, *The Politics of Disability and Feminism: Discord or Synthesis?* (2001:716), demonstrated the masculine bias in the social model. It engaged oppression and discrimination only to, unintentionally, perpetrate it against women with disabilities: "Thus disabled women have been caught between, on the one hand, an analysis and movement in which they have been invisible as women, and one in which their disability has been ignored or subsumed, on the other."

In opposition to the feminist critique, however, Davis (1987:277) sounded a warning that women with disabilities who were pushing their agenda needed to be careful lest they fell into the same trap of creating a new system of oppressors and oppressed. Secondly, against the homogenisation and monolithising of the experience of people with disability, they asked whether it was possible to create a "grand theory of disablement, which is valid and pertinent for all impairment groups across all cultural settings". The social model had, they argued, in the process of fighting oppression perpetrated against people with disabilities, emphasised collective solidarity even at the expense of glaring, individual experiences that were not embraced by its agenda. In this way it became a "sacred cow" (Shakespeare & Watson 2002:6), "the dominant discourse", running "the risk of developing a form of oppression from within to justify liberation from without" (Gabel & Peters 2004:596). Its main challenge has been how to balance ethical tension resulting from the need for group cohesion and the justice for individual self-determination. One of the participants put this tension into perspective:

*DPOs have adopted what they refer to as a politically correct language on issues of disability. They prefer to be called people with disabilities. You can call me visually impaired, handicapped it does not really matter as long as I do not sense any intention to degrade me.*

(Reg 2009)

There are varied responses on the extent to which the social model needs to be holistic. Some scholars have declared the social model, especially the strong British version,

irrelevant to the modern challenges. Shakespeare and Watson (1997; 2002), positioned within the postmodern paradigm, are quite radical in their critique of the social model, arguing that not only can it not be reformed, they that it has become a “sacred cow” which has been overtaken by the changing context (2002:5-10). Others, such as Gabel and Peters (2004), and Barnes et al. (2002) have maintained a rather moderate stance on the issue, advocating a more eclectic version, the latter suggest a deepening of rather than an alternative for a materialistic theorization of disability, and one that encompasses questions of culture, difference and impairment.

## **b) Disability and culture**

In advocating a model of disability that is sensitive to issues of culture, proponents have been prompted by the realisation that disability is a culturally mediated phenomenon and that its meanings are determined by the social environment and cultural background. As a result, a number of studies addressing themselves to issues of disability and culture have since been undertaken (Ingstad & Whyte 1995; Kisanji 1998; Ng’andou 1999; Ogechi & Ruto 2002; Devlieger 2005), all disenchanted with the hegemony of monoculturalism, and with its universalisation of norms, values, cultural beliefs and practices. Their arguments have not only exposed the insufficiency of what Haskell (1998) calls a ‘cultural imperialism’ of Western Ideologues, but have also made possible the contribution of a cultural voice of disability in a global arena. The positive contribution of Ingstad and Whyte (1995) and Kisanji (1998) to the debate surrounding the impact of culture on disability was profound.

The common experience of people with disabilities has also added another dimension to the disability-culture debate, and there are those scholars who view disability as a culture that defines and creates a collective of disabled people with common experiences, tacit rules, language and discourses (Rioux 1994; Linton 1998; Charlton 1998; Gilson & Depoy 2000). In their view, culture is about beliefs and practices that one shares in common with other-like persons and which distinguishes them from those who are different (Lindsey, Robins & Terrell 2003:41; Barnes & Mercer 2001:522). People with disabilities, therefore, have what Brown (2002:52) sees as a common history of oppression and a common bond of resilience. Despite the varied individual experiences and backgrounds, people with disabilities have a shared identity and voice, which would warrant a talk about disability culture (Peters 2000:587).

Galvin (2003b:676) concurs that identity politics has enabled a sense of connectedness and has broken down feelings of isolation and alienation common to people with disabilities.

Humphrey (1999:174) has, however, warned that identity politics' penchant for stability and unified identity, essentialises them and places them in an 'inescapable tomb', founded on exclusionary logic. It is this kind of identify, which divides and excludes, that arouses suspicions in authors such as Galvin (2003b:688), who argues that we have to release ourselves from their grip, "let go of them and devise new ways of living that exist outside their limits."

An idea of an holistic or eclectic model augurs well in that it takes into consideration different perspectives of disabilities that were marginalised in the traditional social model. However the eclectic model has an elitist stroke to it, and despite an attempt to rehabilitate the concept it remains one that exacts a greater degree of intellectual rigour (McLeod 2003:65). This is evident in the language and concepts of models and theories that accompanies a discussion on such issues. The majority of people with disabilities, because of their low standard of education, particularly in the South, would not be able to comprehend the distinction between the pure model and the integrated model or in what that purity and integration consists of. This was confirmed by Jack, who when asked about the models of disability simply said, "*I still have to understand what these models are all about. I am at the level of a university and if I understand little about them imagine what it would mean to somebody who has gone up to primary school.*"

Integrationism and eclecticism are not in some circles too different as concept. Further, within each concept there are different types that further complicate the issue (McLeod 2003:64).

#### **4.2.4 Developing an alternative model**

The models of disability that have defined disability and people with it have tended to focus on what non-disabled people (medical model) have to say about people with disabilities. Even when it was becoming clear that the problem did not lie with people with disabilities but with society, (social model) the temptation to universalise the experiences of people with disabilities could not be avoided. Assimilation, integration, independence and inclusion were adopted as solutions that were seen as consistent with the said models. All of the above concepts contain elements of the "us and them" polarity, implying a movement from one point to the other, from a *passé* to an ideal. Assimilation means being absorbed into a system that is purportedly better, with integration and inclusion seemingly different qualitatively, as they too presuppose a whole into which something or someone can be brought (Graham & Slee 2008:278), through the agency of someone who is supposed to

have the knowledge and the power. In Ferguson's words, (quoted in Graham and Slee 2008:278), these terms "simply work to (re)secure an invisible centre from which constructions of Otherness and the designation of marginal positions becomes possible." Independence and its cognates of autonomy and privacy sound too ill-timed to appeal equally to all contexts. As Bosch (1991:362) observes,

The individual is not a monad, but part of an organism. We live in one world, in which the rescue of some at the expense of others is not possible. Only *together* is there salvation and survival. This includes not only a new relationship to nature, but also among humans. The "psychology of separateness" has to make way for an "epistemology of participation". The "me generation" has to be superseded by the "us generation". The "instrumental" reason of the Enlightenment has to be supplemented with "communicative" reason (Habermas), since human existence is by definition inter-subjective existence.

Independence would, therefore, evoke the unchecked liberalism of the Enlightenment, with its unethical consequences on the entire human family. Perhaps interdependence would be the best replacement as it resonates with scriptural metaphor of the Body of Christ (1 Cor 12). Though one body, it is made up of different but interdependent members. With the various alternatives having been shown to be inadequate, I therefore propose a different model of disability.

#### **4.2.4.1 Participatory model of disability**

In light of the limitations of the above models, I propose a participatory model which resulted from the weaving of ideas gleaned from Heshusius (1994;1996) and Kotzé (2002), as well as from the research participants themselves.

##### **a) Participation**

When both Tsili and Reg made reference to what has become a defining motto of people with disabilities, "nothing about us without us", they were underlining the importance of participation of people with disabilities in all issues that concern all people in general, and people with disabilities in particular. The salient feature of a participatory model is thus participation, the notion of which has been defined in different ways, beyond the scope of this research to outline and compare. Nevertheless, one definition is particularly relevant here, from WHO (2002:10):

a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change.

This is well-formulated, particularly for people with disabilities who are often marginalised on issues that affect their lives. Of particular importance are the comments of Stohl (1995:160) that, among other things, participation decentralises and breaks down hierarchical boundaries that often disempower and push people with disabilities to the margins. Participation works more toward reviving and establishing democratic values and ideals.

Participation, however, is not a simple panacea, and ideas associated with it make certain assumptions that need first to be unpacked (Radermacher 2006:27). For instance, there are degrees of participatory involvement that have to be clearly defined, and Radermacher provides a useful adaptation from Fajerman and Treseder (2000) of distinctions between different degrees of it. Issues of a practical nature in the realisation of participation have also been noted by research participants, as, when asked what participation would mean to him, Reg said,

*It may not be possible for all people with disabilities to be present at every forum where policies are made and implemented but their structures are there and should be recognised at every level especially on issues that affect them.*

Reg's observations attach importance of listening to the voice of those who are often subjugated (Kotzé 2002:19) and the sometimes unhealthy emphasis on participation which might render social intervention numb and ineffective.

## **b) Features of a participatory model**

On a much deeper level, the notion of participation is based upon recognition of the reality of plurality (Kotzé 2002:17). While participation appreciates the difference between the self and the other it does not stop with the distinction but goes further to underline the other mode of interaction that can be defined in terms of ontological unity, hermeneutics of connection, deeper level of kinship and an attitude of profound openness and receptivity (Heshusius 1994:15; Heshusius 1996:131). This re-ordered self-other relationship, which Kotzé (2002:4) calls 'threads of understanding', expresses itself through listening and responding, ordered towards healing rather than inflicting more pain (Kotzé 2002:5). It is a listening demanded not by duty or any fixed regulation but by the same consciousness to which people belong. Within a participatory model, a corresponding response loathes judging and prescriptions,

emerging from a “dance in the silence of dark.” (Kotzé 2002:4,13). It is not predetermined but spontaneous and open, and in that way, different voices have the space and latitude to air their concerns, to participate. Such participation, which involves all, especially those who are usually marginalised and silenced, evokes the ethical consciousness to which it leads as its end (Kotzé 2002:18). Within the framework of this connection, even knowledge can emerge from silence (Heshusius 1994:16). The openness that characterises such a kinship lends itself to an array of possibilities which earlier models had not been able to achieve.

### **c) Participatory model and disability**

Reg, in response to what could be the way forward in ameliorating the lives of people with disabilities in Lesotho, said, “*No better way than consultation with people with disabilities with their full participation, especially on issues that concern them.*” The same concern was raised by Tsili, in words common to PWD movements: “*Nothing about us without us*”. These responses are a form of resistance to a disempowering discourse that has long characterised the lives of people with disabilities.

The medical model, with its penchant for normalisation and its professional orientation, tends to marginalise and silence the voices of people with disabilities. It contains within itself the source of truth to which people with disabilities have contributed nothing, and therefore tends towards prescriptive knowledge claims (Kotzé 2002:14). The question of who benefits from such prescriptions clearly points away from people with disabilities. This is not to suggest that nothing good can come out of the medical model, but that the expertise that does not inform itself through context and individual experience tends to hurt. The social model, in all its manifestations, and despite its achievements on the political front, has stumbled through its homogenising tendencies. Voices of women and voices from the global margins have raised their concerns about the social model’s inadequacy in addressing all issues sufficiently, while leaving aside individual experiences and local contextual issues (4.2.2). Even with its eclectic manifestations, the social model has not been able to shed the elitist aura which puts it out of reach of the common person. It appears that participation, in ways that are defined and determined by people with disabilities, is better positioned to involve the voices of all on issues that affect them.<sup>4</sup>

In summary, the exploration of the voices in disability studies reveals that the construction of bodies in general, and disabled bodies in particular, remains in the hands of society. The

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<sup>4</sup> The notion of participation so central to this research is taken up in Chapter 7, where it is linked with the concepts of communion, *ubuntu* and interdependence.

process of constructing disabled bodies works through discourses, linguistic patterns and models that reflect power disparities between the constructed and those who construct. The different models created by contemporary society to manage disability seem to be, for the most part, at the service of professionals and the elite. They not only shape people with disabilities in varied ways but also testify to the volatile and elusive nature of the notion of disability. The more people try to control it through definitions and models the more evasive it becomes. Voices of research participants have shown that, if given space and time, they could deconstruct disability in ways unimagined before and contribute immensely in the co-construction of an alternative disability story. The latter they can achieve despite their relatively poor level of education and comprehension of disability models and concepts. Disability does not have to be seen through the eyes of a Disability studies framework alone but also through the eyes of culture. In the location of this research journey, it is the culture of Lesotho.

### **4.3 CONSTRUCTIONS OF DISABILITIES IN LESOTHO**

Disabilities are socially constructed, their meanings and connotations determined by and mediated through the norms of the culture within which they exist (Ogechi & Ruto 2002:64). As such, they are shaped by a set of relationships that are institutional, cultural and interpersonal. Not only are disabilities social constructs, they are also “sustained by social practices that often serve the interests of the dominant groups in society” (Burr 2003:38). In this section I examine the contextual nature of disabilities and the particularity of every experience of disability, and therefore discuss the cultural and institutional (public) constructions of disability. Lastly, I focus in on the experiences of people with disabilities who are the participants in this research.

#### **4.3.1 Cultural constructions of disability in Lesotho**

Because of paucity of written literature on this topic, I rely heavily on snippets gleaned from Sesotho folktales, historical anecdotes and some language experts from the sister department of African Language and Literature at the National University of Lesotho.

Culture is simply defined as a shared way of life (Barnes & Mercer 2001:516), with one becoming a member of a particular culture through birth and socialisation within it. It is the culture that teaches an individual what should be done and what should not be done; what is normal and what is abnormal. Meanwhile, disability is, as Ogechi and Ruto (2002:64) suggest, a culturally bound and determined notion. The indigenous belief system of the Basotho, though only fragments of it exist today, is evoked to provide an appropriate

framework upon which the notion of disability can be understood. This is because perceptions, attitudes and behaviour of people toward persons with disabilities are determined by belief systems. In this section I examine the traditional culture of the Basotho, which is both traditional and creative, and how it perceives the notion of disability. I will be very careful to avoid falling into the trap of using Western models that are more often than not quite alien and foreign to the Basotho worldview. I begin with an overview.

#### **4.3.1.1 Communalism among the Basotho**

The Basotho's way of life, like that of many other African communities, was traditionally governed by communality, hospitality and participation (Machobane 2001:12), as attested to by some of the missionaries to the then Basutoland (Lesotho before independence). Basotho were renowned, among other things, for their much cherished social life (Germond 1967:518-523). Unlike their Western counterparts, who were inclined toward what Sindima (1990:202) termed 'liberal individualism,' in keeping with their worldview, they emphasised the bond between individuals and the community (Machobane 2001:14). One's identity did not make sense outside the family, clan or community, and a nation is a large family; a family with many families, and the rituals performed by members of the community were a re-living of this cohesion and bond, not only with the living but also with the living dead (ancestors) (Moitse 1994:4,26). Social responsibility and communal participation were highly esteemed, and whatever social task was to be done it was the responsibility of the whole community rather than of any individual alone (Rakotsoane 2009:13; Matséla 1990:4-5). One person's problem or predicament was seen as affecting the entire community, and it is within this framework that disability has to be understood. Mbiti's (1970:141) adage, "I am because we are, and since we are, therefore I am" sums up the seriousness with which the relational dimension of life was taken by the Basotho.

#### **4.3.1.2 Communalism and people with disabilities**

Like all societies, the Basotho recognised the existence of persons with disabilities, however they did not have an umbrella term that covered all forms. The present Sesotho nomenclature "*Batho ba nang le bokooa*" (people with disability) is an attempt to match Western categorisation which creates, through survey, projects, public systems and policies, the disabled as a social category (Ingstand & Whyte 1995). Historically, the Basotho had specific terms and conceptual categories for persons who had this or the other perceived difficulty or problem. Even people who, though normal by today's disability standards, were not responsive to society's usual expectations were regarded as abnormal (Guma 1971:53).



These were generally people with mental, moral and physical defects. In a class of mental and physical defects there were, for example, the blind (*sefofu*); deaf (*setholo*); dumb (*semumu*); cripple (*sehlotsa*); maimed (*sehole*); and stupid (*segoqofane*).

In a class of moral defects there were, for example, glutton (*senyofu*); prostitute (*seotsoa*); and concubine (*seraburabu*)<sup>5</sup>, and one for persons with undesirable moral, mental or physical defects, such as an unmarried woman (*lefetoa*); stammerer (*lehoelea*); eunuch (*leqhalaha*); and mad person (*lehlanya*)<sup>6</sup>. Both classes of nouns (7 & 5, see footnotes) are ones that mark certain people from others as abnormal in some way, however a term which might have brought all these people together in a single category was missing. The Sesotho term *sebupuo*, which literally translates as 'creature', was used to cover only persons with mental and physical defects (Phafoli 2010). Those with moral defects, though undesirable and abnormal by societal standards, were not considered as *libupuo* (plural of *sebupuo*). The Sesotho term *sebupuo*, loosely translated, comes very close to the term 'innocent of God'.

The perception by society of people as having disabilities (mental and physical defects) was, on the whole, negative and unwelcoming, and they were a source of shame for a family that begot such a child. It was not demanded of them to marry, to go to the circumcision school or to perform other rituals (Thetso 2010). Children with physical disabilities, for example with an inability to move around, were confined to the house. Not only were they considered a burden, but also the family was ashamed to have them seen by others, as it reminded them of their failure to adhere to tribal sanctions (Thetso 2010). In general, disability was something that nobody would wish upon him/herself. Birth of a disabled child, for example, usually posed a threat to the integrity of marriage, and often women felt responsible or were blamed for it, and so would keep the child at home in order to lessen the pain of shame (Khatleli, Mariga, Phachaka & Stubbs 1995:6). Some of the participants had more or less similar experiences of rejection by family members:

*My parents moved me from pillar to post in search of doctors of all sorts to get me healed. Eventually they posted me to Maseru, where they had heard about a school for people of my kind. It was clear to me that my parents did not take my visual impairment kindly.*

(Jack 2009)

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<sup>5</sup> Grammatically, the classification falls within class 7(c) of nouns (Guma 1971:53), a class with a prefix of *se-* in its singular form and *li-* in its plural form.

<sup>6</sup> These belong to a different class of nouns (class 5 (v)) (Guma 1971:46) It has a prefix of *le-* in its singular and *ma-* in its plural form..

*My mother, unlike my grandmother thought that I was something of a burden to the family and that the best I could have was to be taken care of by my siblings. If it were not because of my grandmother I could not have come to school. My grandmother was more enlightened and understanding. Perhaps her work in the kitchens of white people in South Africa gave her a different and enlightened perspective.*

(Tsili 2009)

There are cases, however, where people with disabilities were considered part of the family and were not arbitrarily excluded from participating in family rituals (Khatleli, Mariga, Phachaka & Stubbs 1995:6; Ogechi & Ruto 2002:68). One of the participants attested to this:

*After my birth, I am told, my mother stayed at the hospital for some months. I was taken home where I was taken care of by my Grandmother. They (Family members) realised only later that I might be disabled. They however did not discriminate against me. They supported me all the way.*

(Maki 2009)

#### **4.3.1.3 Causes of disabilities among the Basotho**

According to Ogechi and Ruto (2002:69), causes of disabilities can be discerned at two broad levels of relationship, namely vertical and horizontal, often so intertwined that any discussion about the other can always be conducted in reference to the other. The vertical level includes relations with God and the ancestors, and any transgression that injured these could invite their anger or wrath, expressed through a form of disability. Any failure to observe certain tribal-sanctioned rituals could bring about some form of disability to the parent or to the child. One of the participants in this research, with both mobility impairment and learning disability, quoted what some people said about her disability: *“In their words, ‘If she were the first born we would attribute her disability to a failure to observe tribal-sanctioned-rituals’.”*

This perception underlines a deep-seated belief of the Basotho that some forms of disability can be attributed to a failure to observe tribal-sanctioned rituals (Thetso 2009). Failure or reluctance to comply with tribal-sanctioned rituals, for example, could result in a disabled child being born into a family. To the Basotho’s strong sense of communalism, there was a corresponding need to maintain strong relations with everyone within the group (Matsēla 1990:2), whereas failure to meet such demands had the potential to strain relations and cause illness or debilitation in the individual concerned (Moitse 1994:26).

Women were prohibited from doing certain things at certain times and places, for instance failure to carry out appropriate rituals as demanded by the ancestors, which could cause some form of mental disorder called 'maroko' (*Sechefo 's a*). This was characterised by apprehensions of death, hallucinations and dreaming incessantly about the dead. It was curable through adhering to proper rituals, notably slaughtering a beast to appease the ancestors. The horizontal level involved relations with other humans, and defined the norms that regulate relations within the clan or community. Marriage between close blood relatives (incest) was believed to result in the birth of disabled children. Imitating, ridiculing or making a mockery of a disabled person was strongly discouraged as it could bring a curse upon the offender, the child or future generations in one's genealogy.

Witchcraft is also cited as one of the major causes of disabilities among the Basotho (Thetso 2009), as so-called witches, because of their supposed supernatural ability to manipulate the evil forces, inflicted misfortunes on some people and thereby caused incapacity and some form of illness or disability. There are cases of insanity or mental illness reportedly attributed to witchcraft, with witches also able to interfere with natural processes such as conception and birth, and through them cause disability of either child or parent (Lapointe 1986:49). This understanding was confirmed by Jack: *"My parents had a suspicion that I was bewitched. Hence they consulted witchdoctors to normalise the situation."*

In what Ravaud and Stiker (2001:502) saw as exclusion through elimination, old people who had become helpless but would not die were killed. They would be placed at the entrance of the kraal so that the cattle upon entering would trample them to death (*Sechefo 's a*). It must be pointed out, however, that this practice only made sense within the worldview of the Basotho. Given the frequency of the wars at the time, an elderly person who could neither flee nor protect him/herself, was better being killed in this way than humiliated by the enemies (Lesitsi 2002:51). This practice has since been discontinued.

The causes of disability make sense only within the context in which they are understood. While some causes discussed above interface with those in Chapter 3, there is a contextual touch to them that make them different from the others. The context of Lesotho today is a mix of cultural, Christian and Western influences, and its discussion would make one appreciate the extent to which what I have termed Christian cultural context shaped perceptions about disabilities in the country. In a culture that has a hierarchy of beings and forces, it makes sense to understand disability as being caused by ancestors, witches and other forces, a discussion of which provides a glimpse into the worldview. What emerges clearly is that the worldview of society is a framework that functions to give shape and form

to whatever is discussed. Disability understood from the point of view of the Basotho makes sense within the context of that worldview.

#### **4.3.2 Christian cultural constructions of disabilities in Lesotho**

With the advent of Christianity, through its missionaries, and the colonial powers, the cultural legacy of the Basotho was influenced from all angles, seldom remaining the same. These missionaries in particular were, as Lapointe (1986:55) observes:

true sons of their time, nineteenth century romanticists, filled with superiority of their culture, convinced of the exclusive place of the Gospel which they came to proclaim. They were eminently sincere, unshakeable in their faith, unconquerable in their courage, convinced to the marrow of their bones of the good effects of their message. We should not be surprised if, together with all these qualities, they brought a few prejudices and ideas of Christianity inherited from the turbulent past of their Church in Europe.

Their arrival in Lesotho coincided with the time in Europe when the society was bent on rehabilitating people with disabilities with a view to facilitating their integration into society. At the same time that these people were rehabilitated they were also being institutionalised (Stiker 1999:107; Braddock & Parish 2001:28-29). According to Ingstad (2001:778), contact of people in the developing countries with what is now referred to as rehabilitation came through missionaries and representatives of colonial powers. Despite the gains achieved through these institutions, they remained institutions (Stiker 1999:107), and through institutionalisation, people with disabilities were excluded from mainstream society.

The first missionaries to Lesotho were thus caught up in a cross-fertilisation of perceptions about disabilities which displayed features of compassion on one side and subtle marginalisation on the other. The paradigms inherited from the Greco-Roman and Jewish mentalities, founded on the binaries of whole vs. unwhole; perfect vs. imperfect, were still very much alive within the traditional thought of the church, but there was also the legacy of Jesus, who had shown compassion to the most marginalised. This legacy came to burden Christianity in Africa (Pato 1994:153), and it is against this background that the work of the first missionaries, which coincided with the colonising thrust of the British, should be understood. The conflation between the encroaching and receiving cultures resulted in a hybrid of thought, attitude and perception on disability and people with disabilities. Though disability does not seem to have been a priority for the first missionaries, their attitude toward people with it could be gleaned from practices and doctrines of their respective churches which they had no choice but to think of as they thought fit.

My search for written documents on disability from church archives was unsuccessful, and while there were cases of homes for people with disabilities founded by Christian churches, there were no corresponding statements by churches on issues of disability. The common practice among all churches in Lesotho was to deny ordination for a disabled person, evident in the lack of case of a pastor or priest who was disabled prior to ordination. This suggests a bias against people with disabilities inherited from the long legacy of Christian ambiguity perpetrated against people with disabilities.

It is therefore possible to infer that the teachings, attitudes and perceptions of the missionaries on disability could not have left intact the indigenous beliefs. The syncretism that developed as a result of the contact of the two cultures meant the Basotho could not have survived the onslaught of imperialism, with its new demands on their way of life (Machobane 2001:10-11,41). It affected their outlook to life in many ways, and these factors combined were to affect the earlier perception of communalism and hospitality for which the Basotho were renowned, and all that accompanied it (Machobane 2001:12-14). It is to this Christian cultural context, as a locus for discovering constructions of disability in Lesotho, that reference was made in Chapter 2.

The prevalent attitudes and perceptions that people currently have of disability and people with disabilities result mainly from the pressure emanating from different sides. There are perceptions of culture and its communal orientation on one side and the modern way of life, with its demand for education and productivity, on another. The lack of clear written policies or statements on disability from the ecumenical and denominational bodies contributes to the ambiguity of disability in Lesotho. In the ensuing tension, people with disabilities are caught between parents and/or caregivers, who feel ashamed, and pragmatic, educational and industrial demands for personal autonomy and self-direction. This is especially the case because of the marginalisation of the voice of people with disabilities in the policy conceptualisation and design processes (Peters, Johnstone & Ferguson 2005:141).

Too often, dominant societies have worked hard toward cultural assimilation (Johnstone & McIntosh 2009:67), imposing foreign value systems which have alienated cultural and individual experiences from their natural loci. The assumptions and epistemologies underlying such foreign value systems, and their critique thereof, are often overlooked in working out policies and programmes. In the process, an important principle, where understanding differing cultural belief systems can often provide an important conceptual tool when working within a culturally diverse society, is undermined (Groce & Zola 1993:1048). The result has been what Haskell (quoted in Kisanji 1998:2) calls a

“contemporary cultural imperialism of western ideologues.” This tendency has affected policymaking at political, welfare and educational levels in adverse ways. Models promoted on disability were devoid of indigenous cultural as well as individual experiences and flavour, almost all emerging from the West, and elitist. They could not, because of their complexity, be understood by any of the research participants, reflecting Kisanji’s (1998:1) questioning of the relevance of studies and practices evolved and tested in the West, only to be implemented in diverse cultural conditions without adapting them to local conditions:

Indeed, many studies of inclusive school practices have so far been carried out in the North. Unfortunately, political, social, economic and cultural conditions in the countries of the North are markedly different from those in the South. To what extent, then, is the concept of inclusive schooling/education relevant to the South? Should planning for inclusion follow models of the North?

Failure, therefore, to adapt programmes, policies and practices on disabilities, to local genius and understanding will not make significant impact on the lives of either people with disabilities or their significant others. The existence of indigenous systems of belief does not imply that change will not occur, or as Groce and Zola (1993:1054) argue “Traditional belief systems on disability have at times proved to be quite adaptive, shifting in response to social, economic, and educational experiences gained during the acculturation process.”

Such novelties and adaptations have to be embraced with openness, as at times they constitute the experiences, as lived, by people with disabilities. Merging the best of the indigenous beliefs and the best of the Western systems may therefore be the best option, and have pragmatic consequences. The good of the people with disabilities should be the deciding factor. However there are cases where traditional belief systems militate against the rights and the wellbeing of people with disabilities (Groce & Zola 1993:1054; Peters et al. 2005:144). In such cases, changes should be advocated, not *without* people with disabilities but together *with* them.

#### **4.4 CONCLUSION**

This chapter sought to explore ways in which contemporary disability studies and Christian culture have shaped the construction of disabled identities. Emerging from this exploration is that the competing and shifting voices within the framework of the models and definitions of disabilities are evidence of the instability of the notion of disability. They also reflect the inadequacy of the modernist paradigms, within which some models are immersed, in their attempt to globalise, harmonise and assimilate the ‘different other’ into the normal. The

medical model has constructed the disabled people as pathological others who require normalisation through medical cure so that they become functional. The social and the integrationist models have departed from the pathologising tendencies of the medical model. The greatest challenge from the social model and its manifestations, despite its immense achievements, has been its elitist status, which tends to leave out the experiences of the man and woman who cannot speak their language, or balance the ethical tension that results from the need for group cohesion and the justice for individual self-determination. In this way, a disabled identity is shaped, but with the resultant power implications.

Society, religious and cultural, itself has set standards of what goes and what does not as far as a disabled body is concerned. Consequently, it is the bodies of people with disabilities that remain ambiguous as a result of how society perceives them. They have no voice and they are at the disposal of others who alone decide what is good for them. This is an issue of power skewed in favour of the non-disabled as opposed to those who are disabled, a power discourse founded on the binaries of abled vs. disabled, and normal vs. abnormal. Manifest in both church and culture is a machination which sustained the dominant disability story.

These details align the chapter to the stated aims of the research, which are to show how disability remains a social construct as well as to expose the politics of power in disability discourses and that of examining the machinations of the dominant disability discourse. I will pick up further the machinations of the power discourse in Chapter 7, to unpack the binaries that sustain it and the unique outcomes that emerged from it as a result of participants' release of their silenced voices.

In the next chapter, I identify the influence of the two dominant models of disability in the policy and legal framework formulation within different public institutions in Lesotho. Their contribution in not only constructing people with disabilities as objects of rehabilitation and medical expertise but also in maintaining the dominant disability discourse will be emphasised.

## CHAPTER 5

### INSTITUTIONAL DISABILITY DISCOURSE IN LESOTHO

#### 5.1 INTRODUCTION

In this chapter I explore the evolving scene in Lesotho in regard to the constructions of disabilities within public modern institutions. Reference is made here to the different government Ministries, particularly of Educational and Training, Health and Social Welfare and that of Justice and Constitutional Affairs, Disability People's Organisations (DPOs), and Non Governmental Organisations (NGOs) as to what disability models inform their work and service provision in Lesotho. Written literature, though very scanty, is critiqued in the light of the foregoing frameworks, reflections and observations, as well as experiences of people with disabilities. The aim is to problematise and critique discourses and philosophies (Dunne 2009:42) around disability models adopted by different ministries, sectors and institutions. The ethical question as to whose interests are served by the way that disability is (re)presented and talked about in the Educational, Health and Social Welfare, and Justice ministries, other than forming the fulcrum of this research, will retain the focus on maintaining the ethical and critical stance.

I also read discourses that emerge from within different government ministries through the lens of Foucault's (1982:220-221; 1991:91,103) notion of governmentality and power, arguing that through different policies as discursive weapons, people with disabilities are constituted educational, welfare and legal subjects subject to power relations over which they have little control (Gathiram 2008:151). Power valences inherent in the language of ministerial and departmental policies and documents are explored, and the results checked against views of research participants with a view to identifying ways in which such power disparities marginalise and construct people with disabilities in ways that incapacitate them.

#### 5.2 DISCOURSES IN THE MINISTRY OF JUSTICE

Rights of people with disabilities are enshrined in general legislation, specifically Section 33 of the Constitution of Lesotho, which provides for the "rehabilitation, training and social resettlement of persons with disabilities". Since 1995, a number of Acts of Parliament addressing issues pertaining to people with disabilities have been promulgated, including the Building Control Act 1995 that provides for user-friendly buildings to different categories of people with disabilities. A number of other Acts, such as the Local Government Act of 1997; the Criminal Procedure and Evidence (Amendment) Act 2000; the National Assembly



(Amendment) Act 2001; and the Sexual Offences Act 2003 make provisions for protection against discrimination and participation of people with disabilities in the development of their society.

On December 2nd 2008, Lesotho took a significant step in ratifying the Convention on the Rights of Persons with Disabilities, signalling its intentions to recognise the legal rights and fulfil its duties towards people with disabilities. Although the Convention was operative in Lesotho from the beginning of 2009, the country is yet to sign the optional protocol, a separate document that will enable individuals to seek redress after treaty violations.

In the practical domain, the justice sector still has a long way to go in respect of providing for and protecting the rights of people with disabilities. Legal documents are not written in Braille and there is no provision for sign language interpretation or translation for people with speech and hearing impairments (DNDRP 2008:20). As far as the electoral process is concerned, PWDs do not exist, effectively being barred from exercising their democratic right in electoral processes that do take into consideration their particular requirements. One of the participants confirmed this:

*Courts cannot call me to testify in court because their language of acceptable evidence does not accommodate people with visual impairment. If they ask, "Regy how do you know that this man is the one who did this when you cannot see?" and I say I identified him through his voice and odour, they would press me to show how. This suggests to me that sight is more privileged than other ways of gathering knowledge. People with hearing and speech impairment, too, face a lot of challenges in our courts because of lack of qualified interpreters of sign language.*

(Reg 2009)

The legal sector in Lesotho is still steeped in the rehabilitation model of disability, and people with disability are seen as in need of rehabilitation, training and resettlement. The principle of rehabilitation that was at the forefront of efforts in the twentieth century society to treat people with disabilities was only a slight variation of the one prevalent in the eighteenth century, which saw the "birth of educational facilities to raise disabled people to a level of functionality" (Stiker 1999:xii). Also retained was much of the nineteenth century rehabilitation discourse, characterized by its desire to fill a lack in person with disabilities through medical and technological correction. As Reg said,

*in the eyes of some people I still do not have a legal capacity to effect certain transactions with corporate business bodies. I still cannot vote for the party of my own choice. Only somebody can do it for me. How do I know what he/she has done? I cannot give evidence*

*in court because legal structures do not recognise that knowledge can come through means other than seeing.*

Though there is a shift in terms of appreciation of rights of people with disabilities as worthy citizens, the absence of a national policy truncates efforts to address issues around disability in Lesotho. According to Ntlatlapa (2007), the lack of national policy has denied all stakeholders sound direction on issues of disability, and an Act of Parliament, he argues, would go a long way in providing a legal basis for such a policy.

In the absence of such structures, people with disabilities will always be reliant on others in their efforts to demand what is rightly theirs. In the absence of a policy or policies that govern the relations between different departments and public institutions and people with disabilities, there can only be ambiguity from both sides. However, silence and ambiguity are as good as complicity, and this has to be interrogated. Beneath that silence and ambiguity lie power valences that have ethical implications, the meaning and quality of which are dependent on which side of the disability divide one is; welfare authority or a disabled person? Maluleke (1997:50) identified different forms of silence, which he suggested must be questioned. Is it a calculated silence of power or a crushing silence of powerlessness? Who stands to benefit from this silence?

From the above, it is clear that the Justice sector is still steeped in the rehabilitation and deficit model, which views people with disability as lacking in something that must be restored before they can be resettled into society. Despite developments in the global arena, with conventions and statements, the lives of people with disabilities are far from being given a stake in the Justice sector. In the process, they are declared incapable of participating in issues of justice that concern them.

The discussion on the Justice sector has laid a foundation for examination of other ministries that depend on the legal framework for the formulation and implementation of their respective policies.

### **5.3 DISABILITY DISCOURSE IN THE MINISTRY OF EDUCATION AND TRAINING**

Different conventions, conferences, congresses, statements and summits form an important background to the policy of inclusive education, which has become “the philosophy” in educational circles in recent times. Not only do they represent shifting challenges and perspectives, they also underline the fluidity of the notion of inclusive education.

### 5.3.1 International policy on inclusive education

The World Conference on Education for All (WCEFA) in Jomtien, Thailand in 1990, placed “Education for All” (EFA) high on the international policy agenda (UNESCO 1990). It highlighted the importance of basic education and committed all nations and organisations in attendance to achieve EFA’s main objective. Unlike the Convention of the Rights of Children, where availability of resources and the child’s condition were criteria for integration, the Jomtien EFA declaration enjoined all governmental and non-governmental organisations to provide resources and funding toward implementation, management and evaluation of educational programmes (UNESCO 1990).

The 1993 Standard Rules on Equalization of Opportunities for Persons with Disabilities expanded the scope of their rights, and further represented a definitive move toward the adoption of the social model of disability as an appropriate guidepost in the development of relevant plans and programmes for inclusive education. The World Conference on Special Needs Education, in Salamanca, Spain in 1994, took the issues of the World Conference on Education for All of 1990 to another level. Taking up the idea of social equity, it situated itself within the social model of disability and embraced the philosophy of inclusive education, affirming that:

... every child has unique characteristics, interests, abilities, and learning needs and that, those with special education needs must have access to regular schools which should accommodate them with a child-centred pedagogy capable of meeting those needs

(UNESCO 1994:2)

The 1995 World Summit for Social Development, though a social summit, made clear its intentions to embrace disability as an issue through the participation of Disability People’s Organisations (DPOs). While accentuating the links between education, poverty and disability, it embraced a notion of development that puts people at the centre. In particular, it drew attention to poverty as a barrier to education and “a *prima facie* cause of disability.”

In 2000, at the World Education Forum in Dakar, Senegal, nations re-committed themselves to achieving the goals of EFA by 2015, identifying inclusive education as a key strategy for the implementation of EFA (UNESCO 2002:17). The forum propped up the objectives and guidelines of the Salamanca Statement, and in its attempt to weigh up progress made since Jomtien, underlined the value of following up on commitments. It also represented an important shift in focus from preceding conventions and conferences in that Inclusion was no longer about how best the child could be assisted for inclusion but rather how exclusionary

policies and practices in education could be challenged to accommodate those previously marginalised (Peters 2007:105). It was more about preparing schools to reach out to children than about preparing children for inclusion.

This summit represented an important shift in the conceptualisation of inclusive education, with long-term consequences for its implementation. As elaborated upon below, many policymakers and implementers are stuck in an old paradigm of inclusion, where the school as a place for inclusion becomes also a norm when measuring the 'different', and works toward bringing it (the different) back to order. This reflection lays important groundwork for a better appreciation of the contributions and constraints of inclusive education in Lesotho.

### **5.3.2 Inclusive education discourse and the Ministry of Education and Training in Lesotho**

Lesotho's journey into inclusive education dates back to 1987, when the government of Lesotho, through its Ministry of Education and Training (MOET), acknowledged the need to reach out to children with special needs. In the light of this urgency, it contracted an external consultant (Csapo 1987) to assess the needs of children with special needs and the relevance of residential care schools that housed students on a long-term basis. Prior to 1988, provision of education to children with special educational needs had been the responsibility of churches, NGOs and individuals (Mariga & Phachaka 1993:10). Csapo's conclusion was critical of the long-term care centres, as she argued that inclusive education was better adapted to the local situation, specifically the extended family systems, and was cost-effective (Csapo 1987; Jackson 2005:14). Inclusive education would ensure that a child was not uprooted from family and society, with the emotional and psychological deprivation to which that led (Csapo 1987).

Spurred by Csapo's (1987) report, the World Conference on Education for All and other relevant conferences and international declarations, the Ministry of Education established a Unit of Special Education to attend to the educational needs of children with special needs. The commitment of the Ministry of Education toward improving the educational conditions of children with disabilities was demonstrated in its setting in motion of the Education Act 1995, which provided for access to education of children with disabilities. In its effort to achieve its goal of promoting the integration of children with special educational needs into regular school system at all levels, the Special Education Unit, undertook various studies, which, together with other similar ones, provide the subject matter for our subsequent analysis.

In 1993, Mariga and Phachaka conducted a feasibility study entitled, *Integrating Children with special Needs into Regular Primary Schools in Lesotho*. It sought to determine the number of children with special needs; the attitudes of teachers, pupils and parents toward integration of such children into regular school system at all levels; the feasibility of such an idea and, perhaps in the background, the extent to which such integration and inclusion could be aligned with the foundational principles of Education for All (EFA). The authors' conclusion was that total integration was feasible (Mariga & Phachaka 1993:30); and that the government should be invited to fulfil its role of facilitating policy and legislative framework formulation, as well as ensuring accessibility of school buildings and provision of adequate instructional support systems. These included curricula flexible enough to accommodate the needs of children, adequately trained teachers and a welcoming environment that went beyond simple tolerance (Peters 2007:106).

In 1995, Khatleli, Mariga, Phachaka, and Stubbs undertook another study, entitled *Schools for all: National Planning in Lesotho*, a reflection that represented a progression in thought from the feasibility study of 1993, that had adopted an integrationist model that differed qualitatively from the philosophy of inclusive education. The '*Schools for all*', other than embracing the in vogue inclusive education model and terminology, and realigning their earlier way of thinking to a contemporary one, addressed robustly the complex and sometimes contradictory expectations within the Special Needs Education (SNE) discourse. It also tackled the gaps in literature, policy and practice within the SNE discourses in Lesotho.

The intentions of the MOET in fostering integration of children with special needs into regular schools were well meant, and the gains made are not in dispute (Stubbs 1995; Johnstone & Chapman 2009). With the efforts of Lesotho towards inclusive education having been hailed as bold (Peters, Johnstone & Ferguson 2005:141), Stubbs (1995) has identified them as pioneering and radical, especially given the limited resources of the country. There were, however, a number of constraints and challenges that accompany any programme of the magnitude and complexity of inclusive education.

The work undertaken in this research resembles that of a vigilante, looking for ways to improve things. Asking questions, some of which may be very uncomfortable, is one way of going about it (Graham & Slee 2008:277). More often than not, hegemonic discourses and universalising tendencies develop from *statis* and complacency, which result from common-sense, taken-for-granted knowledge, practices and assumptions. Once such assumptions cease to be challenged or questioned, they become truth claims, which propose themselves

as given for everyone, everywhere. I wish to interrogate the idea of inclusive education as seen by the Special Education Unit (SEU), within the MOET, with a view to finding factors that contributed to its downturn and assumptions behind it, understanding its potentially normalising effect, and determining the extent to which it affects the welfare of children with disabilities.

### **5.3.2.1 The notion of inclusive education in Lesotho**

The idea of inclusive education has covered significant ground in the global and local contexts (Graham & Slee 2008:277), to the extent that it represents a new philosophy. Despite its popularity, however, it remains fraught with competing meanings and interpretations (Peters 2003:2-3; Peters, Johnstone & Ferguson 2005:141; Dunne 2009:43). Often these different meanings, as Graham and Slee (2008:277) observe, are concealed by the continued use of the generalised sense of this term. For instance, Miyamoto (2005:33) views inclusion in terms of the elimination of factors that create social exclusion, which would include facilitation for social participation of people engaging in mutual interaction. Others define it in terms of presence and participation measured by how those included achieve in the mainstream educational setting (Department for Education and Skills 2005:9). One of the participants viewed inclusive education as:

*In my opinion inclusive education is about taking education to the communities without removing students (disabled or abled) from their natural environment. Yet I am aware that it cannot be fully inclusive unless there are well-trained teachers, adequate supply of equipment for learners with special needs as well as infrastructural development that meet the needs of learners with disabilities. My question is: would the government alone manage to provide such equipment and infrastructure at all places?*

(Jack 2009)

For Dunne (2009:43), inclusion has become a buzzword that has assumed a potentially normalising effect and so needs constant interrogation and questioning. It is a social construct that assumes different shapes and meanings, depending on who defines it and the context within which it is defined. The above definitions betray these diversified interests and contexts, thus rendering inclusion a highly contested notion.

According to Dyson (as quoted in Clark et al 1999:158), that the term hinges on “a complex range of theories, assumptions and principles” further complicates any attempt to pin it down. My interest in following this idea is to determine the success of the policy; the models it aligned itself with in the context of Lesotho; whose interests were served by the policies

and practices that seek to include; and ways in which such understandings constructed people with disabilities.

### **5.3.2.2 Contributions and constraints of inclusive education in Lesotho**

According to Peters, Johnstone and Ferguson (2005:151) and Johnstone (2005; Johnson & McIntosh 2009) Lesotho's inclusive education has been seen as pragmatic in that it draws from available cultural and institutional resources. Despite the many gains, especially in addressing barriers of negative attitudes, there are varied constraints to the successful implementation of inclusive education in Lesotho, which I group into three main areas, namely pedagogy, policy and reorganisation of schools.

Firstly, pedagogical practice is vacillating between the old colonial education mentality, which is predominantly teacher-centred, and the in-vogue student-centred approach aligned with the EFA principles. According to Muzvidziwa and Seotsanyana (2002), with the system of education remaining largely colonial and teacher-centred, and access to education increasing as a result of free primary education policy adopted by government (Peters, Johnstone & Ferguson 2005:152), failure in effecting the demands of inclusive education cannot be avoided.

Teaching practice at classroom level has barely changed to accommodate new demands that result from growing numbers of students with special needs in schools. Teachers, who are only a reflection of the kind of training they received, felt that an additional responsibility was placed upon them with no incentive or recognition on one side and lack of appropriate teaching material and support human resources on the other (Johnson & McIntosh 2009:138;141). They therefore viewed students with special needs as 'add-ons', whose educational needs could only be met during teachers' spare time (Peters, Johnstone & Ferguson 2005:138). This is an issue that was raised by one of the research participants:

*Are our teachers ready to offer education to both students with visual impairment and speech impairment in the same class for example? The practical implications are that the teachers have to be conversant with sign language. There has to be enough time or at least innovativeness from the side of the teacher to cover enough ground as demanded by the examiners while at the same time meeting the needs of every individual learner. Do our teachers have such capacity? Is the quality of mathematical education we receive, for example, (as a result of our visual impairment and teacher's lack of innovativeness) not inferior in quality?*

*If it is, as I believe, how can it be called equal education with equal opportunities? Are all these not resulting from inclusive education which was implemented with half-hearted commitment?*

(Jack 2009)

Secondly, the shortcomings at the policy-making level impacted negatively on the implementation of inclusive education. The often-cited broken link between policy and practice notable in many developing countries (Mandesi 2006) is to blame for the failure of the policy on inclusive education to take hold in Lesotho in the almost two decades following its implementation. The 1989 policy for special education suffices as a general statement of policy in Lesotho, but although it is forward-looking, it is not comprehensive enough and fails to address important issues such as different cadres of disability and how they are going to be catered for. The document apparently equates special education with disability, and students who are gifted are not in the equation.

While the sincerity of the government in aligning itself with international agreements and conventions relevant to inclusive or special education is not here in question, its inertia in expediting policy and legislation formulation or approval, as well as its inability to fulfil the promises made in the form of infrastructure development, ongoing teacher training and reinforcement of the SEU, does raise serious questions about its commitment (Lesotho College of Education 2007:vi-viii; Johnson & McIntosh 2009:143). One of the participants referred to this inertia as endemic in Africa:

*There is no rush in Africa. We in Africa are quick to sign protocols and statements often because there is money attached to them. Our record in the implementation process leaves much to be desired. I do not know whether it is because the support promised by donors is half-hearted or because of lack of proper planning. Whatever the case, disability does not appear to be an issue for governments in Africa. It is good on paper but quick to be forgotten when donor monies dry up.*

(Reg 2009)

Reg's ideas leave the question begging: who benefits from the signing of these international protocols? If it is people with disabilities, why do their lives not improve? Khatleli et al. (1995:4) see the answer as residing in the disparity in power between the consumers (people with disabilities) and the funding agencies, and the lack of participation by people with disabilities in policy and practice. As a result, the people with disabilities are rendered perpetual beggars.



Reg's ideas further resonate with the observation that the National Report of Lesotho 2008 of the MOET made no mention of special education or disability as a category alongside early childhood, technical and vocational training or non-formal education. Special education appears as a footnote under Orphaned and Vulnerable Children (OVCs) (MOET 2008:25). While this may be an oversight, it is however suggestive of the low status afforded this issue within the MOET.

Thirdly, the reorganisation of the entire school environment is equally vital for the realisation of inclusive policy. However, it requires a very different way of thinking, seen by Linqvist (1999:7) as a "complete change ... necessary for the realization of the goal of EFA." The change of external infrastructural environment is a step in the right direction, And to that end, the Ministry of Education has improved access through establishment and expansion of both the primary and secondary school infrastructure (National Report of Lesotho 2008:13-14). Despite this positive development, much still has to be done in terms of offsetting the overcrowded classrooms and supplying facilities that meet minimum standards for conducive learning environment. Reg (2009) and Jack (2009) agreed that the number of schools equipped enough to accommodate students with disabilities was far below: "*Speaking from the perspective of students with visual impairment there is only Saint Catherine that can accommodate only a small number of such students*" (Jack 2009).

A baseline Study on Inclusive Education (2009) conducted by the Centre for Management Development and Professional Studies, in twenty selected schools in the Maseru Peri Urban area and in Butha-Buthe Urban area, to pilot inclusive education, found that most of the schools were not conducive to people with disabilities. For example, they had no ramps, adapted toilets or special furniture, and none had a trained special education teacher. Sign language was little known, a deficit that denies deaf children learning opportunities and consequently employment opportunities (Mendis et al 2009:36).

As Tsili (2009) observed, children with disabilities are as good as switchboard operators:

*IRC is not an option for people with disabilities. It is like they have to go there if they want to make it in life. But where else can they go? Are our institutions of higher learning ready for children of all forms of disabilities? If not how can we talk about quality education for all under the circumstances?*

My visit to the recently constructed schools revealed that they have been built without taking into consideration the needs of children with certain forms of disabilities. A sizeable number, mostly built after 2000, were double-storied with little provision for children with mobility or

visual impairments to navigate without assistance. As Jack (2009) concurred: *“I hear that there are newly built double story schools. While we need these schools we should also think about their accessibility especially for pupils with disabilities.”* There were few if any means of transport to take children with certain forms of disabilities to and from school. Though this is not the sole responsibility of the MOET, this situation is an indictment of its commitment to inclusive education, founded as it is on the right of all to quality education with equal opportunity, while developing their potential and respecting their human dignity (Salamanca Framework for Action 1994:# 7).

This poor success record of the policy of inclusion, and the concomitant adverse consequences on the lives of people with disabilities, has largely been attributed to inadequate organisation, priority-setting, funding and commitment of resources (Lesotho College of Education 2007:26). While international communities are providing collective commitment in the form of statements and conventions, there is little evidence in Lesotho of such commitment to providing realistic financial assistance to see the commitments made towards inclusive education (Peters 2007:107; Lesotho College of Education 2007:26). Reg (2009) agreed that inclusive education was a good thing and that the government of Lesotho did well by adopting it; however he cautioned that it requires schools to be equipped to accommodate people with different forms of disabilities. Being a person with visual impairment, he said: *“It would be nice if students with visual impairment were to be products of all schools not only Saint Bernadette or Saint Catherine’s.”*

### **5.3.2.3 Total inclusion at the expense of quality**

The failure of the Government of Lesotho to follow through commitments made on inclusive education translates into disparate educational quality between children with disabilities and those without. Various reports and studies conducted on the implementation of inclusive education (Regstone 2009; Peters et al. 2005; Lesotho College of Education 2007; DNDRP 2008) converge on identifying the slow pace of implementing inclusive education. With very few trained teachers, inadequate materials and physical equipment, as well as lack of supervisory support, all that inclusive education has achieved is social benefit, with no academic competence that would allow students to compete squarely on the job market.

By pursuing inclusive education in this manner, the question arises as to whether the system is not creating another group of students who, by the failure to create a conducive environment for their learning, have become marginalised in their chances of securing employment? Are we, by our desire to include *totally* not creating another group that is

different by the limited choices they have? Are we not *in esse* looking at children with disabilities as burdens, whose needs can only be met if resources are available? Are we not perhaps saying with Jack (2009) that education provision to students with disabilities is a charitable endeavour (*re etsetsoa mohau*) and not a rights issue? How can we best address issues through policy interventions without perpetrating and perpetuating new injustices? (Soudien & Baxen 2006:154).

These are nagging questions which do not admit for a simple answer. However, they keep us on the alert for what Slee and Allan (as quoted in Graham & Slee 2007:278) call “the rhetorical inertia of instrumentalist gestures ‘towards inclusion’”. This is punctuated by a litany of broken promises and unsuccessful policies, captured in the words of Caroline Mohapi (*Lesotho Times* 7-13 May 2009): “We have been left out for too long.”

#### **5.3.2.4 One policy different paradigms**

Perhaps the problem of working within different disability paradigms at the same time has affected the adopted policy of inclusion, confirming Bosch’s (1991:349) warning that new paradigms “take decades, sometimes even centuries, to develop distinctive contours.” The Special Education Unit within the MOET has not been immune to such challenges, and its commitment to inclusive education needed to be augmented by the strengthening of the SEU, infrastructural development, legal frameworks and intensification of the monitoring efforts. In the event that policy does not translate into practice, inclusion remains vulnerable to political whim (Peters et al. 2005:144), and those on both sides of the disability continuum have to fight the same battles repeatedly, at different levels and different times (Mohapi, *Lesotho Times* 7-13 May 2009). As a result, there is a leap back into the Enlightenment mode of thinking, when “disability was transmogrified into an ontology of failure, hopelessness requiring surveillance, repair and management” (Campbell 2003:52).

In addition, the desire to remove barriers that frustrate full inclusion has been aligned with the social model of disability (Khatleli et al. 1995), but the attitudes still reflect a deficit and medical model of disability. Johnstone (2005:18-19) observes that interviews conducted with teachers reflect that disability is still viewed as a deficit or inability, which often results in feeling of sympathy. He adds that the Ministry of Education has not provided a mode for changing a deficit and medical model. It is in this sense that one can talk about one policy but different paradigms.

### 5.3.2.5 Othering discourse

In this section I read inclusion discourses through the lens of Derrida's hierarchy of binaries and Foucault's idea of power relations embodied within notions of inclusion. I therefore look into words used and how they might uphold meanings and discourses they intend to flush out. Words within discourses, as Dunne (2009:48) suggests, do not so much describe as produce understandings, knowledge and subject positions. Dunne's assertions conjure up Foucault's position on power that it is not essentially repressive but productive (Foucault 1982:212).

The expressions, 'special education', 'special needs', 'inclusive education' and 'integration', all of which are used frequently in the above studies, are often taken for granted. However, they need to be questioned because they make sense only within certain discourses. There is a sense in which they can produce an 'othering discourse', which sets up a division between 'us' and 'them', and between 'normal' and 'abnormal'. The terms 'special education', and 'children with special educational needs' represent this language and division of 'othering', as they create a sense of the 'not special' or the normal and regular, as opposed to those that are irregular and abnormal. When asked what he thought about the terms, Jack (2010) rhetorically asked:

*You know these words have always been there but I have always taken them for granted. I never thought it was my business. But when you ask, it dawns on me that I have been using them without thinking about what they implied. Yes, special.... why special and why should my needs be special as opposed to other people's needs? Does this 'special' not suggest that we are not like others; not normal?*

Read within a context in which integration and inclusion are buzzwords, one gets a sense that there is a kind of forced alliance between discourse of inclusion on one side and those of special education needs on the other (Dunne 2009:49). The question is to what extent they can accommodate each other. Though the MOET has retained the special education jargon, the function of the SEU is to pursue the inclusion of disabled children in the mainstream school system.

The stated aim of the MOET is that of integrating, and by implication including, children with special educational needs into mainstream schools or regular school systems (Mariga & Phachaka 1993:14). This aim betrays an implicit centred-ness that presupposes a prefabricated, naturalised space or whole into which the 'Other' is included or integrated (Graham & Slee 2008:278). It evokes binary notions of inside vs. outside; regular vs.

irregular schools; special educational vs. non-special educational needs; and integrating the previously marginalised vs. those at the centre of integration (those who naturally occupy the centre stage of integration). Such a mode of conceptualising invokes Derrida's notion of centres, which tends to exclude and marginalise (Powell 1997:21). An adoption of integration and/or inclusion produces the idea of margins and centres, yet while adopting another word or concept is often seen as a solution, Derrida would propose putting a word under erasure to underline both its limitations and its resourcefulness (Powell 1997:47).

In the case of this study, putting the word integration or inclusion under erasure would underline both its inadequacy and its necessity, and would point to inhabiting the word in ways that shun tokenistic attempts to 'include' the marginalised Other, while being open to new meanings previously ignored or neglected (Stiker 1999:17; Graham & Slee 2008:279). Adoption of such a perspective shifts a question to another level: from how to include to how to embrace inclusion in a way that disrupts the construction of centres from which exclusion and marginalisation derive (Graham & Slee 2008:279).

#### **5.3.2.6 Naming as 'Othering' within the ambit of power relations**

Naming has been a subject of intense debate, especially in the creation of identity (Muhlhausler & Harre 1990; Swain & Cameron 1999; Woodward 1997). The shared belief of these voices is that the process of naming creates a subject whose sense of self is connected with the society's definition (Galvin 2003:152). In this way, individuals are recruited into identifying with labels and identities created not by them but by society.

To the question, 'What's in the name?', asked by Galvin (2003:153), the answer might be "there is power in a name", that is valences between what names or labels represent and what is labelled in the process. Borrowing from the analogy of the Hebrew Bible, naming is not only a creative process but also a separation, differentiation and a setting apart. By means of naming, which is a linguistic device, one is subjected to someone else by control and dependence (Galvin 2003:152). The deployment of the above, I argue, can provide valuable lenses in interrogating the identification of children as those with special needs. This process sets them apart from those who have non-special needs, and to name them as such is to point up the difference, and to distinguish and separate (Stiker 1999:5).

Special needs in the MOET's purview are interchangeable with disability (Mariga & Phachaka 1993), according to which perspective children with special needs should be understood as children with disabilities. However, disability cannot be defined except with reference to its opposite "able" (Galvin 2003:155), which becomes an invisible insignia of the

norm (Galvin 2003:149). Need therefore implies a lack and evokes desire for adequacy or non-need. As Jack (2010) suggested, naming some children as 'those with special needs or disabilities' is in itself an act of separating them from those with no needs or no disabilities. On the other hand, "naming of Others functions to preserve existing relations of power" (Allen 1999:5; Graham & Slee 2008:289; Foucault 1980:32).

Through naming, those who inhabit the acknowledged centre produce relations of power that are now exercised over the bodies of those who are dubbed 'disabled' or 'with special needs.' Such students, through being named, are marked out, and they become the objects of the process of inclusion into that which is whole. This categorisation, seen by Foucault (1969:42) as 'grids of specification', classifies and regulates pupil and student identities, bodies, spaces, and social practices in different relations of knowledge and power (Dunne 2009:50). In the process, not only are power imbalances and structural inequity maintained but also the named are made to identify with the taken-for-granted labelling, which makes them feel that they are what they have been named, 'children with special needs.' As Popkewitz and Lindblad (2000:9) write, "what is named and what goes unnamed is an effect of power... where those with power can depict others but not themselves as possessing" special needs or disabilities. Not only are children with special needs recruited into this position, but also everybody else is expected to recognise this manner of representation unquestioningly.

Important questions that arise here are: who determines what need there is? On whom does the normative power to name rest? Whose interests are served by naming? Whoever has that leverage and power brings it to fruition through the creation of what Graham and Slee (2008:281) term "a common referent to consult". This is a norm and a standard around which the normal is created and privileged (centred). External to this centre is the negative, which is other than normal and which is privileged (Macherey 1992:177). Another question is: who benefits from these relations of power? (Kotzé 2002:6).

Evidently, those on the receiving end of the naming process hardly benefit from the process, and while they can be consulted they do not have the last word. "*Sometimes the consultation is not even done,*" says Jack. The naming of 'Others' as seen by Allen (1999:5) "functions to preserve existing relations of power in a reified mode of invisibility" in favour of policymakers who are at the forefront of designing and implementing educational programmes. However, the question remains: how can one possibly achieve inclusive education through ways that do not preserve existing relations of power and hierarchies? To this question Graham and Slee (2008:280) write:

It can be argued that an authentically inclusive education invites the denaturalisation of 'normalcy' to arrive at a ground-zero point from which we banish idealisation of centre. In this way, the language of special and regular education is rendered redundant. If we listen to teachers, education administrators and academics as they discuss inclusive education and the range of kids who present for schooling, we soon hear that we are a long way from where inclusive school should take us. There remains a firmly embedded notion of what a regular school is and more particularly, who it is for. Others may be allowed in but theirs remains a conditional entry and tenure, for inclusion by no means guarantees inclusiveness.

From the reading of Mariga and Phachaka (1993:30), it is evident that inclusion is not new, and that it existed in some form in the past, represented as a voice of previous knowledge that tends to lie on the margins of inclusive discourse. Within this voice of previous knowledge are learners, parents and teachers who appear to be rich sources of indigenous knowledge, belief and practice. Their experiences are nominally acknowledged, yet theirs could not be inclusive discourse because power and knowledge did not constitute it, and it was not implemented, controlled or built by those who knew and had power. This is, I argue, a voice that has been denied an opportunity to be heard. In its silence and marginalisation, it continues to exert its influence in subtle ways among parents, teachers and students, representing an indigenous voice of resistance that has the potential to undermine the policy of inclusion. As Clark et al. (1999:169) observe, official policy is often interpreted, subverted or even replaced by an interplay of actors involved in the implementation of policy.

The exposition above was not intended to discredit attempts at inclusive education, but rather to interrogate how it has been constructed and how it, in turn, it constructs the so-called children with special needs or disabilities. Who benefits from such constructions and relations of power implied in those constructions has also been explored. It is apparent that quality education for children with disabilities is not a right but perhaps as Jack (2010) sees it, "*thuto ka ho hauhelo*" (education as charity). It is something for which the only response can be gratitude. Donor agencies and the World Bank, with its structural adjustment programme, often attach conditions that deny people ownership of policies and practices on the "what" and "how" of inclusive education.

Understood within such a context, children with special education needs or with disabilities become a burden and not a resource. They are, as in the fourteenth century, constituted as needy objects deserving only of charity or a 'hand-out' kind of education. An attempt to include them within the mainstream educational system, as the language suggests, becomes a sign of 'our' commitment to 'them' (the poor and unfortunate). From the above one should be reminded of Arrieta and Cheynut (quoted in Peters 2007:98), who in

addressing the United Nations Special Session on Children in May 2002, said: “We are not sources of problems. We are the resources that are needed to solve them. We are not expenses, we are investments.” These words resonate with Khatleli et al. (1995:3), that only participation can ensure sustainable, effective and relevant change.

I now turn to the discussion of the dynamics of the understanding and construction of disability in the Ministry of Health and Social Welfare.

#### **5.4 DISABILITY DISCOURSE IN THE MINISTRY OF HEALTH AND SOCIAL WELFARE**

This section is concerned with how the Ministry of Health and Social Welfare in Lesotho construct disabilities. Read through the lens of Foucault’s (1991:103; Rose 1999:19) notion of governmentality, I posit that people with disabilities are constituted through state knowledge and government policy. Through different policies as discursive weapons, people with disabilities are constituted welfare and legal objects at the disposal of power relations over which they have little control. Power valences inherent in the language used in the ministerial and departmental policies and documents, especially the Draft National Disability and Rehabilitation Policy: Mainstreaming Persons with Disabilities into Society (DNDRP (2008), will also be explored.

##### **5.4.1 Welfare systems in the global and national arena**

Globally, economic, social and political factors have influenced the development of welfare systems within countries and nations. Their aim was to look into the welfare of those citizens who could not meet the requirements of a militarily, industrially and economically viable human resource within a competing capitalist economy (Drake 2001:413). Social concerns such as poverty, suffering and proliferation of vulnerable groups were also at the origin of welfare systems.

As seen by Grönvik (2007:14), the main task of the welfare state is to count the numbers in view of distributing support to some people, as well as providing justification for not giving it to others. Theirs is to delimit categories of people eligible for certain grants and support through the process of assessment (Swartz & Schneider 2006:240). The definition of disability within the context of welfare agencies will be devised to suit this very purpose. A person who has been given a wheelchair, for example, has been administratively defined as needing such an aid and perhaps other forms of support. It also justifies why certain people do not deserve similar support.



#### **5.4.2 Social Welfare Department in Lesotho**

In Lesotho, the Department of Social Welfare was first established in 1976, as a way of responding to increasing levels of poverty and other social problems (Nyanguru s.a). It was first housed within the then Ministries of Internal Affairs, Justice and then Employment, before being transferred, in 1993, to the Ministry of Health and Social Welfare (MOHSW). According to Nyanguru (s. a) its six moves in 17 years, are indicative of a low status afforded the Department, which together with a longstanding lack of departmental policy has left its service provision fragmented, dispersed and lacking in focus. This consequently impacts negatively on the extent to which it is able to deliver services to its intended clients. There are however positive indications that point to a switch to giving it a higher status (DNDRP 2008:4,25).

#### **5.4.3 National policy foregrounded in the social model**

One positive development is that the Department of Social Welfare, which was consulted in the course of this research and showed interest in the final product of this research, within the MOHSW, is spearheading a formulation of a Draft National Disability and Rehabilitation Policy (DNDRP 2008), which is in its draft stage. This document serves as a major resource in the ensuing discussions. This draft policy was a very ambitious document which served to give direction to the delivery of services, creation of opportunities and inclusion of people with disabilities in mainstream society. In keeping with the international trends in disability, the draft policy aligns itself with the in-vogue social model of disability, which situates the problem away from the individual and towards society. It is further informed by the constitution of Lesotho, various conventions; regional and international legal frameworks, as well as important national policies and legal structures such as the Education Act 1995, Section 3; Local Government Act 1997, Section 5 (1) and (2); National Assembly (Amendment) Act 2001; and Children's Protection and Welfare Bill 2005, Clause 12.

The adoption of a social model marks an important theoretical and practical shift, from the individualistic medical model (old paradigm), with its emphasis on diagnosis and treatment or elimination of a condition (Gathiram 2008:146). As such it embraces a view that disability is a natural and normal part of human experience that in no way diminishes a person's right to participate fully in all aspects of life (DNDRP 2008:2). It works towards the elimination of the environmental, institutional, attitudinal and economic barriers that prevent people with disabilities from participating meaningfully in society (DNDRP 2008:iv). Situating the policy formulation within the framework of the social model, will also curb the temptation, inherent

in the location of the DPOs within the MOHSW, to view disability as an exclusive preserve of the medical and welfare professions.

The draft disability policy states clearly that disability is a human rights and developmental issue, a view that lends itself to sustainable and people-centred development (Gathiram 2008:147). To buttress mechanisms for achieving objectives of this developmental approach, the Community Based Rehabilitation (CBR) strategy has been adopted, with the potential, if followed through well, to yield good results in the rehabilitation, equalisation of opportunities and social integration of people with disabilities (Gathiram 2008:148). Its community-based, participatory and action-oriented nature has made it better placed to enhance ownership, agency and accountability of programmes of integration of people with disabilities into society.

In the context of Lesotho, with cooperation and partnership, Mendis et al. (2009:2), suggest, it could move towards a coherent rights-based framework; with MOHSW in management role; the Lesotho National Federation Of the Disabled (LNFOD) in advocacy and monitoring roles and the local government structures in the implementation roles. Such cooperation and clarification of roles would also help to stem the duplication of efforts that threatens to derail the social integration of people with disabilities (Mendis et al 2009:2). Reg (2010) commented that even with this division of roles, people with disabilities have to participate at all levels, or at least be consulted at every stage.

Despite the positive developments evident in the tone and orientation of the disability policy, anxieties remain. Gaps and rough edges of a theoretical and practical nature will always be there, briefly elaborated upon in the following sections.

#### **5.4.4 Conflicting perspectives: social model and welfare agencies**

There is an obvious clash in perspectives between the social model and the welfarist orientation which drives the Welfare department. The focus of the social model is to point away from an individual with impairment to the society which disables him/her through limitations imposed by the same society. It targets removal of disabling barriers and advocates equality and rights for people with disabilities (Albert 2004:4). The social model views disability as a fluid concept that is dependent on the context.

On the other hand, welfare agencies were founded on the realization that citizens do not have equal access to the country's resources. Others, through no fault of their own, are vulnerable, poor and marginalised and therefore in need of some form of grant. If provision

of social grants for individuals who are disabled, and who have been declared so through appropriate assessment procedures, is at the centre of machinations of the welfare state, the question is: how can this stance be reconciled with the social model stance which locates oppression in society and not in the individual? In other words, can the developmental approach, which aims at breaking economic dependency of people with disabilities (Gathiram 2008:149), be reconciled with a service-based approach, which creates the same dependency it intends to break from? The National Disability Policy (2008:16) recognises this theoretical quandary:

There is a need therefore for Government to provide Social Protection Grant to PWDs... Changing the way people regard disability from a purely health and welfare issue to a primarily human rights and development issue has significant implications for the principles, objectives and goals of existing welfare services. It implies that welfare services need to be designed to facilitate independence in society, rather than dependence on welfare services.

Could this be indicative that the policy is tending towards adoption of a model that combines social security with social and community development in line with international disability policy, where the focus has shifted from guaranteed income security towards economic integration? (Mont 2004). It appears that the policy balances theoretical considerations and pragmatic concerns. Within the framework of a social model, where disability is seen more as a human right and developmental issue than an individual issue (Swartz & Schneider 2006:234), skills provision and creation of job opportunities are more important than disability grants. For disability activists the catchphrase is 'human dignity and not separate services'. As one of the participants, Tsili (2009) said, "*we want equal opportunities not handouts. However, in our case in Lesotho where equal opportunities is a distant dream to realise, we will have to learn to live with the Devil in the house.*"

Swartz and Schneider (2006:236) concur that the social model is founded on the assumption of a society that is as equal as possible for all. However, given gross poverty, inequality, inequitable distributions of resources, lack of skill development as well as high unemployment rates in Lesotho, application of a social model with its focus on creation of equal opportunities alone becomes a mammoth task. A stark reality to contend with is that people with disabilities invariably bear the brunt of these adverse consequences.

#### **5.4.5 Assessment of needs: whose needs?**

As noted above, disability is a fluid concept (4.2.1.1), with its definition dependent on who is attempting it and for what purpose. The Department of Social Welfare in Lesotho was

founded with the purpose of attending to poverty and other social problems. That people with disabilities' concerns are taken care of within this department suggest that disability is an issue that is in one way or the other associated with poverty or viewed as a social problem. Lesotho is rated among the poorest economies with high rates of unemployment and poverty, as well as differential access to resources (Global Policy Network 2006). Though these needs are of a general nature affecting the whole society, people with disabilities feel most the effects of poverty and marginal opportunities in the job market.

Under these circumstances, their reasonable option is to wait for disability grants, but this is not as simple as identifying oneself as such and then receiving it. Rather, it involves a normal welfare process of diagnosis, normally referred to as 'assessment,' with the question it seeks to answer being whether an individual qualifies to be categorised as disabled, and therefore deserving of a welfare benefit or disability grant (Swartz & Schneider 2006:240). Looked at very closely, the diagnostic assessment goes beyond serving just as a mechanism that helps administrators to distinguish ability from disability. It renders that distinction, as Rhodes and Scot (1997) observe, "real' in a practical, lived way." However, the assessment cannot be made without an assessment tool, otherwise such an assessment would depend on the whims of the person in the office. Developing such a tool raises questions: Would the development of such a tool depend on the state of being of a person with disability or on the complex and changing environment? (Swartz & Schneider 2006:240). Who would have the last word on the development of such a tool and the criteria adopted in administratively identifying a person as disabled and therefore deserving of a disability grant? Whose needs are met by the development of such an assessment tool: the welfare authorities or people with disabilities?

The tendency is nearly always to assume that the needs served are clearly those of people with disabilities, but this is not the case. There are two kinds of need here: those of the welfare authorities and those of people with disabilities. The welfare authority is interested in the proper administration of a welfare benefit, which can only be ascertained through an assessment procedure. A person with disability would like to be acknowledged as such and given his/her due. These needs do not have to clash but they often do, and the people with disabilities usually benefit the least, if at all.

Through this procedure a person is labelled 'administratively disabled,' which becomes a need that can be met by a welfare authority. Thomas and Loxley (2001:52) regard this case as one in which a welfare authority, "with a stroke of a wand", is changed from assessor and labeller to benefactor and helper. Not only is there a change of roles but also a play of power

valences, the effects of which are “hierarchizing, and forever, pushing x above y” (Thomas & Loxley 2001:84). What Foucault (1991:308) terms a ‘disciplinary regime,’ permeates “almost seamlessly and unquestionably the day to day workings of institutional life of people with disabilities.”

The assessment tools are developed to ascertain the correctness of the decisions made about the welfare systems’ classification of ability and disability, so their purpose is to describe and classify. Assessment is also about constructing that which is described and classified, but classification also leads to apprehensions about who qualifies and who does not. Perhaps even more sensitive is the issue of who has the final say on who qualifies for a grant and who does not, on the basis of which norm is applied (Soudien & Baxen 2006:158). This sensitivity has to be understood in the light of a sentiment expressed by many people with disabilities and Disability People’s Organisations (DPOs) that projects are often written in their name but they are the last to enjoy the benefits. This sentiment, whether real or unreal, is an issue of power relations and justice, and calls for the re-examination of the kind of ethics that drive the interaction. It calls for a review of power valences that create the hierarchy between the ‘us’ and ‘them’, with the ‘us’ responsible for the setting of norms and standards and, for the administration of disability grants. The ‘them’, meanwhile, can only be thankful or else they are dubbed ‘ungrateful’.

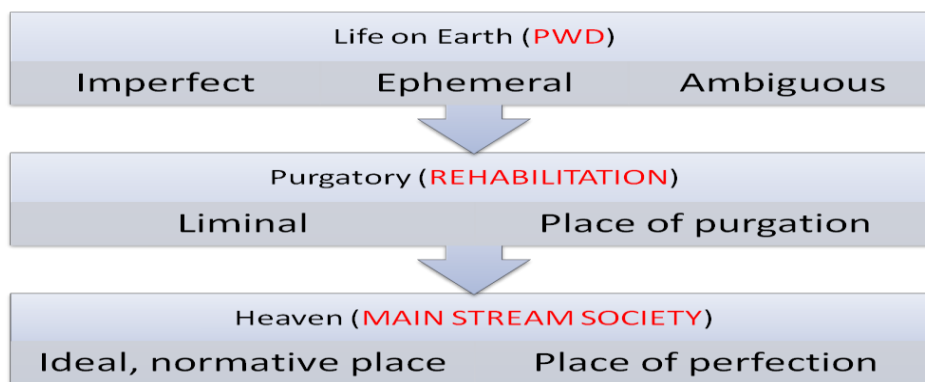
The Lesotho Disability draft policy does not yet have an answer to many of the above questions, but anticipates guidelines that would provide for the assessment of those who do and do not qualify for a social security grant.

#### **5.4.6 Rehabilitation of society or PWDs?**

Community Based Rehabilitation is adopted as a key strategy in achieving the objectives of the policy. Though a tested strategy, especially within the health sector, its relevance and appropriateness within the context of a socially oriented policy on disability still needs to be run through. The adoption of the language of rehabilitation within the policy is quite problematic and needs to be teased out. The questions that guide our reflection in this section are: what does rehabilitation mean? Who or what needs rehabilitation? Who does the rehabilitation and who stands to benefit from such an exercise? Are rehabilitation practices not a reconstitution of old discourses to re-secure another centre from which to advance coercive practices in the government of disability?

### 5.4.7 Rehabilitation language

The policy (DNDRP) is replete with references to rehabilitation as one of the *modi operandi*, an important one, in addressing the plight of people with disabilities. The term ‘rehabilitation’, lexically, implies a return to a point or to a prior situation. Stiker (1999:122) suggests that this is the situation that existed for the able, but one postulated for the others. The whole understanding is premised on the centre, on the norm which has to be re-inhabited through the process of rehabilitation. This way of thinking can be likened to a traditional Catholic image of stages toward heaven, as represented in Figure 1:



**Figure 1: The Heavenward stages chart**

The above diagram has three distinct stages. The first is life on earth, distinguished by its ephemeral nature, ambiguity and imperfection. In the middle is the stage of purgation (purgatory), a liminal stage where all dirt is eliminated before final incorporation, integration into the third stage, heaven. The latter represent the ideal, the norm and perfection in its purest sense. Following upon this analogy, people with disabilities represent an imperfect humanity, in its physical and moral sense, which has to go through some form of purgation (rehabilitation) before they can be included into mainstream society. According to Stiker (1999:136), this mainstream society sees itself as having the duty, mission and task of voiding disparities into its norm. Disability, according to this analogy, is sustained by the desire to flee from itself towards the mainstream. Until such a desire is fulfilled, disability cannot rest. If this is the understanding, as implied in the draft policy, then disability will forever remain the “different” and the “alterity” that must disappear (Stiker 1999:xii).

The language of rehabilitation is associated with the medical model of disability, stemming from the hospital (Stiker 1999:136). The adoption of the rehabilitation language within the policy, consciously situated within the social model, the new paradigm, is evidence of this medical shadow and the dominance of the medical model. Despite the intent to shift

perspectives and nuances, the link between rehabilitation institutions and services, and medicine is so glaring that any effort to divorce them becomes a futile exercise. The rehabilitation model as a substitute appellation for the medical model betrays this tendency. The trouble in shifting from one paradigm to the other is evident in this policy, and could create conceptualisation problems that are often part of working with and within models and paradigms. It begs the question as to whether one is working within the “new paradigm” but with nostalgia for the “old paradigm”.

The policy defines rehabilitation as a means to *help* (my emphasis) people with disabilities to fully participate as members of society (DNDRP 2008:13). One cannot fail to see the common power implications of helper (powerful) and helpee (vulnerable); doctor (powerful) and patient (vulnerable), which have been a subject of intense debate in the field of modern therapy (Van Wyk 2008:256-257).

Reading the definition together with the objectives of rehabilitation as a priority policy area (DNDRP 2008:25), it becomes clear that the focus of rehabilitation is not society but people with disabilities. The objectives of rehabilitation are stated as promoting availability of the necessary skills and services to all people with disabilities; and enabling them to achieve and maintain their optimum physical, sensory and functional level. Nowhere under the objectives is mention made of society as the object of the rehabilitation services. It is indisputable, therefore, that rehabilitation services are directed to people with disabilities, and their accessibility and availability are made possible by the presence of rehabilitation professionals at all levels. McNamee (1996:145) used the term ‘identity adjustment’, which is what the medical model seeks to achieve, to refer to the process of rehabilitation.

This use of words evoke the relations of power between the rehabilitation service provider, who is skilled and equipped, and a person with disability who is portrayed as lacking in something that must be filled by professional medical personnel (Stiker 1999:xii). This does not seem to square up well with the social model of disability.

The word ‘achieve’, used together with ‘optimum’, has a sense of ‘not yet there.’ What would be the ‘not yet there’ as compared to the present condition? Is it not suggestive of the undesirable state of disability as compared to the desirable state of optimum physical, sensory and social functional level? On what basis does one measure that optimum and functional level, and who determines the achievement of that functional level? It evokes memories of the ideal, the normal into which the promise to restore a disabled individual comes alive. Is the promise to restore an individual to the ideal and the normal not a

reassertion of the binaries of abnormal and normal? If answering in the positive, as I think I should, the binary logic harbours workings of power. It is founded on the moral and political hierarchy of the normal over the abnormal. This hierarchy, as Danforth and Rhodes (1997:359) assert, can be seen in the way the abundant social value accorded the first term is negatively mirrored in the corresponding devaluation of the second term.

By embracing this form of a rehabilitation discourse one is not far from the late eighteenth and nineteenth century discourses, where restoring disabled people to a level of acceptable functionality was achieved through educational facilities and medical correction and technology (Stiker 1999:xii). The definition of disability in the DNDRP only helps to entrench this nostalgia. It further underlines power valences, between people with disabilities and rehabilitation professionals through the language used (Stiker 1999:164).

Rehabilitation represents the medical gaze, as an eye of surveillance with immense power and an exclusive claim to knowledge, watching over and controlling people with disabilities (Foucault 1973). In Oliver's (1990) view, that is not appropriate because disability is not a medical condition but a social state, but I argue that it may not be necessary to pit one against the other in an either/or dichotomy. Read within a postmodern context, disability surpasses the social–medical dichotomy and represents a complex and contingent variable that “describe[s] different aspects of a single experience” (Shakespeare & Watson 2002:24). Care has to be taken therefore that the rehabilitation strategy embraced by the DNDRP does not become a way of carting off the oppressive conditions of the medical model of disability through the front door only to bring them back through the back door.

This is not however to suggest that people with disabilities do not have medical needs, but rather that the situation of a rehabilitative language, which insinuates the medical model, within the social model of disability is problematic. At issue here is whether there is a role for rehabilitation language and practice within the social model of disability. If, according to the social model, it is society and not individuals that has to change, why should the language and practice of rehabilitation that target people with disabilities be dominant in a policy that adopts the social model as its guidepost? Perhaps as Derrida would have suggested, we should put the word ‘rehabilitation’ under erasure to underline both its necessity and its inadequacy.

The Health and Social Welfare sector also straddles two paradigms, having adopted the social model with its one foot in the deficit and medical model. In the process, people with disabilities are constructed as ambiguous, while within the context of this research there is



no intention to pit one model against the other, as both have their usefulness. The above discussion on the discourses within different public ministries in Lesotho reflects what in liberation theology terms is termed 'social analysis' (Lartey 2003:127). The aim was to explore ways in which power relations within different public institutions held sway over the human person, particularly one with disability.

The following section represents a critical theological analysis of the findings of the social analysis conducted above (5.2 - 5.4).

## **5.5 PARTICIPATORY PASTORAL REFLECTION ON POLICIES AND PRACTICES**

The pastoral disposition adopted in this research journey is participatory and as such it does not only call for sensitivity to the plight of the marginalized and silenced (Kotzé & Kotzé 2001:6). It also embraces participation, collaboration *with* people in challenging oppressive discourses and negotiating ways of living in ethical, ecological and accountable ways (Kotzé & Kotzé 2001:8).

People with disabilities have been, as a result of the internalisation of the so-called perfect body, put on the margins of everyday living. Despite their presence in every sphere of human life (Anderson 2003:2), the absence, alienation and discrimination that characterise their life experiences is unashamedly glaring. Jack (2009) captured their experience thus: "*We have no eyes, ears, voice, mobility and everybody feels entitled to do and say things on our behalf without even asking us.*" Commitment to participatory action research demands that one take seriously the voice of people with disabilities. Not only is this choice demanded by commitment to contextual practical theology and pastoral care, but also by ethical positioning which shuns doing *for* as opposed to doing *with* (Kotzé & Kotzé 2001:7), as well as the call for believers as members of the body of Christ (1 Cor. 12:27).

### **5.5.1 Committed to contextual theological practices**

Contextual theology, to which this research is committed, is, as Bosch (1991:423) writes, theology "from below". The social sciences, among others, constitute its main dialogue partner. The discussion in Chapters Four and Five, on the different models of disability as well as their role within contemporary public institutions, constitutes the context within which experiences of people with disabilities are lived. A critical reflection on them is part of a contextual theological analysis carried out in the sections that follow.

It has emerged from the discussions that the experiences of people with disabilities have been placed in contemporary Western categories, which refer to lived experiences of people

with disabilities. This has been challenged by some research participants as undervaluing their interaction with disabilities, and most participants related their stories without using the jargon of models of disabilities. For instance, Jack went to the extent of saying he did not know what the social model was, while Reg did not want to see himself as disabled in a medical or a social model, but rather, as Shakespeare and Watson (2002:19) put it, “he simply seeks access to a mainstream identity”. Shakespeare and Watson add that people with disabilities “do not have a political identity, because they do not see themselves as part of the disability movement either”. The latter reflects the features of the lives of ordinary, living persons (Lartey 2003:177) and the expression of the plurality and complexity of disability, which is a feature of a postmodern paradigm. Chapter Four and Five do not wholly represent the voices of people with disabilities, but represent some voices within the disability discourse.

A contextual practical theology would be at home with commitment to the plight of the marginalised, which is not homogeneous but analogous to a river with many streams (Cochrane, de Gruchy & Martin 1999:37). An attempt to homogenise the experiences of people with disabilities by conceptualising them through models has left unattended some of their concerns. Disability can be seen as a context different from others, but within disability as a context are different experiences and perspectives. Contextual practical theology challenges the attempts of disability social theorists in their attempt to homogenise the experience of people with disabilities, instead providing a voice to people with disabilities to share their concerns and theologise from below, no matter how different that voice may be. That provides for the emergence of a space for the meaning of doing and caring *with*, as opposed to doing and caring *for*.

### **5.5.2 In the ethics of doing and caring *with***

Doing *with* requires that the plurality and heterogeneity of lived experiences of people with disabilities be taken seriously (Kotzé 2002:16). Such lived experience does not necessarily have to be couched in traditionally acceptable sociological, theological and philosophical jargon, but can also be communicated in the familiar and ordinary-ness of everyday life (Kotzé, quoted in Swart 2006:52). That would still be valid theological discourse but local and from below, with an opening to previously unheard voices and experiences. One such discourse is represented in Lee’s (2010) words, in response to a review of Tom Shakespeare:

Why do we have to be put into *any* model? Why is it that we cannot be treated like the human beings that we are and simply provide for our needs and *share* the costs will all society if we are unable to pay as is the case with everything and everyone else. Improve our lot and bring us to the same level and we won't need any bloody *models* [my emphasis].

Lee's words are a cry for a meaningful recognition of people with disabilities to be treated like anybody else. If there is no need to talk about others through models, it should be the case with people with disabilities. It is not models that make the difference in their lives but dignified human treatment, the caring *with*. It is one of the moral battles in the struggle to be integrated into and taken seriously by society.

The result of a commitment to care *with* should benefit all who take part in the research, especially those whose voice has been marginalized (Kotzé & Kotzé 2001:6-7). Below are some of the local experiences of how people can best pastorally care *with* each other as opposed to some of the experiences seen above.

Listening to the voice of people with disabilities has unravelled some of the dilemmas that constituted relationships with people with disabilities. Reg (2010) cited an experience that was spurred by this research study, saying it has now become possible for people with disabilities, especially those with visual impairment, to talk with their pastor and share their own experiences of living with disabilities: "*Not only that but also the fact that for the first time the congregation has had an experience of seeing a person with visual impairment read in church.*" Caring *with* is made possible by our being true to the injunctions of 1 Cor 12:25, where members need to "have the same care for one another".

### **5.5.3 Called to be members of the body of Christ**

In theological terms, to be configured to Christ is to become a member of Christ. It is to be incorporated into the body of Christ and to share in the treasures that accrue as a result of that incorporation and participation in the life of Christ. 1 Cor 12:12-13 aptly uses the image of the body to describe the relationship between Christ and the Church and the relationship between the different members within the Church itself. The salient features that emerge from this image are those of unity in diversity. Believers are one in their participation in the body of Christ, but participation and the expression of that participation depends on the role of each member in the body (de Gruchy 1994:126-127). This image resonates well with the notion of Trinity, where Godship communes and participates in its different manifestations of Father, Son and Holy Spirit. As alluded to above, within the body, members care for one another or care *with* (Kotzé 2002:30). Where members care *with*, they suffer and rejoice

together (1 Cor 12:26), because the subject-object schema has been transcended and what reins is solidarity, captured “in a self-other consciousness” (Kotzé 2002:19).

Considering the social analysis in Chapters Four and Five, it emerges that the tendency of the models, in overt and covert ways, is to homogenise the experience of disability. In particular, the medical and rehabilitation tendencies are founded on the ideology of normality, in which people with disabilities are restored to normality or as near it as possible. The discussion also reflects research and theorising that tend to define self-concepts, goals and inner motivations of people with disabilities, and to determine their real wishes and potential without asking them about their problems and preferred solutions and alternatives (Safilios-Rothschild 1981:5). This is prescriptive ethics which is loathed in this research journey.

Prescriptive ethics does not augur well where there is communion and participation. The frameworks and the practices adopted by public government institutions are in a way operating through a non-participatory approach, or at least a participatory approach which is not preferred by people with disabilities. Throughout my conversation with research participants the word that resonated was that of consultation and participation through listening and being listened to by the public institutions. As Reg (2010) observed, “*things are the way they are because there is no consultation between government ministries and people with disabilities.*” Asked about how that consultation can be done, he replied,

*It is not necessary that one of us be made a Permanent Secretary or a Minister to show that we are included. Government through its structures should have the time and the fora to engage on a serious note the concerns of people with disabilities at policy formulation and at the implementation level.*

For Tsili (2009), “*if wishes were horses, people with disabilities would be involved at every level of policy making and implementation,*” while Maki (2010) shared similar sentiments:

*Our situation cannot improve much because even as we speak there are new state and private buildings that are erected without due consultation with people with disabilities. As a result they remain inaccessible despite the laws and the regulations that have been enacted.*

Jack (2009) recalled the many times he had fallen in a hole left uncovered on the main street “*because non-disabled people remember but soon forget for disability is not their life experience.*” That can be done by listening attentively to the voices of those marginalized and silenced. Attentive listening, as Veck (2007:8) observes,

involves an existential leap, a transformation in being that moves the listener beyond the security of the known. It requires listeners to prepare for change and to allow themselves to be changed by the words they hear.

It is through attentive listening that the unique contribution that others can “make to the space shared” emerge (Veck 2007:7). This is possible where the meanings of communion are constantly engaged through constant dialogue between one another. Society and the Church have to become places of dialogue and friendship. If they were, people with disabilities would not be objects of charity (Rose 1997:399). Within the context of communion, friendship is founded on equality, acceptance and genuine valuing, for it emerges not from the mind but from the heart (see 7.2.1.1). “Such friendship is not borne out of pity or duty but out of a genuine desire to get to know the individual, and to share in their lives and allow them to share in ours” (Swinton 2000:105). It is a friendship that results from a transformed society which has *Shalom* (human and societal well-being and flourishing) as its hallmark (Cochrane, de Gruchy & Petersen 1991:67). Through such a friendship, mutuality and enablement substitute power and authority that characterise professionalism that is so common within modern public institutions. The public institutions contain many professionals who know what people with disabilities need without consulting with them (Safilios-Rothschild 1981:5). Such knowledge has to be looked at with suspicion for it does not carry within itself lived experiences shared by people with disabilities themselves.

## **5.6 CONCLUSION**

Contesting notions and models of disability, informed by different theoretical underpinnings, have been at the centre of debates around issues of disabilities. They have become a powerful force influencing social policies, practices and legal frameworks (Dewsbury 2004:146). The above discussion has examined the extent to which government machinery is influenced, in a disabling or enabling way, by these models.

The constitution of Lesotho, which is the grand law in the country, identifies the needs of people with disability as rehabilitation and resettlement. It therefore identifies and constructs people with disabilities as ‘abnormal’ and in need of regularisation before they can be accepted into the fold of ‘the normal.’ On this score, the Justice sector resembles the MOHSW, which through its draft policy embedded in the social model puts people with disabilities at the mercy of professionals and medical experts. In the educational sector the problematic nature of the language of inclusion and integration, adopted and used without critique, has not only made its implementation difficult if not impossible but it has further

constructed people with disabilities as institutional subjects whose lives depend on the policies, laws and protocols of the powerful.

Through the use of social constructionism and Foucault's idea of governmentality and power, I have explored how policies and laws connive to create social meanings and power relations through language and models as per the aims of this research (1.4). Foucault's ideas have served to unwind the structural composition of the public institutions in terms of power relations. Power and knowledge combined in how educational, justice, health and welfare as well as religion contributed to the construction of ambiguous but objectified disabled identities. Foucault's ideas have also revealed that disability is sustained by social practices which serve the interest of dominant groups in society (Burr 2003:38), through constructing people with disabilities into "particular and shifting forms of objectification" (Jolly 2003:517).

All these have effects on the lives of people with disabilities, to be discussed in Chapter Six. The experiences of research participants have been included to confirm, challenge and subvert some of the taken-for-granted knowledge claims about disability that are imposed by superior and dominant cultures and given reality status. The participatory pastoral reflection on the status quo reveals that where communion (see 7.2.1.1) is an important feature, there is love, there is doing and caring *with*. The voices and experiences of the other are paid attention to seriously because it is demanded by membership to the body of Christ, and because no one is a better image of God than others.

The following chapter documents ways in which dominant disability discourse that emerge from the public contemporary institutions and the legacy of the religious model affect people with disabilities. In addition, the binaries that sustain the dominant disability stories are identified and exploded, and the stories that lie outside the dominant disability discourse are pursued and thickened, together with voices of the research.

## CHAPTER 6

### DECONSTRUCTING DOMINANT DISABILITY DISCOURSE

#### 6.1 INTRODUCTION

In Chapters Three to Five I sought to examine ways in which the disabled identity has been constructed by society, including the church. Chapter Three followed through ways in which the Christian Church in particular has constructed the disabled body and ways in which such constructions had a spill over effect on the present understanding of disability and people with disabilities. Four and Five focused on the voices of literature emerging from disability discourses, models of disability and their contribution to the formation of disabled identities (Chapter 4). Voices of institutions responsible for varying services to people with disabilities in Lesotho have been listened to and read in the light of Foucault and Derrida's ideas, particularly those relating to power vs. knowledge binaries (Chapter 5). What emerges from these associations is that disability is a shifting notion and therefore susceptible to cultural, social and individual determinations, and can thus be deconstructed by the same society. The discovery and acknowledging of the beliefs and practices of the society within which people with disabilities live (carried out in the preceding chapters) was already an exercise in deconstruction.

This chapter takes this deconstructive process to another level, unfolding in two steps:

- a) The identification of the binary oppositions and the system of power on which they are founded. The limited signification on which dualistic thinking that undergird disability is based, will be exposed. The effects such systems and limited significations have on people with disabilities will be explored.
- b) Underlining and following through narratives that lie outside the plot of the dominant disability story line. These are what White (1990:15; 2003:165) terms 'unique outcomes'.

#### 6.2 IDENTIFICATION OF THE BINARIES

This section corresponds to step a), identifying the faces of the binaries or dualities that undergird the dominant disability discourse from the point of view of the research participants. It contributes to unpacking the overall objective of the chapter, which is a deconstruction of the dominant disability discourse. It does so by focusing on the binary

constitution of the cultural, institutional and Christian discourses, with a view to exposing the beliefs that feed them.

### **6.2.1 Deconstructing cultural, institutional and Christian disability binaries**

Culture, public institutions and the Christian church provide a space for the discovery, acknowledgement and explosion of the beliefs, ideas and practices assisting the dominant disability discourse founded on the binaries. This is because disability remains an object of institutionalised discourses of control, revealing a series of constructive and regulatory operations (Shildrick 2005:757). Parts of responses highlighted (in **bold**) in the text represent the deconstructive statement from the research participants. The deconstructive process begins with the binaries within cultural discourses, which stem from the research participants' stories.

#### **6.2.1.1 Deconstructing cultural discourses**

It was argued in Chapter Four that disability discourse is a social creature, with its meaning determined by and mediated through the norms of culture within which it exists. In this section I glean themes from participants' stories which link with the cultural disability discourse among the Basotho, and to unpack its binaries with a view to understanding the beliefs, ideas and practices that sustain them.

##### **a) The powerful ancestors vs. powerless humans**

The disability discourse read through the lens of culture suggests that a disabled body is caught between the control by powerful ancestors and the powerless disabled body. Culture portrays ancestors as powerful and influential forces that tolerate no dissension or violation of norms by humans. Their visitation upon anyone who violates the norms is swift and decisive (Idowu 1973:185; Mbiti 1975:73), and they do not relent until amends are made to assuage their anger. Preying on their protégés' miseries seems to be a way to explain them. Normally the traditional doctor is consulted to interpret and prescribe ways to make amends for the violation. In a divinely instituted hierarchy of beings, ancestors occupy a privileged space between God (gods) and humans (Mbiti 1975:76; Idowu 1973:138). Ancestors are little less than God or gods, but a little more powerful than human beings (Mbiti 1975:76). However, there is also a powerless, vulnerable, dependent human being, who is constantly sacrificing to the ancestors to appease them.



According to Mbiti (1975), understanding of the dominant ancestral discourse is as follows:

- Ancestors visit their surviving relatives to make their wishes known
- Sickness and misfortune in the family are attributed to the ancestors
- When misfortune is attributed to witchcraft and sorcery, ancestors withheld their protection
- To satisfy the ancestors a ritual is performed to correct breaches that may have occurred
- The diviner or medicine man is consulted to find out what the ancestors want.

The stories of Jack and Maki reflect the above understanding. When they were both taken from one traditional doctor to the other, from one healer to the other, the parents were searching for latent reasons of patent encroaching disabilities in both families. They were under the spell of the ancestors' power and control (Enzeanya 1969:44). Parents were seeking counsel and ways of placating the ancestors who were visiting upon the family for possible neglect of some sort.

The images of ancestors who only punish sustain the dominant discourse of retributive ancestors who police their subjects. This discourse supports the binaries of ancestral power and human powerlessness (Landman 2009:107). They further feed on the power of culture as opposed to the powerlessness of an individual, who feels very insignificant in front of the immense power of culture.

Later, Jack had this deconstructive statement to say about his disability: "*Though I certainly cannot be blamed for my visual impairment, what kind of animal I would have been if I had my sight... [with a smile] ...only God knows. So ancestors do not only prey on miseries.*" Jack's deconstructive question contradicts a taken-for-granted knowledge claim and exposes the subjugated claim that ancestors can also be benevolent. Jack suggests that there are other ways of conceptualising the ancestors' role within society.

Mbiti (1975:73) underlines this marginalised perspective of the ancestors:

- On the whole ancestors are benevolent towards their families.
- They show interest in their surviving families.
- They visit their surviving relatives.

## b) **Sleeping ancestors vs. vigilant ancestors**

According to Jack (2009):

*But there is also a possibility that the ancestors were not directly involved, but that I was bewitched according to the beliefs of the Basotho. If that is the case the ancestors were either withholding their protection from me and the family or they were not vigilant enough. But then why do I have to bear the brunt?*

He adds that, *“in the war that ensued between the witches and the family, while the ancestors were asleep, I was crushed.”* Given what Galvin (2003:687) write that a desirable identity can only be defined in relation to its antithesis, then the sleeping ancestors imply vigilant ancestors. As structures derive their sense from what it is not, the idea of the sleeping ancestors derives its meaning from its relationship with vigilant ancestors.

Mbiti (1975:73) lends credence to the discourse that ancestors do sometimes withhold their protection, especially if there are breaches of proper conduct towards them. These are the sleeping ancestors. Jack, however, suggests another perspective, involving being bullied into submission by the dominant discourse of ancestors withholding their protection (sleeping ancestors): *“I am told that death is sometimes caused neither by sorcery, spirits nor curse but it is also caused by natural factors. By the same token sickness and disease can also be caused by natural factors.”* Mbiti (1975:113) confirms the latter assertion that visual impairment can be sought from causes other than ancestors alone. In that way he reiterated that ancestors do not prey on miseries. These deconstructed ancestors will be taken up and developed in the sections of this chapter that follow (6.3.1).

The next section focuses on the binaries within public institutions that emerged from conversations with research participants and from interacting with literature.

### **6.2.1.2 Deconstructing Institutional discourses**

Various public institutions in Lesotho have embraced a “different as special” nomenclature with respect to people with disabilities, founded on binaries that are supported by certain discourses. There is also the language of rehabilitation that evokes the medical model and its language of deficit and lack in the labels used of people and children with disabilities. Following through this labelling, I investigate the binaries inherent and ways in which they can be deconstructed.

### a) **Special needs vs. non-special needs**

In its documents, the Ministry of Education refers to 'children with disability' as 'children with special needs,' the term 'special needs' implying that there are also needs which are not special, and that as it is applied to people, some people's needs are not qualified as special, as opposed to those that are (Conway 2005:3-8). While the term 'special education' is quite familiar and easier to say, its opposite is unknown, unfamiliar or better left to the imagination of the writer or reader.

Johnstone (2005), Veck (2007) and Graham and Slee (2008) summarise the special needs vs. non-special needs binaries to clarify the beliefs and ideas that sustain them:

- Special education has been associated with negative stereotypes (Veck 2007:3).
- When the label 'learning difficulties' assumes a 'master status' it becomes the 'lens' through which the labelled are viewed (Veck 2007:3).
- Special needs students are viewed as students with learning difficulties (Veck 2007:4).
- Disabled students are viewed as special needs students and therefore as students with deficits (Johnstone 2005:13).

The above picture supports the special vs. non-special binary opposites. The opposite of learners with special needs exerts its authority by its absence and non-name, and its normalcy is established through unsaying it. Ferguson (1990:11) regards as dominant any discourse that tries not to speak of its name, because its authority is based on absence. Learners with special needs belong within the context of special education, which itself is sustained in existence by the binary between special needs learners and non-special needs learners. This is so because labelling does not make 'other' but rather depends on the 'other' for its existence (Graham & Slee 2008:287).

The categories of special needs vs. non-special needs, therefore, perpetuate what Graham and Slee (2008:285) call "an invisible nerve-centre from which socio-political relations of power that strengthen existing structural arrangements are strategically and anonymously deployed." The categorisation itself functions not only to bring the difference to the fore but also to maintain power disparities. This is achieved by "reifying unnamed attributes that carry social, political and cultural currency" (Graham & Slee 2008:287). The power disparities are embodied in the disparate standards between the so-called special education schools and general schools. In addition, that special education has become a haven for low academic achievers becomes apparent. Maki (2008) concurred:

*Year in and year out there is always a promise of improvement of this or the other aspect accompanied by an excuse that I have just come and I am familiarising myself with the needs of this new Ministry. The more special we become the lesser quality of education we receive.*

Tsili's mother said about her son: *It will not help to send my son to school. He would rather be taken care of by his siblings*, reflecting an internalised discourse that views children with disabilities as special in a disempowering sense. Her understanding of the school as a place for non-disabled, non-special and students with non-learning difficulties is confirmed by her words.

When quizzed about the meaning of special needs appellation, Reg (2008) said:

*I have always thought that **each one of us is special in a way**. The most intelligent, average and the less intelligent by our educational standards are all special. Each of those categories is special in its own way. Instructors or teachers have to be prepared to deal with each of those categories in the context of their special needs.*

## **b) Inclusion vs. exclusion**

The notions of inclusion and exclusion feature prominently in issues of marginalised categories and groups, such as race, disability and gender. They are also associated with special education issues, in particular the ideological divide between learners with special needs and those without. This binary of special vs. non-special learners evokes links with the concept of inclusion, which is indefinable outside the discursive distinction between exclusion and inclusion (Slee & Allan 2001:181). Inclusion came to challenge what was perceived to be a segregating and labelling language and philosophy of special education (Graham & Slee 2005:278), and has become a buzzword in educational circles and policy frameworks in Lesotho.

Foucault (1977), Graham and Slee (2008) and Popkewitz and Lindblad (2000) identified aspects at the foundation of the inclusion vs. exclusion binary:

- Inclusion functions to assign each individual "his 'true' name, his 'true' place, his 'true' body, his 'true' disease." (Foucault 1977:198).
- The included are the previously excluded and the marginalised.
- The need to include is occasioned by the alleged difference which is founded on the binaries of normal/abnormal; natural/unnatural (Graham & Slee 2008:282).

- Who decides who is included and who is excluded evokes relations of power. The one who includes and excludes exercises power and the one who is included and who is excluded is the effect of power (Popkewitz & Lindblad 2000:9).

The maintenance of the inclusion vs. exclusion binaries not only labels those who are perceived as abnormal but also creates a category of the naturally included who are naturally excluded from the category of those whose inclusion needs to be negotiated. The specially needy students, who are disabled students vs. the non-specially needy who are non-disabled leads to a vicious cycle of inclusion and exclusion. In its operation, it defines the abnormal “through transgression of boundaries and limits of identification and disqualification, recognition and non-recognition” (Graham & Slee 2008:283). Whether it operates from the position of inclusion or exclusion it “constructs not simply position but the play by which borders and limits are conceived” (Derrida 1967:369). As Graham and Slee (2008:284) observe, “those at centre ride the boundaries determining centricity and ex-centricity. However, privilege and position at centre is dependent upon subjection and marginalisation of the Other.”

This inclusion vs. exclusion binary led to the participants’ internalising of discourses such as:

- *There is no use going to church to interact with God who would not listen to me.* (Sam);
- *How would I be able to live with such a person?* (Rev Frank).

The latter are the internalised, disempowering conversations leading to very thin conclusions about people (Morgan 2000:29-30). They are all founded on the assumption that people with disabilities are the “other” and “the different”, which are convertible with sin, evil, ill and abnormal, deserving only of exclusion or else to be included through negotiation.

When asked what he thought of being included and being excluded, from a philosophical slant, Jack (2009) replied:

*What is included is what was outside. What is in needs no inclusion because it is in already. Am I right sir? But what is out can only be invited in. I stopped going to church where I thought I belonged. When I did not feel welcomed I simply left. Did I also tell you about a nasty incident that happened in 2007? I had been complaining about lack of services for visually impaired students at the Library and only promises had been made. One day I went to the Library. I spilled out the books from the shelves. The following week I and my colleagues were called by the Librarian to identify areas that needed improvement for*

*learners with disabilities. The following week those changes had been effected. My point is: though we were part of the student body we were not afforded the same opportunities as other students. So I and others like me were nominally included but effectively excluded.*

c) **Normal vs. abnormal**

In the Health and Welfare and Legal sectors, people with disabilities are viewed as abnormal and therefore in need of rehabilitation and resettlement (Constitution of Lesotho 1993:#33). In that way they are contrasted to the 'others', so-called 'normal', who need neither rehabilitation nor resettlement. These labels are founded on binaries of disability - abnormal – ability - normal discourse. Based on this discourse, people with disabilities are viewed as in need of rehabilitation in order for them to fit in society. The society (ability = normal) is seen as constituting a perfect space within which they need to be included once they have been rehabilitated and normalised, hence the term 'resettlement.'

Stiker (1999:180) identified ideas underlying the binary of normal vs. abnormal.

- In the biological realm disability is defined along the lines of abnormal and the pathological.
- The normal and its opposite abnormal represent natural and unnatural respectively.
- Normal is defined as natural and the latter stands for integralness or integrity.
- In the ethical realm, disability represents the monstrous, which deserves physical suppression as it is a bearer of misfortune.

The above portraits feed the normal vs. abnormal binaries, as they surfaced and re-surfaced in conversations with research participants. They further lead to internalisation of the following discourses:

- *I am feeling so sorry about my son* (Tsili's mother).
- *What kind of a person is my son-in-law?* (Rev. Frank).
- *Disability is God's and the ancestors' punishment* (Ken).
- *Prime Minister should pray for us that we may have life* (Ken).

During our conversations, very powerful and deconstructive statements, which subverted the internalising conversations, emerged from the research participants:

- *I am disabled but I am not unabled. I am not in need of healing. **Disability in not inability*** (Ms M)
- I wish to reiterate that **we are different but not abnormal** (Jack)

- *The fact that they [non-disabled] are not able to see the obvious and act on it suggests to me that they need a lot of rehabilitation (Tsili)*
- *I can work day and night without any light and you can't. I can walk night and day without light and you can't. So who is disabled? I am able to listen to two conversations at the same time and you just cannot, who is normal then? (Reg)*

What has emerged from the analysis of the discourses within the public institutions is that naming makes visible. This has become patent in how, by naming and thus categorising certain groups of people, the power of a fictionalised normativity is strengthened and secured (Dunne 2009:52). Special education's needs child (SEN child) = included child = disabled child = abnormal child. The philosophy and the language adopted in the education, health and social welfare sector, as well as legal sectors, make visible and construct by naming children and people as SEN and included. They are therefore seen as in need of rehabilitation and resettlement.

### **6.2.1.3 Deconstructing Christian discourses**

The various Christian denominations, by their attitudes and practices, as research participants said, are not doing any better than the public institutions. The bigger picture, as the research participants see it, is that the church, especially the clergy, has inherited the caring *for* attitude as opposed to an empowering one (*caring with*). Through its clerical ministry the church has always been an active church and the laity a passive and receiving church. The consequence has been a one-way process from the pastors to the congregation, but not back. The experience of the healing, teaching church and that of the healed and listening church, which are only manifestations of an only caring *for* as opposed to a caring *with* church, occupy centre stage in the stories of the research participants. There follow discourses that emerge from stories of research participants, discussed here so as to identify the binaries that sustain them and the discourses that give life to them within the Christian context.

#### **a) The caring *for* church vs. the caring *with* church**

Clericalisation, which is a policy (overt or covert) of maintaining or increasing the power of the ordained within the church, took its upward surge at the time when the church had heresy as its greatest challenge. As a viable solution at the time it felt that if the laity were to follow directives from the clergy this would serve as a "reliable antidote" (Bosch 1991:468). The long-term consequence of this disposition was a church divided into two categories: the clergy as the dispensers of care, grace and the sacraments, and the laity as the recipients of

care, grace and the sacraments. This variable played itself out in different ways at different times in the history of the church (Stiker 1999:xi).

We agreed with the research participants that this view was still very much alive in the life of the church, and that the laity was still the done-to. People with disabilities who cannot be priests or pastors can only be seen as objects for charity or projects through which others carry out acts of kindness. They can be dispensed from certain ritual obligations because their full and conscious participation is in doubt (Rose 1997:399). Others in the church know better what their needs are without even having to ask them. They are subjected to a double stigma. They are part of the laity who can only receive and within the laity they are the less visible and recognised. When I asked if the research participants had experienced some of these things their answer was an unequivocal 'yes.' They went on to provide the examples discussed below.

#### **b) The holy healer vs. the sinful in need of healing**

Jack's persistent rebuff of different pastors who showed readiness to pray for his healing (cure) is an indication of the presence of a larger discourse that feeds the binary logic of healer vs. healed; holy vs. sinful. Such a discourse defines people with disability as not only essentially sinful and in need of both physical and spiritual healing, but also as demon-possessed and in need of exorcism. Healing here is understood as cure. In their words, there is no way God can show love by creating a disabled creature.

Rose's (1997) insights help in understanding the discourses that are consistent with the above binary opposites. The dominant disability discourse supports the negative representation of disability. For Rose (1997:396) the root of this representation derives from the Judeo-Christian theology, within which disability and people with disabilities were seen as an embodiment of evil and disease and posed as foils of God's goodness and perfection. They therefore needed to be prayed for and healed.

The above discourses support the following internalised conversations in the research participants:

- *I would be grateful if anybody could pray over and cure my daughter* (Maki's mother)
- *You need to be prayed for, accept Jesus and you will be healed* (Pastor)

Ms M's mother's statement was reflecting a healing power discourse that kept her captive despite her daughter's inhabitation of a different discourse, "*I need no physical cure. I only need healing from the pain caused me by society.*" As Jack said, on one occasion he



acceded to the laying of hands just to show the pastor that their convictions with respect to healing are at cross-purposes. When he could not be healed, as the pastor said, it was because he (Jack) had no faith. It could not have been because of the lack of faith from the side of the pastor, for it was possible, according to the discourse, the pastor (as conduit of God's grace) could not have faith. They are supposedly holy healers. Only the disabled, because of their waywardness and sinful tendencies, are potential defaulters and sinners in the realm of faith. They are supposedly the suspects.

Maki and Jack, however, agree on one thing, namely that all people ("we") are in need of healing. "*We have been abused and pained, and continue to be, by ministers of religion who would not listen to what we have to say as disabled people. They also need healing from their intransigence and hard-heartedness.*" Reg's and Jack's statements confirm that the notion of healing is overflowing with multiple meanings that may at times conflict. Healing in the context of disability cannot be confined to people with disability alone. In that binary logic of disabled vs. non-disabled, the latter can also be in need of healing. This confirms Balkin's (2004:3) view that within the same context the boundaries of healing can be parsed in many different ways, as they are looked at from different angles. From Reg's perspective, they would represent a church that is called not only to heal but also to be healed. The caring *for* church also manifests itself in the teaching vs. listening church.

### c) **The teaching church vs. the listening church**

When Reg said, "*we do not only need to be a teaching church but also a listening church*" he was breaking open a discourse and laying bare the binaries that support it. Reg's words showed how caring *for* expressed itself in knowing what the people needed even without asking them. The caring *for* discourse fits in with the clericalisation paradigm, as both maintain and support each other.

Bosch (1991:470-472) and Kotzé (2002:12-20) traced the interface between the "caring *for*" and "prescriptive ethical" discourse and the "clericalisation" paradigm and how they feed each other:

- There is a watertight division between the teaching church (*ecclesia docens*) and the learning church (*ecclesia discens*).
- Religious leaders were entitled to speak on behalf of the deity or interpret the word of God (Kotzé 2002:12).
- They were empowered to tell the people the "right way", what to do and what not to do

- Missionary enterprise was firmly under the control and jurisdiction of the clergy.
- The laity's participation was only auxiliary.

Within these paradigms the clergy constitutes the teaching church (*ecclesia docens*) and their role is seen in terms of actively mediating grace. This is the church that viewed itself as “stocked with heavenly graces which the clerical proprietors could disburse to customers (Bosch 1991:469). Though the clergy were taken from the community, they were seen as cut off from them, put over against them now as mediators of God's graces. The laity was seen as immature and utterly dependent on the clergy for their spiritual sustenance. Kotzé's (2002:14) question as to who benefits from these dominant claims to knowledge and truth becomes pertinent. The question seeks to discover alternative ways of relating to God within the church, which has been under siege by prescriptive ethical discourses outlined above.

Despite a shift in the models that the church, particularly that of the church as communion (*koinonia*), has adopted lately (Starkloff 2000:409-430; Phelps 2000:672-699), the predominant discourses are still those of the church as a hierarchical institution with the clergy at the top of the ladder of power and the laity at the foot (De Jong 2002:190-191). As a result, Sam and Jack were very clear that the church was very insensitive to their concerns and consequently they saw no use in going to church. Others were adamant that though they went to church and that the church had done much in improving lives of people with disabilities in Lesotho, on the whole the church still treated them as outsiders, patients and victims, and not as brethren. “*The church embraces people with disabilities in its bosom but it does not give them an ear,*” Reg said, thus relegating it to a teaching church as opposed to a listening one. “*How can they [clergy] claim the right to teach me and speak to my concerns when they do not listen to me?*” Jack asked rhetorically.

Reg's and Jack's words represent a resistance to the colonising effects of the dominant clerical paradigm, and are an expression of the hitherto marginalised voices that have refused to be silenced. The persistent and dominant clerical paradigm contains within itself seeds of its own undoing, and the words of Reg and others are a clear challenge to the prescriptive ethics that sought to marginalise and oppress those who the power of truth has judged as worthy of only listening to and obeying, and nothing more.

In chapters I sought to identify the binary opposites underlying the dominant cultural, public and Christian discourses around disabilities, and went on to expose the ideas that support and sustain such discourses. In the course of this exposition I identified the unique

outcomes, which I marked in bold, as they emerged from conversations with research participants. I now explore the effects of these binaries on disabled identities.

## **6.2.2 Effects of binaries on disabled identities**

Having identified the binary opposites on which the system of power on the dominant disability discourse is founded, this section examines further the effects such systems have on people with disabilities.

### **6.2.2.1 Alienating experience of disability**

In a number of conversations, research participants suggested that being alienated formed part of their experience as people with disabilities. Alienation as a concept lends itself to various meanings associated with different types of practical responses (Brown et al. 2003:4). From Fromm's and Seeman's sociological definitions of the late 1950s, through Schacht and Kanungo's psychological descriptions of the 1970s, to Hirschfield and Field's 21<sup>st</sup> century definitions, the common denominator is separation, a dissociative state or estrangement from self or other people and things (Fromm:1955:120-121). For the purposes of this research, alienation points to estrangement or disconnection from self and environment or context and a sense of not belonging.

According to Seeman (1954:784), this estrangement leads into powerlessness, meaninglessness, normlessness and isolation, all of which are different manifestations of alienation. *Powerlessness* is a feeling of vulnerability to manipulation by others, with no corresponding feeling of power to determine one's future. *Meaninglessness* refers to a sense of uncertainty regarding the reason why, and the purpose for which certain things have to be done the way they are. *Normlessness* is a loss of socialized value that gives purpose to life, manifested through engaging in socially unapproved behaviour (Dean 1961:754). Almost all the participants in this research journey, as well as significant others, reported some feeling of alienation, in their social, religious and psychological forms.

### **6.2.2.2 How I wished I could inhabit my different self**

Jack recounted what he described as a very painful experience that led to his feeling of alienation from self. When the parents had exhausted all possible means of finding some medical solutions to an encroaching blindness, they posted him to the Queen Elizabeth II hospital for help. While there, he was rescued by a Good Samaritan who sent him to the resource centre for the blind: "*I was rebellious and stubborn and nobody could convince me to do anything not even my best teachers,*" he said. From Weingarten's (2003:160-161)

perspective, Jack was viewed as 'other' and, therefore, as less than human, because human beings are not posted. This treatment became a gateway to his dehumanization, confirming Galvin's (2003:160-161) argument that to become disabled is to be relegated to a marginalized status as opposed to those who allegedly inhabit an unacknowledged centre. A perceived rejection by parents (alienation) led to alienation from self, which in turn expressed itself through meaninglessness, social isolation and normlessness: "*I had cultivated a sense of dislike for myself. I wished I could inhabit my different self which I did not even know how it would look like and what new experiences it would bring upon myself,*" Jack continued.

### **6.2.2.3 Social alienation**

Society gives birth to what and who people are, and they in turn maintain society in its power to create and recreate. This is mainly achieved through language and what Butler (1993:231-232) calls 'performative repetitions', which represent and perpetuate certain systems of meaning within society (Galvin 2003:160). Society has, through language and performative repetitions, crafted and constructed people with disabilities as abnormal and undeserving, thus alienating them socially. My conversations with research participants reflect these constructions, for instance in Sam's statement: "*Sometimes people think that because I am deaf and dumb I am a fool. At times they want to cheat or take advantage of me simply because I am deaf and dumb.*" Though these attitudes have not managed to sidetrack him, by his admission they sometimes make him angry.

Reg and Maki shared similar experiences: "*Though my family had accepted me, I had a problem in mixing freely with other kids at school. Almost every student looked at me with wariness*" said Maki. Meanwhile Reg, whose other sister is also visually impaired, recounts how people who passed by their house called it *lifofung* (house of the blind). This was not only derogatory but also imposed a fixed identity on the house and on those who lived in it. Through that label, others were invited to re-live not only the name but also the discourse that the society has put around the name.

### **6.2.2.4 Alienated and classified by the institutions**

Institutions can also work as agents of the techniques of social control for what White and Epston (1990:24) call 'objectification' of bodies of persons. In that way, people, because of their perceived differences, are organised and arranged in space for better surveillance. I have related how public institutions have embraced the idea of naming and categorising people with disabilities for purposes of evaluation, welfare administration and other services. They are 'children with special needs', and "*Unlike other people our permanent home is the*

*Ministry of Health and Social Welfare, where our needs are served*” (Jack). The underlying assumption is that they are sick and are better placed under the Ministry of Health and Social Welfare for better care, rehabilitation and welfare grants.

Maki’s experience during her application for enrolment at a tertiary institution, and also during her time as a student there, brings to mind a sense of anguish and being out of place:

*I was the only and the first student with mobility impairment to enrol in that school. I would say the school was not ready for me. I had no access to the library, which was upstairs. The toilets and their doors were not disability friendly and I had to call the security officer to open the door for me every time I wanted to use the toilet. Unlike other students, I was not able to fulfil an internship requirement because the envisaged place of attachment was upstairs and could not send my letter of application and the one responsible could not come downstairs. There was a feeling of ‘I had no point being here’*

(Maki 2009).

When Maki eventually gave up her quest to fulfil the internship requirement, her decision was influenced by a feeling of powerlessness and belief that there was little she could do to influence her future or the future of others with similar impairments in that school. As we talked, Maki pulled no punches in taking to task her *alma mater* for what she called its insensitivity to her plight whilst there. Her moods, feelings and spirits were affected by the treatment she received: “*it nearly affected my future in very adverse ways. There was a time when I contemplated quitting the college altogether.*” This experience echoed Lane (1992:6), who wrote that exclusion diminishes people and that it is more de-humanizing and painful than disability itself.

#### **6.2.2.5 Alienated from God!**

*I have stopped going to church. I feel there is no point being there when people do not want to recognise my presence. It did seem like we were praying to two different gods, the god who simply tolerates me and all those like me but loves everybody else unconditionally.*

(Jack 2009)

Here Jack found resonance with the metaphysical assumptions of Western theology, which views God’s being and existence as grounded in and explained in terms of metaphysics, or what Wallace (2001) calls ‘*ontotheology.*’ Within this worldview, especially the Thomistic metaphysical worldview, God, essentially, possesses the attributes of perfection, omnipotence and omniscience. In God there is no room for imperfection, lack or any form of

abnormality. Coupled with the dualistic perspective common also in Western Christianity, this worldview achieves a deep sense of alienation between spiritual and material; heaven and earth; spirit and matter; and good and evil, with disability fitting within the second and marginalised term of the binary.

Jack's experience of two gods prayed to in the same church is a reflection of a dualistic tension between the Christian God, who is perfect and cannot embrace people with disabilities because they do not conform to God's perfection, and a disabled God in whose image the disabled are created. For Jack and other people with disabilities, God as Emmanuel cannot be real because, as Mairs (1993:3) would have argued, God would not have put on their bodies and walked about in those bodies because they are missing the mark of a perfect God. It is a God who is so smart as to have no place for those who do not meet the conditions of a socially constructed order, beauty and perfection. It is a God who equates holiness with wholeness, perfection and sacredness. With such a god many would be left out, for there are many who are beautiful and sacred and yet are lacking in perfection (Senior 1994:15). Sam related what it meant to be excluded and unwelcome:

*The church has not advanced towards dealing with my disability. I go to church... just sit and stand as they sit and stand but I do not get the message for the day, so I end up feeling that going to church is not of help because it does not cater for my needs.*

(Sam 2009)

As a result of this socially constructed God, who cannot give audience to a blemished or sinful individual, people with disabilities are uninvited and unexpected guests (Webb-Mitchell 1994) in communities of faith.

Christian theology, in its different manifestations, has struggled to break from the shackles of this legacy to this day. Given its close links, in its origins, with Judaism and Greek philosophy, it has been difficult for it to shed the burden of the disability-sin association, which gave rise to interpretations that viewed disability as loss, tragedy, weakness and punishment.

#### **6.2.2.6 Victims to calculated power of silence**

In this section, I follow through experiences of silence of people with disabilities. After protracted struggles for improvements to make life at the institutions of higher learning bearable for people with disabilities in general, and with mobility impairment in particular, Angel stopped urging herself or anybody. She retreated into herself and said nothing more on the subject. Maki had a similar experience, being unable to access the library because it

was upstairs and there was no lift. Nor could she use the toilet without having to ask the security man to open the door for her. She could not fulfil the placement requirement because she could not deliver her letter of application and nobody was ready to collect it. Reg, Jack and Sam have no access to friendly and confidential medical services because there is no provision for them in all hospitals or health centres.

Effectively silenced by these powerful institutions of higher learning, hospitals and other public institutions, and overwhelmed by their rotund form and their inaccessibility, theirs was a silence of powerlessness. Angel felt, as she described it, *“totally submerged by its imposing décor; ambitious vision and yet its detachment from the most obvious human need.”* Her silence was an expression of disagreement, complaint and objection (Cohen 2002:194), and her decision to quit was occasioned by the realisation that no one would listen. She was, as Butler (1997b:27) wrote, “given a place, put in a place through silence, through not being addressed.”

This longstanding objection and disagreement was met by a deafening silence from the institutions of higher learning, despite the adoption of inclusive education by the Ministry of Education. Almost two decades later, these institutions have reluctantly moved towards, drafting a policy on students with disabilities. In the process, what Friere (1993:30) describes as the “culture of silence”, where the voice of the ‘other’ remains silenced, became entrenched.

#### **6.2.2.7 Disability and HIV and AIDS**

*“Lack of access to crucial information for people with disabilities has been the most embarrassing footnote in the efforts of nations to curb the spread of HIV,”* said Reg, an observation corroborated by Ntlatlapa (2008:25), who observes that HIV&AIDS information is available to persons with disabilities in inaccessible format and as a result puts them at greater risk of infection. Ntlatlapa (2008:25) adds that girls and women with disabilities are more in danger of being sexually assaulted than other women because they do not easily access relevant information on the pandemic and measures that are available for risk reduction. The perception that persons with disabilities are sexually inactive and less disposed toward drug and alcohol abuse exposes them more to HIV infection (Groce 2005:215), whereas their poverty, illiteracy, ignorance and marginalisation actually does expose them further to risky behaviour and greater risk of infection. That there is very little interaction between HIV&AIDS prevention programmes and Disability People’s Organisations is suggestive of the low status accorded people with disabilities and their

concerns (Ntlatlapa 2008:25). It is a further indication that their voice on issues that concern them and others is marginalised. One of the consequences of being unduly silenced and marginalised is anger, which I discuss below.

#### **6.2.2.8 Engulfed by anger**

The feelings of anger that engulf people with disabilities are a logical sequel of the kind and intensity of alienation, isolation and marginalisation that they experience. Jack, Sam and Maki had, in their own words, been angered by the attitudes of non-disabled people who seemed to be “taking them for a ride”. The attempts by disabled people to voice objection to their treatment are often met with what Young (1990:134) calls, powerful but subtle gestures of silencing. Their objections and protests are, as is often the case, interpreted as ingratitude or madness. They cannot be angry because in normal discourse anger and reason, let alone theology, do not mix, or as Kacela (2005:201) writes: “Christianity and niceness are synonymous and nice Christians, therefore, neither feel nor express anger.”

This language maintains discourses that render people with disabilities ‘invisible’, and they are expected to reproduce, through language and practice, nothing apart from what they are expected to say. As Maki suggests, they are angry because, though visible, they are rendered invisible; though they have always been crying to be heard, their voice is not taken seriously. Thus Maki asks, “*What would be the proper response except to save ourselves from bursting, through venting out that anger?*” The anger drives them from important relationships, such as relationships with God.

#### **6.2.2.9 Summary**

In summary, the above two sections focused on the identification of binaries and the systems of power that undergird the dominant disability discourse, tracing their adverse effect on the lives of people with disabilities and their significant relationships. The result is an alienated, HIV vulnerable, broken and angry society and church whose language betrays a very divided and disempowered community. Silence adversely affects people on all sides of the disability continuum. Those who profit from it or who do not feel the pinch of living with disability can afford to be silent and theirs is the calculated silence of power. Those who resist painful effects of dominant disability discourses are denied a voice, are muzzled, are ignored and are not taken seriously. Theirs is a crushing silence of powerlessness. The eloquence with which people with disabilities are present through being silenced will be a constant reminder of their cry to be present and to be heard, and of our call as church and society to be present, to listen and to respond in caring and transforming actions.



Painful as these experiences may be, they do not have the last word. Hope protects people with disabilities from being weighed down by pain and suffering. That glimmer of hope that kept all of us on both sides of the disability divide from being overwhelmed by pain has borne fruit in the form of unique outcomes. These are the narratives that lie outside the dominant disability plot, and are discussed in the next section.

### **6.3 UNIQUE OUTCOMES**

This section corresponds to the second step above (b), under 6.1. The deconstructive process, which is the focus of this research examine the binaries on which the dominant disability discourse is founded with view to a co-construction of an alternative and more habitable disability discourse. The collaborative discovery of unique outcomes, within the narrative metaphor, is an important part of that process. Discovery of the unique outcomes helps in fulfilling the third aim of this research, namely a participatory deconstruction of dominant disability discourse and the embrace of an alternative disability story that is more relational, inclusive, responsible and accountable. It is to these unique outcomes that I now turn. The resounding phrases, taken verbatim from the research participants, which stood out in the face of the problem discourses are the following:

- Ancestors are also supportive of their protégés
- Disability is an opportunity
- Words alone do not hurt
- Society needs rehabilitation
- Being different is godly
- We are all special
- We all need to be a listening church

Having identified them as unique outcomes in the stories of dominant disability discourses they are discussed in turn below.

#### **6.3.1 Ancestors are also supportive of their protégés**

Ancestors have always been viewed as “taking no nonsense”, that is they are intolerant of people who do not take their word seriously. This discourse has been internalised by both disabled and non-disabled people and has forced them to think of ancestors as unrelenting police and tough judges. They are seen as preying on the miseries of their kith and kin. For instance, Maki’s mother, in her story, made allusion to the involvement of the ancestors in the story of her daughter. According to her, her daughter was having visions or premonitions

that were later associated with her mobility impairment. Jack's parents also consulted the traditional doctors to inquire about what the ancestors could have thought about her loss of sight. In both cases the interpretation of the traditional doctors was that the ancestors had momentarily withheld their protection, hence both Maki and Jack were disabled.

Jack viewed ancestors differently, their having allowed him to develop a sense of urgency in fending for himself, something he calls *Sfatelism*. *Sfatelism* is innovation neologism from Jack, coined from his name 'Sefatela', which connotes fending for oneself and others. He therefore proposed this as a kind of a meta-theory that represents the need to beat procrastination by doing things for oneself instead of waiting for handouts which may not come. In that way, one improves one's lot and sets an example for others to do the same. Despite the odds, Jack went out fending for himself and has thereby discovered the other side of the ancestors, that they not only prey on miseries but are supportive of others' efforts (*Sfatelism*).

### **6.3.2 Disability is an opportunity**

Current society has inherited an environment where disability has commonly been identified with tragedy, impurity, sinfulness, weakness, malformation, moral aberrancy and being less human. Nonetheless, all the research participants reiterated that disability is not inability. As far as they were concerned, their disability was not a problem. Despite the negative perceptions that have informed the mind of the church and society with respect to people with disabilities, the latter have held their own and have proved that if opportunities were equal they would be competing with the so-called non-disabled people at the highest level.

Tsili views disability as a challenge to adjust to. *It is in fact an opportunity to explore my capabilities*, he says. He considers himself as both able and disabled which is the case with everybody. His contact with Mrs Coaker (who was running a centre for the disabled at the time) made him understand himself differently. It helped him to unleash his potential. This is what he had to say:

*Many of the goals I had set for myself have been achieved. My resolve has always been to make people aware that, given equal opportunities, I can do things on my own. Despite my mobility impairment I am able to drive my own car. I have a decent house and I see myself contributing something to the cause of the people with disabilities. All this I have achieved.*

(Tsili 2009)

Tsili has outlived the limiting stories that his mother attributed to him, such as "*I feel pity for this my son; my other children will have to take care of this son of mine.*" Tsili's mother was,

as a result, adamant that he did not need to go to school, which was the reason he delayed doing so.

Reg, Jack and Maki agreed that disability was not a problem, but that it had become for them an opportunity to use talents that would have otherwise remained unused. Reg had found a decent job and was performing quite well: *“I have defied the odds. My performance is such that some people doubt my disability. They say I am feigning disability,”* he said. Meanwhile Jack was studying for his last year of a BA in Pastoral Care and Counselling, and was a seasoned musician and composer. Maki had graduated with a Diploma in Business Management, while Sam was self-employed with multiple skills in carpentry, plumbing and tiling.

One problem they did admit to were people who claim not to be disabled but who will not appreciate what people with disability are capable of doing: *“They claim to know what our needs are without engaging us”*. For Dewsbury et al. (2004:148), this problem does not lie with disabled people but with the lack of appropriate services. If all buildings had ramp access and other people with disabilities had some necessary assistive devices there would be no problem for them.

### **6.3.3 Words alone do not hurt**

A great deal has been written about the role of language in marginalising and hurting people with disabilities (Corker 1999; Galvin 2003a; Gronvik 2007). The Disabled people’s movements through the aid of the social model of disability have managed to expose, identify and follow through some of the appellations that were found to be oppressive of people with disabilities. Terms such as ‘cripple’, ‘invalid’, ‘spastic’, ‘blind’, ‘deaf’, and ‘dumb’ were found to conjure intensely negative images and representations (Galvin 2003a:157), and were challenged as inappropriate by disability activists.

My conversation with Reg and Jack begs to differ in some way from the rest of the Disability Movement activists. Reg said, *“the word alone does not hurt”*, while Jack, in a similar vein, said:

*I have moved beyond words to the context within which such words are used. You can call me blind with no intention to hurt and you can also call me a person with disability pejoratively. Call me whatever you want, sefofu sa Jericho [the blind of Jericho], impaired, disabled as long as there is no intention to degrade me I am fine.*

Galvin (2003b:686), citing the children's rhyme concurs: "Sticks and stones may break my bones, but names will never hurt me. A name alone cannot hurt, but when backed up by such deeply oppressive images, it can wound beyond repair."

In this way, Reg and Jack have deconstructed disability as a problem label, confirming in the process that language in itself has no meaning. The words, the statements and the symbols used constitute language. Words derive their meaning from the framework within which they are embedded (Galvin 2003b: 676). In saying what they said, Reg and Jack laid bare the instability of the word 'disability', exposing in the process its subjugated meanings which could be inhabited in more life-giving ways.

#### **6.3.4 Society needs rehabilitation**

The Draft National Disability and Rehabilitation Policy (DNDRP), as discussed and critiqued in Chapter Five, makes constant reference to the word 'rehabilitation', betraying its penchant for the philosophy and practice of individual medical model to respond to issues of disability. After reading it, one is tempted to ask together with Reg, the question: *who needs rehabilitation, people with disabilities or Society?*

While the document seems to be adopting a tendency towards seeing people with disabilities as the beneficiaries of the rehabilitation practice, people with disabilities think differently. In a statement that lies outside the dominant disability story line, research participants, in a blending unison, stated that it is society more than people with disabilities who need rehabilitation. The latter position resonates with what Vash (2004:248) writes: "We observed that the world needed more rehabilitation than our patients did – from ramps and wider doorways to people with better attitudes and behaviour".

Jack and Tsili ask: "*When we are fully rehabilitated but the environment remains the same, what would be the next step? We would still be at point A.*" Reg asked a very pointed question:

*What does rehabilitating a person with visual impairment consist in? What does rehabilitating a person with hearing and speech impairment consist in? While it is true that, like everybody else, we have problems that would require a medical attention, it is not true that because we have an impairment or disability we, ipso facto, need rehabilitation. Neither physical rehabilitation nor vocational rehabilitation has improved the lives of peoples with disabilities.*

(Reg 2008)

In reference to some of the centres established for people with disabilities in the country, Tsili commented: *“While physical rehabilitation is not necessary for everybody, vocational rehabilitation as it is practised in Lesotho is simply a window dressing which does not afford people with disabilities equal opportunities in the job market.”*

For Barnes (2003:18), rehabilitation is far from, “enabling disabled individuals attain economic and social parity with non-disabled peers in societies organized almost exclusively around non-disabled lifestyles.” Maki concurred: *“after my experience during my internship, I am more convinced than ever that the so-called non-disabled society needs rehabilitation more than we do.”* Various authors have argued that society is the group in need of rehabilitation, for their patronising attitudes (Morris 1991:183), their failure to meet the needs of PWDs (Safilios-Rothschild 1981:5) and for packaging them into a generalised category and therefore depersonalising them (Kotzé 2008).

### **6.3.5 Being different is godly**

The dominant disability discourse has seen people with disabilities dubbed ‘sinful’ because of their differences, and their disability is a mark of such difference (Stiker 1999:29). From the Biblical times to this day, difference has been an occasion for sequestration, erasure and/or obliteration. Though identified differently throughout these years, the temptation to view the physical and cognitive differences of people with disabilities as unnatural never actually died out. From ancient times through the Middle Ages to contemporary times, people with disabilities have continued to be regarded as those who must be assimilated (integrated) or made to disappear (see Chapter 3).

A number of things said by research participants did not fit this dominant disability storyline. They felt their being different should not be equated with sinfulness, or as Maki said:

*Whether disabled or abled, being different is a hallmark of being human. I think God created everybody differently and we have to appreciate that. After all, we are both able and disabled at the same time. I think the perfection of God lies in God’s ability to create everybody differently. I hope I am not going to be excommunicated for saying that to be different is to be godly.*

(Maki 2009)

This is a very powerful representation of theology from below, claiming that when God created, God separated and rendered each part of creation different from the rest. There is a

sense in which God's creation may be understood as separation, where to separate would be to differentiate. To differentiate, therefore, is an expression of godliness.

According to Stiker (1999:viii), love of difference, if it becomes socially contagious, is life-giving. On the other hand, its antithesis, passion for sameness, leads to exploitation, repression, sacrifice and rejection. The experiences of people with disabilities suggest that passion for sameness accounts for much of their marginalisation and rejection by society.

### **6.3.6 We are all special**

In Lesotho, as in many other countries, the terms 'special need' and 'disability' are interchangeable (Khatleli et al. 1995:2). People with disabilities, especially children with disabilities, are categorised as children with special needs (1995:8). Of this Jack asked, "What does it mean to say we are special? In relation to what are we special? Who are not special?", or as Reg added:

*I have always thought we are all, as humans, special in a way. Each one of us is unique and therefore should have special needs. My take of the meaning of special is that it is used of people with disabilities to denote a lack in something and therefore needing more attention.*

(Reg 2009)

Reg's conclusion is that all are special in that they have both special gifts and some limitations. Reg's deconstructive statement that every person has a special need breaks open the discourse that sustains the special vs. non-special binary. Even the most intelligent of students who appear 'normal' by society's standards have special needs. Reg's statement is confirmed by Clark et al. (1999:158), that students' difficulties in learning, therefore, do not necessarily arise from within themselves but out of inappropriate responses made to those students by their schools.

### **6.3.7 We all need to be a listening church**

*We do not only need to be a teaching church but also a listening church.*

Reg (2009)

For many years the assumption has been that the word 'church' is interchangeable with the hierarchy or the clergy who were the custodians of doctrinal teachings (Lumen Gentium # 25-31). Authority, understood as power and as vested in the clergy, was a defining feature of this model of the church, particularly the Catholic Church, with accentuation on the virtue of obedience (Falcao 1988:74; Lapointe 1986:124), which was demanded of the laity who

occupied the last ring of the ladder of hierarchy. During this time, the role played by the priest was more exalted than that of the laity. The Trentine mass was for the most part an issue for the priest, who celebrated it on behalf *of* rather than *with* the people. Most of the prayers, if not all, were in Latin and were said in private, without the full participation of the people. People (laity) had no direct access to the Bible except through the priest or pastor, because of their alleged inability to interpret it correctly.

When Jack said that he had given up going to church because it treated them as if they were not there, he was saying the church was not listening to them. Reg was upfront that the church should not only be a teaching church but also a listening church. This powerful and deconstructive statement contradicted the taken-for-granted knowledge claim that the clergy only teaches and the laity only listens. Sam was adamant that he found no point in going to church because as far as it was concerned he did not exist: *"I am expected to hear what others are saying but others are not expected to hear what I am saying. So how can the church hear me if it is not listening?"*

In summary, I have identified and followed through the unique outcomes as they emerged from conversations with research participants. It has emerged from this section that the dominant disability story is supported by certain beliefs and convictions. They connive to impart truth status to some taken-for-granted knowledge claims which in turn hurt people on both sites of the disability divide. Within the framework of a poststructuralist, postmodern and narrative frameworks it is necessary to be suspicious of such truth claims, while breaking free from their colonisation and searching for stories that lie outside the domain of dominant plot, the unique outcomes.

#### **6.4 CONCLUSION**

The previous three chapters (3-5) have demonstrated that disability is a fluid category which is therefore prone to determinations of time, place and individual location in society. Despite this feature, societies, through what are termed regimes of power, have imposed on disability a fixed status and in the process people with disabilities have also been made to succumb to Bakhtin's monological determinations (1.7; 2.5.2.1). Thus, they have been pronounced dead, through being labelled (thinly described) abnormal, special, sick, sinners and impure, with no possibility of redemption except through obliteration at worst and assimilation or rehabilitation at best. The effects of such thin descriptions on disabled identities have been explored and their tactics of power and control exposed. They disempower people with disabilities through alienation, anger, silence and being cut off from

noble human interaction. However, stories that lie outside the dominant disabilities stories have been identified and followed through.

The next chapter will be a reflection on the meaning of these unique outcomes for research participants. Enhancing richer descriptions of these unique outcomes and co-construction of an alternative pastoral disability story will be a focus of the chapter. The participatory model of disability has been proposed as best adapted to the concerns of not only people with disabilities but of every person. Its disposition toward ethical consciousness and accountability links with themes, such as communion, *ubuntu* and interdependence, which have emerged from the conversations with research participants. These themes not only emerge from research participants, they also function to thicken participation as a central idea in this research.



## CHAPTER 7

### CO-CONSTRUCTION OF AN ALTERNATIVE DISABILITY STORY

#### 7.1 INTRODUCTION

Deconstruction is central to this research, particularly because of its promise to challenge the assumed binary structure which defines the normal and able-bodied, as opposed to and privileged over the abnormal and disabled. Identification of the binary opposites which support the dominant disability story, the effects such stories have on people with disabilities, and the events that do not fit the dominant disability story, was undertaken in Chapter Six. This chapter takes that deconstructive process to another level, thickening the unique outcomes toward the co-construction of an alternative and preferred disability story. It unfolds in two steps:

- a) To expand on or thicken the unique outcomes gleaned from conversations with research participants. These will serve as building blocks for the alternative and preferred story, which is richly described (White 1990:55-62).
- b) To focus on co-create alternative stories which have the potential to heal perpetrators, victims and witnesses of the dominant disability discourses.

#### 7.2 THICKENING THE PLOT

This section corresponds to the first step, following through the reflections by research participants on the unique outcomes and their meanings. It thickens the plot towards embracing an alternative and habitable dominant story. This part further outlines and unpacks themes gleaned from reflections by research participants on the unique outcomes. It consists of what I call 'foundational metaphors' of the church, which are amenable to a participatory pastoral care model adopted in this research. The unique outcomes further translate into theological paradigms that tie in not only with what the research participants envisage but also with the ethical positioning adopted in this research.

##### 7.2.1 Thick descriptions

In this section I explore and expand on the metaphors that emerge from the unique outcomes, gleaned from research participants in response to the question: *What is it that the society and the church are or have that has not been explored well enough to improve the quality of life of its members?* The answers challenged the pre-modernist and modernist

orientation toward religion (Kotzé 2002:14), and provided a framework within which the unique outcomes can be richly described and expanded. The metaphor of the church as family and as people of God stood out in conversations with research participants, who when asked to say more about what the idea of family entailed, spoke of the nuance of fellowship, communion, belonging, sharing and participation.

### **7.2.1.1 Communion as participation**

To the question: *What is a family?* the following responses were gathered from research participants: “*It is a place where one is born; it is a place where one is nurtured; it is place where one belongs; it is a place where though different we belong.*” These responses, especially the latter, clearly evoke the notion of unity in diversity, which is expressive of the model of the church as communion or *koinonia*. Other than being more pronounced than other metaphors, in both Protestant and Catholic circles today (Aram 1 2000:85), it is also appealing to many modern theologians (Bonhoeffer 1963:123; Congar 1965:28-58; Hamer 1964:93; Dulles 1977; Navone 1989:19-44; Starkloff 2000). It also has biblical support (Ac 2:43-47; 4:32-37; Rm 12-13; 1 Cor 1:9; 11-12:4-30).

Lapointe (1986:121) underlines communion as fundamental or foundational to the understanding of the Church, bringing together the notion of family; its biblical features of material and spiritual union; and its Trinitarian implications:

Communion with God and with brethren, is the Church’s most profound value and the end for which it exists.... to present it more concretely, more graphically, more personally: the Church is family, a communion of brothers and sisters in one Father [united to the Son and the Spirit].

This communion is held together by a bond of love, which derives its strength from the Trinitarian intimacy (Navone 1989:26).

Relationship with God and with one another is a defining feature of a church as communion or *koinonia*. This relationship derives from the Trinitarian relationship and it should be seen as a participation in that eternal conversation of the Trinity (Navone 1989:25; Oliver 2006:24). Humans are, as Navone (1989:24) suggests, “communitarian by nature, conceived and born in and through human community. We are interdependent.” Communion or *koinonia* is not absorption but sharing by people who though related are different and distinct (Starkoff 2000:426). In communion, and where participation is a feature, differences are not assimilated but appreciated and celebrated. In such a context, to say that being different is godly, that all are special, and need to be a listening church would make sense.

Again, as Jack (2009), contrary to a view that ancestors and powerful and humans powerless, suggested, “*we share in the same power in our different capacities.*”

Central to and closely related with the notion of communion are the biblical ideas of *kenosis*, incarnation and *metanoia*. These concepts are discussed because of their theological allure towards the metaphor of church as communion or *koinonia*, and because they were alluded to by the research participants.

### **7.2.1.2 Communion and *kenosis***

When Jack said that “*the church has to humble itself and take the form of a servant like Jesus did,*” in making a statement of what the church needs to do in order to respond effectively to the needs of all its members he was alluding to Phillipians 2:5-9. This text uses the self-emptying or *kenosis* in Greek to refer to Christ’s action of total self-giving to the world. I follow through this concept to underline its importance as a relational concept within the context of the discussion on communion. Of particular importance is the weaving together of the academic voice and the meaning some research participants attached to it.

*Kenosis* is a Greek term for self-emptying, and has made its way into Christian use through Phillipians 2:5-9. In her analysis of the term *kenosis*, Tsui Kuo-Yu (2007:359) concludes that:

*Kenosis... is a metaphorical way of expressing the incarnation of Christ which characterizes Christ’s coming into the human world as an act of self-giving love and self-weakening humility. The *kenosis* of Christ signifies a divine renunciation that represents a life of total self-giving love for the sake of others.*

At the heart of *kenosis*, therefore, is Jesus’ example of self-weakening through humility, in the way he was exalted above all creatures. The idea is expanded by Wallace (2002:93), through an exploration of another paradoxical biblical statement in Luke 9:24, “losing the self and finding the self”. Over this self-weakening dimension there is also that of self-giving, in which Christ poured himself out, thus putting himself at the disposal of people in order to enrich them (Tsui Kuo-Yu 2007:360). It is through love that Jesus made communion with God possible. If, as logic demands, members of the body of Christ are so through being conformed to him, then they are called to put themselves at the disposal of others. This is characteristic of members who, as such, are united in a bond of communion. I use Wallace to argue that *kenosis*, in its self-emptying and self-giving aspects, is key to the relational self proposed. Navone’s (1989:39) assertion that “there is no *koinonia* without *kenosis*” thus assumes relevance.

As explained by Lartey (2003:176), *kenosis* refers to being freed from the captivity of selfhood, which does not compromise identity. For Kotzé (2002:12) this would have amounted to a re-ordering of the understanding between self and the other. Acknowledging that people can hurt and that they have hurt is an invitation to forfeit the fixed identity that can only be hurt and cannot hurt. Just as Jesus' *kenosis* opened a plethora of unimagined relational possibilities, so does a *kenotic* acknowledgement of the pain caused to people with disabilities. It opens possibilities for healing of self and others in ways that were not imagined before. This is another way of adopting a listening mode rather than a telling mode, where the former tends to open space for the voice of the other to be heard and the latter tend towards prescriptive knowledge which marginalizes (Kotzé 2002:14).

The church, for many years, has been imprisoned within metaphysical presuppositions to articulate its theology. Its thoughts about God and self were founded on the metaphysical foundations that continue into the present (Wallace 2003:95). While these have served the church in a way, in another way they have, through either/or positions and truth-seeking endeavours, further blocked possibilities for the church to explore the horizons of its potential.

*Kenosis* and losing of self within the postmodern context matches well with possibilities that openness and uncertainty promise. The definition of God as a philosophically perfect, omnipresent, omnipotent and impenetrable being has in some way obstructed discovery of the rich and variegated portraits of God within the biblical heritage (Wallace 2002:97). Within the context of ontotheology since God is perfect and nothing perfect can generate the imperfect, it makes little sense that a perfect God can be associated with an imperfect being. Because people with disabilities have been viewed as natural mishaps, abnormal and imperfect, their existence could not be attributed to God as their creator. It is in this sense that biblical record and Christian theology have often been dangerous for persons with disabilities (Eiesland 1994:74).

Losing the self-assured ontotheological God, who is allergic to disability, would help find the subjugated self that would otherwise be hidden forever. The ontotheological God has been at the basis of a theology that reinforces negative stereotypes against people with disabilities (Eiesland 1994:74). Freeing the church from the captivity of the ontotheological determinations would not only make it discover its real self, if ever such a thing exists, it would also enable it to engage with the real experiences of people with disabilities (Lartey 2003:176), with different possibilities opened to such an interaction. "*As things are now, possibilities for people with disabilities are very marginal*," said Jack (2009). *Kenosis* opens

possibilities for a more authentic participation of people in community, in their different capacities and capabilities, but *kenosis* logically leads into incarnation.

### 7.2.1.3 Communion and incarnation

*Kenosis* is not only closely linked to incarnation, it made it possible. If Jesus had not humbled himself and emptied himself, it would have been difficult if not impossible for him to move amongst the flesh and blood of this world. “*Is incarnation not God’s way of participating and sharing in the human story?*” Jack asked. In describing incarnation as the first moment of God’s communion with humankind, Navone (1989:20) links it up with communion, described by Isherwood (2004:144-148) as a divine totally abandoning herself to flesh; a statement of trust in the flesh to save the world; God leaving the heavens in order to make possible the full reality of life in abundance; the divine walking *with* people (my emphasis).

Incarnation may be regarded as God becoming involved and *participating* in the everyday life of the marketplace (my emphasis). As in a paradox, it is as if God wanted to become more divine by becoming more human and by being human, Christ made it possible for humans to become divine. The freedom that God enjoyed allowed God to embrace the divine through the human, something that may be nonsensical in metaphysical terms. It is for this reason that Isherwood (2004:149) calls it a risk of leaping into flesh in order to make possible for humans to leap into divine incarnation. This is a notion that metaphysics has not been able sufficiently to exhaust.

Perhaps, as in the mould of Isherwood (2004:150), one would propose a removing the metaphysical element from God and Christ. For many years theology and theologising have been essentially linked to Greek philosophy, such that an adage, *philosophia ancillae theologia* (philosophy is the handmaid of theology) had become normative. A non-metaphysical or a differently metaphysical God and Christ shed the assumptive Greek categories that had taken up the *sine qua non* status. A God and Christ not viewed as metaphysical, run little risks of assuming, in ontotheological terms, the so-called ungodly determinations. They are free to achieve redemption for all through alternative means unimagined before. Such means transcend the binaries that have held hostage these unimagined possibilities. Would it be impossible for a non-metaphysical God and Christ to take flesh (identify) in a disabled body? Would it be impossible for a disabled person to be *imago Dei*? (Berinyuu 2004:205). The binaries have buried possibilities for disabled identities and bodies to raise their voices without fear of reprimand or suspicion. Incarnation has

opened possibilities for people to dance within their own skins, abled or disabled (Isherwood 2004:149). It has made it possible for them to embrace their own bodies and the bodies of others in an empowering dance of liberation (Isherwood 2004:148). In that way they can change the world (Isherwood 2004:149).

The incarnation, through *kenosis*, has made it possible for the divine to take flesh in the world and its people, in their variegated bodies. Incarnation has made possible for God to be at home in various cultures, heritages and bodies. It has also allowed people to stand “in awe of the mystery of otherness” (Lartey 2003:176). In that way, the previously marginalised identities have found their voice and are making their desires known (Isherwood 2004:148), but the achievement of such a goal is a process fraught with pain and distress. It is a transformation, a conversion and a change that slowly engages people in a counter-story about God, world, neighbour and self (Brueggemann 1993:25).

#### **7.2.1.4 Communion and *metanoia***

When Reg said, “*the life of the church has been characterised by discrimination for people living with disabilities. In the process the whole body was hurt. There is therefore a need for the conversion and healing of the body,*” he was making reference to conversion as personal transformation that has a trickle-down effect on all levels of the church as a communion. Reg’s words resonate with Navone’s (1989) ideas, in his book *Self-giving and Sharing*, in which he discusses at length the concept of communion and its multi-dimensional nature, in particular its interface with conversion.

Such change of heart, direction, commitment or conversion was encapsulated in the Greek term *Metanoia*, defined by Grant (2009) as transcendence of the mind, or a shift from the old way of thinking to a new way of thinking. *Metanoia* or conversion has traditionally been defined within the psycho-theological framework, from which standpoint it has been seen as involving internal psychological processes of the individual experiencing conversion (Sremac 2010:8). Despite different meanings it has assumed over time, one underlying assumption about conversion is that it involves a radical change in a person’s perspective (Snow & Machalek 1984:169). It is a transformation that “is difficult and painful because the changes required are not only in ways of thinking but also in ways of living” (Romero 1977:64). A call for conversion in that context would, therefore, mean transformation at every level of human life (Navone 1989:37).

Following upon Bernard Lonergan, Navone (1989:36) believes that conversion is foundational for community. In a similar vein, Eiesland (1994:109) calls the church a

communion of conversion that exists as its members struggle to discern the presence of the disabled God in its midst. From the above it is clear that the church is a communion that is called to constant conversion, hence the adage common in traditional reformed circles, *ecclesia semper reformanda est* (Bosch 1991:387), which indicates that the church is both holy and sinful, through its founder and members respectively. As sinful it is in need of conversion and repentance, and it is *en route* to holiness through *metanoia*. The underlying premise is that human authenticity is founded on a covenantal or communitarian base. Every covenant is based on demands, responsibilities and conditions, failure to which is a violation of the covenant and therefore of the communion. Within the Christian context that constitutes sin, which separates and alienates, while conversion re-establishes, heals and brings back together. Conversion emerges to overcome this failure and to restore the relationship to its proper place, but not to an individual in isolation, because human authenticity is relational and interpersonal (Navone 1989:37). Restoration of human authenticity lost through sin ought to take the same interpersonal and relational route.

By commission and omission, the church has perpetrated oppression of people with disabilities. It has silently watched as their rights were trampled upon, and has approved, by its indifference, the laws and policies which objectified and marginalised them further. In so doing, in very subtle ways, they have systematically excluded them from their membership in the body of Christ. In this encounter with the world of the poor embodied in the experiences of people with disabilities is found the most pressing need for conversion (Romero 1977b:69). However, conversion, transformation and healing may be seen as a process, or a journey, and a pilgrim church which is also a communion ought to journey together. There are very few options, if any, for it to journey otherwise.

**a) *Metanoia* as a journey**

The conversion of heart, the *metanoia*, is adopted in this research because of its associations with the notion of a journey which forms an important backdrop of this research (see 1.7 and 1.14). Not only was this research a journey for the researcher, it was also a journey for the research participants, the significant others and the pastors and priests. I now interrogate ways in which disability has had different effects on the people above, depending on their positioning and perspective with regard to disability. I wish to compare dilemmas of stepping out of what is comfortable, familiar, fixed and finalized on one side, to that which is uncertain, dangerous and risky on the other (see 2.3.1). I explore how that conversion connived with the notion of journey to expose the ethic of discomfort (see 1.6) which functions to achieve discomfort (ambiguity, unfamiliarity, uncertainty, risk) through comfort

(sharing of stories). I will in the process of my analysis show how we, the various participants, moved from what was certain, fixed and finalized, and the confusion that obtained as a result of a call to go (primal scream), and how the imperative exposed us to the unspecified future which nevertheless held for us a promise of new possibilities.

## **b) Narratives of conversion**

In this sub-section, I narrate stories of how participants were converted in the process of coming into contact with real and embodied people with disabilities.

### **i) Crisis of certainty, fixity and finalisability**

Rev Frank observes that caring for people with disability has been part of the Anglican Church's experience from the beginning. He endorsed it as a noble effort that befits the church of God and was happy to be part of that project, albeit from a distance. People with disabilities were, in his words, *batho ba sa itekanelang* [unbalanced, ill]: "*It never occurred to me that the experience with disability would stare me in the face in the manner in which it did. What would people say about me and my daughter being married to a deaf and dumb?*" he asked.

### **ii) Categorisation as essentialising identity**

Rev Frank's statement is fraught with meaning. The previously categorised, generalised and disembodied, unbalanced and ill people who had been finalised, fixed as if they were dead, had now become real in the embodied and personalised "*my son-in-law*." This relative was no longer a depersonalised other but a real person to relate *to* and *with*. The '*me*' and '*my daughter*' had stood out in opposition to the undesired 'other' marked by supposedly fixed identity markers of deaf and dumb. It was no possible that such a person could be viewed other than through the eyes of his or her non-essential impairment of deafness and dumbness. This implies certainty, fixity and finalisability, and there is an implied colonisation of the mind that "disability is fine if it is not part of me; if it is not part of my family." There is also a feeling of, "it is not meant for us but for other people". The words of Rev Frank above marked a point of departure in a process known as conversion. Along similar lines, Jack (2009) stated:

*It pains us to be seen only through the eyes of disability. We are bona fide citizens of this country [Lesotho]. We pay taxes like everybody else. We are children of God unless a proof to the contrary is put forth. We, like every body else, have our achievements and our failures.*



*Why should we be seen only through the eyes of visual impairment when others have eyes but cannot see?*

Jack's statement above is an appeal against being associated with a fixed identity that is essentially tied to disability. To single out people with disabilities as a distinctive group identified by its disability when non-disabled people have no special identity marker is an act of finalization (see 2.4.2.1). 'People with disabilities' has become a familiar and comfortable identity marker, but even within DPOs this designation has been regarded as politically correct. By means of this designation, people with disabilities are marked out from others who deserve no special identity marker, except through antithetic inference. They are seen as having no chance or capacity to become someone other than what they are marked out to be, 'people with disabilities' (Frank 2005:967). They are categorised, finalised, finished off as if they were already dead (Bakhtin 1984:58), in what is an act in the exercise of power.

### **iii) Father and daughter, mother and daughter in opposing directions of the journey**

Rev Frank (2009) said:

*The reality of disability came alive when my daughter told me that she was getting married to her boyfriend with a speech and hearing impairment. I was very disturbed. I was saying to myself, why would this child make such a choice when there are so many boys around? What would people say? How would this child live with this man for the rest of her life?*

Ann, Rev Frank's daughter, had embarked on a journey of her choice. She knew, as she said, the resistance she was going to face as a result of her choice, but she was determined to defy the odds. It was, as she put it, "*a journey toward love. Nothing was going to stand between me and that goal.*" Her family, friends and acquaintances were part of this journey. When Maki's mother expressed her wish that her daughter would one day become 'normal' like other children, she was on the opposing part of the journey. As she prayed for the recovery of her child, she was not thinking about what it would mean for her daughter to live under the new conditions of being cured. Both the father and the mother took for granted that because it was normal for them it should be normal for their daughters. They came with their loaded connotations from societal and religious discourses that they were not prepared to sacrifice for the sake of love. Their choices were an invitation to them (parents) to journey with them (daughters). Though they became part of the journey, it was in opposing directions.

In the faces of family and friends were portrayed bewilderment, disappointment and discomfort at the choice she had made. What was supposed to become a new and

rewarding initiative was turning out to be a disturbing and dividing variable. It evoked memories of Israel after leaving Egypt, with Moses assured of the importance of taking that journey and the Israelites being hesitant. Such are the experiences of setting out on a journey with co-travellers pulling in opposite directions.

#### **iv) Colonising influence of dominant disability discourse**

The need to pray for a cure for her daughter to which Maki's mother referred, was a reliving of the dominant religious and societal discourse, which sees people with any form of disability as medical objects and in need of cure. Smith and Winslade (1997) would regard this a colonising influence of disability. As she was praying for the recovery of her daughter, it did not occur to her to find out what it would mean to her daughter to live under new conditions of being cured. The same concern was raised by Reg and confirmed by Jack and Sam (2009):

*People do not ask how I would feel and what would happen to me if I were to recover my sight, my speech and hearing and begin to learn colours and see things and people or communicate in a new language. They probably think that recovery of sight goes with automatic knowledge of things, their shape and their colours and that recovery of speech goes with automatic acquisition of words.*

The point of the above observation is that the so-called able-bodied people take many things for granted. As Gutting (2004:71) argues, disability has always been identified as a creditable challenge to normality imposed by society. To identify with it was not expected, for speaking well about disability does not come naturally, otherwise one had to be content with the constant threat of being judged abnormal by both religion and society. Indeed, this is what Rev Frank's daughter did, catching him off guard. She dislodged him from what he had inhabited as the normal order of things, thus playing out the effects of the dominant disability discourse which forge people as "docile bodies", conscripted into perpetuating unitary knowledge systems and techniques of power (White & Epston 1990:20). Her invitation, in a form of telling them of her decision, was a call to evacuate the colonising influence of a dominant disability discourse. It was an invitation to venture into a new way of life whose prospects were not yet appreciated. It was a call to an unspecified future which loathes finalisability and fixity. Often a call to evacuate any familiar influence, way of life or culture, as White (2004:51) suggests, involves a kind of grief precipitated by real or perceived loss of the certainties out of which we are shaken. This invitation threw Rev Frank into confusion, which connived with uncertainty to plunge him further into a feeling of neither here nor there. I now explore the narratives of that tension and confusion.

**v) Confusion: neither here nor there**

*When my daughter came to me with the news that she was falling in love with a person with disability, I was confused. I thought to myself, what kind of a person would my son-in-law be. What is God asking of me? How would I be able to live with a son-in-law who is deaf and dumb? There was some kind of a feeling that I had not raised my daughter well and that I must assume my parental duty of warning her against the decision to marry her man of choice.*

(Rev Frank 2009)

There was a tension between letting her daughter exercise her right and the parental gaze which viewed itself as more privileged. There was tension resulting from a call to evacuate a familiar, comfortable and fixed territory. Tension, as seen by Lofland and Stark (1965:864), is quite common as a predisposing condition in the life situations of converts.

His dilemma is spelled out in the following questions:

*If I discourage her from marrying a man of her choice and she commits suicide will I be able to live with that as a father and as a priest? What if I let her decide but later on their marriage becomes unsustainable? What about what the church teaches that marriage is a union entered into voluntarily by two mature individuals something I have preached so religiously and with conviction? This was indeed a very hard call for me. The experience of the apostle Paul, of having to evacuate one form of life to embrace a completely different form of life, became so alive. The experience of having to leave the painful but predictable life of Egypt to an uncertain and unpredictable life of journeying through the desert, constituted my dilemma.*

(Rev Frank 2009)

This tension, coupled with his daughter's unyielding attitude, created a disposition to act, and occasioned a turning point in his life. According to Lofland and Stark (1965:870), the turning point is when old lines of action were complete, had failed or been disrupted, or were about to be so, and when they faced the opportunity and possibly the burden of doing something different with their lives. In Rev Frank's case, his old lines of action were disrupted by the firm position of his daughter and obvious consequence of that position. The indeterminacy of the responses to the questions that he asked further contributed to the disruption of the firmly held position. It was indeed a challenge to revisit his convictions.

The witnessing of the entire wedding ceremony (another priest, not Frank, was the main celebrant) was an initiation into the process of conversion. It was in this process that he decided to make an open confession at the end of the mass., during which someone was translating for his son-in-law and some of his colleagues with hearing and speech

impairment who were part of that celebration. He only realized then that he (Rev Frank) had his own limitations. In his words:

*I realized for the first time that I had my own limitations/disabilities. For, if I knew his language he would not be disabled. I did not understand the language of my son-in-law and that I was as a result disabled. Though I had the voice, it was not vocal or effective enough to reach people with hearing impairment. Though I enjoyed hearing, it was not receptive enough to accommodate the voices of people with speech impairment.*

(Rev Frank 2009)

#### **vi) Uncertain Future: new possibilities**

*At the time of making an open confession about the pain I might have caused other people, especially people with disabilities, I had no guarantees that my evacuation of the familiarities I enjoyed would pull off a better future. At that stage the future remained uncertain. I was still not sure what my friends and other people were going to say. I was still not sure whether this marriage would be sustainable. There were possibilities that my friends and other people were not going to be negative. There was a possibility that this marriage would be a model marriage.*

(Rev Frank 2009)

The uncertainty of the future that the choice of his daughter had plunged him into included a plethora of undefined possibilities. What was clear to him was that his daughter's insistence was a visceral announcement that things were not right in terms of relations with people with disabilities (Brueggemann 1978:21). It was a primal scream that permitted the beginning of a journey to conversion. Her insistence brought hurt to public expression, causing a new social and theological reality to emerge. The promises that were about to be given as a result of embracing the difficult yet important step far outweighed that which he possessed and knew, and that was familiar, fixed and finalised. Pertinent in this regard is Brueggemann's (1978:21) observation that people are energized not by that which they already possess but by that which is promised and about to be given, and Rev Frank's reflection: "*Had I insisted I would not have experienced the giftedness of my son-in-law. What he is capable of doing is amazing. It is something that even able-bodied people are not capable of doing.*"

This possibility would have remained hidden to him if he had not allowed himself to let go of fixity, familiarity and their comfort. The discomfort of letting himself lose his privileged status and embrace the uncertain relational self opened possibilities for both Rev Frank and others: "*this was indeed a transforming journey. It was a journey of conversion, not only of acquiring*

*new knowledge, but also of identifying with the new self or selves that I would never have imagined.”*

As it is, these narratives of conversion emphasised the point that *metanoia* and conversion on one side and communion on the other belong together. For Navone (1989:43), conversion is “always a call to communion or community or friendship with God and all others: *metanoia* is for *koinonia* its term,” and is developed by Kallenberg (1995:362), who asserted that conversion is the emergence of a new mode of life occasioned by a self-involving participation in the shared life, language and paradigm of a community. Sremac (2010:15) expressed this idea differently in stating that there is no true conversion apart from community, as conversions are mediated through people, institutions and groups.

In summary, the images of belonging, relationality, participation, listening, being the church *with* as opposed to the church *for*, and being responsive, emerge from this understanding of the church (Pryce 1996:117). These images stem from embracing the model of the church as communion where all, though different, have the right to participate. Such a church thrives on *kenosis* in its self-weakening and self-giving dimensions. Taking a cue from its Lord and master, who took flesh in order to participate in the experiences of the world, the church should immerse itself in the experiences of all its members, and so be able to transform itself as it seeks to transform the world. Because the church is made up of individuals who are prone to sin, it is in need of constant conversion, liberation and transformation. As in a journey, conversion, liberation and transformation are not an event but a process that can only be negotiated in time and space. However, it is only when it is immersed (incarnated) in the life experiences of people, especially with disabilities that such a church can speak with a voice of conviction and authority.

In the next section, I follow through the theologies that emerged from people with disabilities themselves. They further thicken the story of a *koinonic* and participatory church characterised by *metanoia*, *kenosis* and immersion in the experiences of people with disabilities.

### **7.2.2 Embracing local theologies of a *koinonic* church**

The deconstruction of the binaries between the able and the disabled, as a discursive production, has laid bare the artificiality of the separation and exposed the discursive space between the two binaries that has hitherto been inadequately explored. That space has revealed that disability is not inability, and disability itself is not the problem but can be an opportunity. Disability is a reference to limitations which are a common feature of being

human. According to Thorne (1997:29), all belong to the same human race, to the same creation of God and created in God's image. Thorne also believes that they are all members of the body of Christ and should have equal share and participation in the life of the church, each according to his/her call and unique gifts. Nobody is fully independent nor entirely dependent on others, but are better seen as interdependent.

The following theologies to be discussed emerge from the model of church as *koinonia*, not imported but stemming from the liberated voices of people with disabilities. They represent the local voices that are part of a church that is truly incarnate in the experiences of its members. Within such localised theologies, God and Christ are removed from the metaphysical realm, and provide opportunities for the mediation of salvation through various means.

### **7.2.2.1 Theology of 'Botho' (Ubuntu)**

In conversation, Jack said, "*We all need to display 'botho' in order to live peacefully and harmoniously with everybody for as we say motho ke motho ka batho,*" evoking what has come to be known as authentic Africanness embodied in a much celebrated notion of '*botho*' or '*ubuntu*.' 'Botho' is a Sesotho word that captures the essence of what it means to be human (Murithi 2009:226). The concept is found in many forms in a number of societies throughout Africa, in almost all of which it represents personhood or humaneness (LenkaBula 2008:378).

*Botho* touches on all aspects of life since in an African Worldview everything is interconnected, without compartments. The personal, political, economic, psychological, religious and relational are all intertwined, while personhood is defined relationally (Mkhize 2004:4-24). Though the adage of *motho ke motho ka batho* is often cited in the discussions around African notions of personhood, Mkhize (2004:5-24) believes that its dialogical implications have not been fully appreciated, and selfhood within the context of Africa emerges dialogically, through *participation* in a community of other human beings (my emphasis).

As seen by Tutu (2008), *botho* is a way of being in the world and finds its truest expression where people live in harmony and peace. It recognises that no person can exist in isolation and that, as interdependent beings, people exist in a complex network of relationships. In a *botho* worldview, solidarity is key (LenkaBula 2008:381), so an injury to one member is bound to affect the entire web of relationships, whether divine, human or ecological. This notion matches the Christian idea of *koinonia*, especially as articulated in Acts (2:4-14) and

in 1 Corinthians 12. In both contexts the bonding attributes are compassion, tolerance, care, understanding, mutual responsibility and concern for other's welfare. *Botho*' therefore, calls for liberating and life-giving, and respectful relationships among humans (LenkaBula 2008:388). It also awakens the self-giving dimension of *kenosis*.

Christ's pouring himself out is paradigmatic of how Christians should behave towards each other (Ac 2-4). In the African worldview, citizens did not say anything was his or hers as all was common property, stemming from a sense of mutual belonging. The starving of one member was tantamount to starving of self and consequently the starving of the group, and similarly with discrimination. As *kenosis* is part of *koinonia*, so is self-giving part of *botho*, expressed in acts of responsibility to others (Mkhize 2004:4-24). Because the self cannot exist apart from the group or other relational webs of life (Mbiti 1969:214), and individual members are weak and vulnerable, there is a constant need for reconciliation and mending of strained relations. Consequently, there cannot be *koinonia* or *botho* without *metanoia*.

*Metanoia*, read in the light of *botho* consists in the undoing of and turning away from attitudes that seek to relate to other humans in ways that are exploitative and dehumanising (LenkaBula 2008:387). Within the context of *botho* and *koinonia*, dehumanisation of the other, though real, is untenable. As Tutu (1999:35) observes in the process of dehumanising another, the perpetrators are inexorably being dehumanised as well. *Botho* is a local representation of *koinonia*, underpinning the need for people to engage in what Ogbonnaya (1994:77) calls a "dance of harmony" (see Chapter 4, Section 3.1.1). *Botho* and *koinonia*, with participation as their defining feature, should be allowed to shape attitudes toward disability and people with disabilities.

### **7.2.2.2 Theology of healing: but what healing?**

*I have been confronted more than once by ministers who wanted to pray for my healing....Though in sesotho there is only one word for healing and cure, what became very clear to me was that they were making reference to cure which is intertwined with repentance.*

(Jack 2009)

Healing is a multifarious concept with different meanings for different people and groups (Van Rheenen 1998:21). Despite its evolving connotations, its focus, across cultures and religions, has mostly been on the restoration of health that has been deprecated by sickness (Maloo 1991:21), and it is in this sense that it has been viewed as inseparable from the concepts of health and sickness. However, the religious, cultural and relational basis of health and sickness renders healing a very complex and shifting category. Today it is

possible to talk about structures, institutions and cultures as 'sick', and therefore in need of healing. The question, "But what healing?" becomes pertinent in this regard, especially in the light of an oft sought distinction between 'healing' and 'cure.'

Some have suggested that people with disabilities need to be prayed for in order for them to be healed (cured) and eventually restored to the community. Different sectors of society have talked about rehabilitation of people with disabilities. Rehabilitation can hardly be divorced from its medical origins, carrying that nuance of medical curing or physical readjustment (Stiker 1999:174). One cannot therefore talk about healing and disability without asking questions such as: What does healing mean within the context of disability? Who should be healed? What are they healed from? Who heals?

This research, taking a cue from research participants, discounts healing that is defined in terms of physical restoration and cure. Such an understanding would have to be founded on an assumption that disability represents brokenness, and therefore in need of restoration. Research participants neither see disability as inability nor as brokenness, but rather as a construct created by society that fails to create a favourable environment for all to be equally empowered or to compete equally on the job market. It is for this reason that they repeated that it is society that needs rehabilitation and not them (6.4.1.4). The healing of people with disabilities is intricately intertwined with political and social healing, because, as feminists and other theorists would argue, the personal is the political. The whole of society, people, structures and institutions are in need of healing. Healing is therefore needed on every level of people's lives (Ackermann 1998:81).

#### **a) Healing the relational body through healing institutions**

This analysis of disability discourses within public modern institutional structures (Chapter 5) has revealed that they are still steeped in ambiguous relations with people with disabilities. They have become, in Foucault's (1988:19) view, technologies of government that create subjects and citizens through particular forms of discipline. Through policymaking processes, administrative arrangements, forms of management and educational policies and systems, they guide, shape and control ways in which people with disabilities behave (Jolly 2003:511).

I feel that as part of society I have connived with others to marginalise people with disabilities, through omission and commission. I have inhabited knowledge claims and taken-for-granted knowledge claims about disability and people with disabilities. I feel I could have acted better to forestall the plight of Angel, who was in my class in the year before she called it quits (see 6.3.2). Upon learning that she had left because of the intransigence of the



National University of Lesotho community, I felt guilty because I was closer to her situation than many. Though my conversation with her made me more aware, I still feel the process of healing has to take its course. Reg observed that our conversation in the course of this research journey had given him hope that they were not alone in this struggle and that this in itself put him in the process of healing.

The church as well, with the Bible in its hands and a legacy of Christian dualistic history in its favour, continue to manage disability and people with disabilities as objects for charitable works and candidates for both physical and spiritual healing. I am part of that church. The binary opposition that demarcates the disabled (them) and the non-disabled (us) continue to plunge us back into the deep waters of Christian dualistic history founded on the notions of purity and impurity (Newell 2007:326). The church continues, as a result, to be “the company of the pure or relatively pure” (Countryman 1989:38). In the process, people with disabilities have been objectified, alienated, silenced, broken and hurt. From this there is a need for healing for all on both sides of the disability divide. Because the hurt was relational (an unhealthy relationship), the healing has to be equally relational. In other words, the healing of people with disabilities cannot be achieved apart from the healing of people and institutions that continue to hurt them. The question then arises as to how institutions and people are healed or liberated from this legacy of disablism.

**b) Practical theology of healing**

Ackermann (1993, 1998), in her version of a ‘feminist theology of praxis’ departed from a generalised practical theology because of its alleged inherent male orientation and marginalisation of female voices and experiences. She embraced a brand of practical theology that placed the hermeneutic of healing at its centre (1998:78, 80), and proposed a theology that was critical of a status quo theology that was white, male, middle class and abled-bodied. She (1993:84) identified acknowledgement of the quality of suffering as a necessary step in the realisation of this healing process. This step speaks to the experiences of pain, alienation, silence and brokenness perpetrated against some members of the body of Christ and in the process hurting the very body of Christ. The metaphor of the body of Christ, as proposed by 2 Corinthians 12, has no place for a member who is not in one way or the other affected by the pain or the comfort of the other members. Because the personal and the political cannot be separated, healing that is aimed at the personal has to go via the political and vice-versa.

The plight of people with disabilities has an affect not only on their person and their body but also on their political relationality. Their stories are stories filled with pain, alienation, brokenness and a cry for release, while their healing as victims cannot be fully achieved without healing of the perpetrators and witnesses. Our healing as persons cannot be achieved without healing of models, theories, institutions and discourses that mould and construct us (Ackermann 1993:79). However, discourses do not construct themselves but are brought about and maintained by people. In the case of the church, Larney (2003:176) proposes that *kenosis* is indispensable for proper relational healing. I argue that *kenosis* is not pertinent for the church only, but is necessary for any serious relational healing to take place.

The other theology that resonates with what research participants raised is the theology of embrace.

### **7.2.2.3 Theology of embrace: embracing each other**

Reg, Jack and Tsili expressed a common sentiment regarding making the world more humane: *Re lokela ho ts'oaranang ka matsoho*, translated as “We need to hold each other in arms”, although in sesotho it is more than this, but carries the nuance of equality, accepting each other with one’s strength or contribution. I have found the metaphor of embrace or what Volf (2004, 2002, 1996, 1995, 1992) calls a “catholic personality”, more akin to what *ts'oaranang ka matsoho* stands for. Such an embrace comes out glaringly within the context of the *botho* worldview and *koinonia*.

Though the metaphor of embrace has been explored by a number of scholars from a wide range of disciplines, it was Volf (1996) who offered a rounded off theological exploration of the metaphor, exploiting this metaphor to confront the reality of exclusion which has reigned unfettered throughout the history of the church. The object of exclusion at best and hatred at worst has been the “Other” and the “different”, which incidentally became part of Volf’s experience in Croatia. His metaphor of embrace revolved around four structural elements, namely, opening arms, waiting for response, closing arms and opening arms again. They are adopted here with some ideas from de Saint Exupéry’s *The Little Prince* 1943, hence starting with closing of arms:

**1) Closing of arms** according to de Saint Exupéry (1943:58), would be the best place from which to begin. The embrace of Volf would resemble the taming of de Saint Exupéry, and to tame is to establish ties. To establish ties derives from the need for each other, but is not automatic. It takes patience, sitting down a little distance and looking at one from the corner

of the eye, saying nothing. This would be the guarded closing of arms and the patient looking at each other. They would invite the meeting of hearts and an unassuming trust that is necessary for embrace to take place. It is an embrace that expresses itself through caring *with* as opposed to caring *for*.

**2) Opening the arms** is a bodily gesture of reaching out to another. It underlines the inadequacy of the self and its need for the 'other' for its relational survival. It further signals a creation of a space in oneself for the other (Volf 1996:141). The gesture says that "others are seen as potentially enriching friends" (Volf 2002:16). Within the context of the ethic of friendship (see Chapter 1 section 1.6) comfort becomes a prerequisite for discomfort. Opened arms represent the comfort which however creates space for ambiguity and transformation (Wolgemuth & Donohue 2006:1033). That ambiguity conspires with the *kenotic* self-weakening to open possibilities for the discovery of the silenced and marginalised other. This is an insinuation of self-emptying (see 7.4.1.1 above). While self-emptying may sound good enough it has however been a source of pain for people who became too trusting and went into the caring *for* which masqueraded as caring *with*.

**3) Waiting for response** points to the reciprocal nature of the movement of embrace. The waiting arms are actions of allowing the "other" to have the power to respond or not to respond to the invitation (Jacobs 2004:258). It is a reminder that there is no coercion involved in embrace, and reciprocity is at the core of this movement. It loathes manipulation, violence and coercion, and as Volf (1996:142) argues, the power of the waiting self is the power of the self, which does not break the boundaries and force itself into the other but rather operates through respect, gentleness and hope to achieve that reciprocity.

**4) Closing arms** marks the end for which the opening of arms was carried out. It is realised in the active holding of the other and the passivity of being held by the other (Volf 1996:143). It points to the occupation of the space created by both parties on both sides of the embrace continuum. Elsewhere Volf (1995:203) describes it as:

Closed arms are a sign that I want the other to become a part of me while I at the same time maintain my own identity. By becoming part of me, the other enriches me. In a mutual embrace, none remains the same because each enriches the other, yet both remain true to their genuine selves.

For the closing of arms to be accomplished without the other being crushed or annihilated requires gentleness and respect, both of which appreciate the other's need to maintain that otherness and difference, because it leads to possibilities of transformation for both parties

to grow in ways that would not have been imagined before. This is what Volf (1995:199) calls a “catholic personality”, and points to susceptibility to enrichment by otherness and difference. It is a personality that becomes what it is because “multiple others have been reflected in it in a particular way.” This is the holding each other in arms (*re ts'oaraneng ka matsoho*) implied by Reg.

**5) Opening arms again** is an invitation for the other to return, a gesture that acknowledges that embrace was not total identification with the other but a relationship which allows for both becoming part of another while at the same time maintaining their own otherness. Opening arms is letting the other go so that boundary-making does not preclude the embrace of yet others (Volf 1996:145).

Within the context of disability, the metaphor of embrace underlines the importance of regard for oneself which is linked to the other's. Though dehumanization of people with disabilities has fed on their ‘otherness’ (Weingarten 2003:160), without that otherness there is no reason to reach out or to love. According to Levinas (1984:166), love consists of the acceptance of the difference of the other. According to the Bible, this is the love of Christ to humanity who, despite his innocence, loved the unrepentant humanity with the love that surpasses all knowledge (Lk 15:11-32; Eph 3:19). Through his death and resurrection God became accessible, healed believers, developed relationships and made inclusiveness as hospitality possible (Stookey 2003:95-100). Through his cross, he made it possible to go beyond the exclusion vs. inclusion binary to a deeper reflection on interdependence (Newell 2007:326).

#### **7.2.2.4 Theology of interdependence: when we need each other**

As I conversed with research participants, it became clear that there was a shift of paradigms from being dependent *on* others, to independent *from* them and to being interdependent *with* them. The following conversation with Jack (2009) reflects this shift:

*Paul: Could we then say, as people with disabilities, that we are dependent on others for our survival?*

*Jack: That assertion suggests a one way street, that is, we (people with disabilities) depend on others and not vice versa.*

*Paul: Could we then say we are independent from them?*

*Jack: That would be another extreme... Eh... I think it is becoming clear that we need each other and so we better call ourselves interdependent.*

*Paul: So you mean non-disabled people depend on you in some instances!*

*Jack: Absolutely. Yes they do. When there is no light in the house my wife and my children, for example, rely on me to navigate the room. You also see that the whole University staff relies on Reg's memory to connect them to people they want to talk to through phone without having to make them wait as he flips through the telephone directly. Can you imagine how much time, perhaps money as well, are saved in not having to flip through the telephone directory with every call that goes out? Clearly you need us in some instances and we need you sometimes to navigate these ungodly surrounding with steps and holes all over. So I think we do not entirely depend on you and you do not entirely depend on us. It is not correct to say you are entirely independent from us. And to want to live independently from each other would be a travesty of our sociability as humans. But we should not forget that we also depend on God.*

Interdependency derives from people's nature as social beings and from the nature of the church as a communion. This is even more pronounced in the African worldview, where the self is inconceivable outside the community, as what Kwon (2001:43) views as interdependence through a matrix of relational self (communion). An Interim Statement by the World Council of Churches, *A Church of All and for All* (2003) defined the church as a place and process of communion... a place of hospitality and welcome. It is essentially viewed as a true community of people founded and nurtured by God, who though different complement each other in their gifts and talents (Church of All # 85). One can therefore talk about theology of interdependence, with people not interdependent simply because some have disabilities. People are interdependent because they are by nature inadequate and insufficient. They are, as the Interim Statement asserted, incomplete without talents and gifts of other people (# 87).

Including, welcoming and accepting people with disabilities in the church therefore, is not only demanded by human nature, it is also *conditio sine qua non* for the church's existence. If a church is by definition a communion then mutual dependence, and therefore interdependence, is its defining feature. The notion of dependence that is presumed in the medical model of disability is transcended and rendered untenable by the interdependent nature of the communion-bound church. On the other hand, the model of independent living

that has been publicised by certain schools of thoughts within disability studies (Ntlatlapa 2007) would run counter to the ideas of a theology of interdependence. Within the context of the theology of interdependence the sustainability of 'independence' as a disability paradigm would be dubious.

Commitment to the nature of the church as communion and to its feature as interdependent demands an acknowledgement of its members' complicity in the sins committed against people with disabilities. That would be the beginning of the journey towards *metanoia* (conversion). The *metanoia* (change of heart) must be concretised in the seeking of forgiveness from those victimised by the members' injustices and intransigencies (Phelps 2000:695). The reconciliation that results from seeking out forgiveness would open avenues for more acceptance of one another, relationality and communion, which are the deepest human desires.

#### **7.2.2.5 *Theologia viatorum***

The interim statement, *Church of All for All* asserts that every theology is provisional, contingent and interim (2003:#56). Every theology is a theology of the road or theology of a journey. It is not a static theology that is waiting to be discovered but one that is in constant search of ways and means of relating to God and one another. This links up well with a traditional model of the church as a pilgrim church.

A traditional theology founded on the ontotheological presuppositions has defined people with disabilities and has identified their position within the divine order. Within such a theology, God has pronounced a sentence on people with disabilities and will not renege on it. A God of traditional ontotheology is one who cannot be wrestled with and struggled against, for such a God is an apathetic unmoved mover (Wallace 2002:97). The God of a *theologia viatorum* is God who undertook a *kenosis* in order to be immersed in the experiences of the world (incarnation). Just as Jesus' self-emptying opened a wide array of salvific possibilities, so has an enfleshed God made it possible for members to plead, dance, fear, hope, rejoice and cry before God without fear of being impugned (Isherwood 2004:144). As Jack said, "*This is God who is appealing and welcoming to me, a God who is both able-bodied and disabled at the same time. A God in whose image we are – able-bodied and disabled – all created.*" In relation to disability and within the context of a *theologia viatorum*:

theology is challenged to talk about God, faith and life in a way open to a God's future; that can surprise us all, and unite and transcend every human existence. A theological understanding of disability has to interpret this issue in the context of the *unfinished* history of God's salvation.

(Church of All for All 2003: #56).

Despite the positions adopted regarding God and disabilities, God chooses the vulnerable means to subvert certainty. God is present not only in what in believers' eyes is order, but also in what in their eyes is disorder, weakness and vulnerability. By this token it is logical that they would expect this, with God having chosen the *kenosis* and *enfleshment* methods to save humans. Any journey is uncertain, transitory, open-ended and precarious. In a journey of life, disability cannot be discounted for this reason or the other. It is for this reason that non-disabled people have been called the temporary abled, and because non-disability today does not guarantee non-disability tomorrow.

It was this journey that made it possible for Rev Frank to discover the previously impossible, and for Reg and his colleagues at the Cathedral of Our Lady of Victories to have, like everybody else, an occasion to read in church. This journey which made it possible for me to shed the fear and shame that engulfed me and prevented me from interacting more freely with people with disabilities, opening to me the treasures of God, the church and theology that would not otherwise have been possible for me to discover. I had resolved that God, the church and theology were sufficiently known to me through philosophical categories. It was this journey that made it possible for me to discover that God, the church and theology are not out there to be grasped but that they are continuously discovered in and through people's daily and contextual interaction with one another.

The above theologies have been followed through because they represent the voices of people with disabilities. They represent voices of faith from below, from the underside of history. They are indeed consistent with the foundational model of the church as *koinonia* and they chart the way for the pastoral care that should characterise the life of its members. Because the church is a *koinonia*, participation is its important feature, hence pastoral care as participation and not prescription (Kotzé 2002:13-20).

### **7.3 CO-CONSTRUCTION OF A PREFERRED STORY**

This section corresponds to step four of the chapter outline, and is a logical development from the preceding section. Here the deconstructive process envisaged by this research reaches its conclusion, having begun with identification of binaries that feed the dominant

disability story. The discovery of unique outcomes within the context of a narrative metaphor logically leads into the re-authoring of an alternative disability story, which is not only a matter for this part of the chapter but for the entire research.

### **7.3.1 In caring solidarity: pastoral care as participation**

The model of the church as *koinonia* logically leads into a theology of interdependence where participation and sharing while maintaining the difference abound. Within such a model, solidarity and caring *with* one another is a necessary sequel, and the portrait of the church as seen by Paul expands on this notion. The image of the church as expounded in 1 Cor 12:12-26; Rm 12:4-10 exploits the features of unity and diversity, with all the different members called as such because they belong to the body. Once they cease to be part of it they relinquish their right for be called members. The term 'membership' has a connotation of belonging, and is a relational term, implying that one does not become a member in isolation but rather in relation to other members.

There is, however, an equally important component that expands the metaphor, namely differentness or diversity. Each member is different and the importance consists in its being different. Any attempt at absorbing that diversity or difference of members runs the risk of killing the body itself and its beauty. Each member, in its unity, brings different contributions to the whole which no other member is capable of bringing (Church of All for All 2003:# 29;#85-86). This is what one would call 'participation', which culminates in what had, in the emerging church of the Acts of the Apostles (Ac 2:44-47; 4:32-35), become a *modus vivendi*. They engaged in what one might call participatory care giving, with solidarity (compassion) their defining feature (1 Cor 12:26). It is for this reason that the model of pastoral care as gleaned from vignettes of research participants' stories is titled "In caring solidarity: Pastoral care as participation."

There is an emerging conviction that pastoral care is an art of community (Billman 1996:10). Lambourne (1974:37), writing from the perspective of the Reformed tradition, coins the term "we-responsibility", to take the idea of *koinonia and botho* to another level. In his view, pastoral care belongs to the realm of the church and it is achievable through and by means of fellowshiping. While this issue is important it should not lead to an erroneous glorifying of the community at the expense of an individual. There is therefore a need for a pastoral care model of disability that is liberative, ethical and relational, and accountable.



### 7.3.2 Liberative pastoral care

Being prone to constant entanglement in sin and idiocy, points to a need for constant *metanoia* and liberation. Kotzé (2002:198) argues that struggle is part of human existence, and that focus should go beyond particular entities to include socio-political contexts that shape such entities. Disability is one such entity, not separate from the contexts that shape it. One cannot talk about disability and forget to mention the politics of disability and pastoral care. It is often overlooked that pastoral care can become captive to ideologies, structures and theologies, thus limiting its horizons (Campbell 1979:159).

Pastoral care has for some time been captive to Western categories, seen primarily as a clerical activity directed towards the individual and less within the corporate and socio-political dimensions. It has also aligned itself with Western principles that govern academic disciplines, and it is against this narrow perspective that Pattison (1993:12-13) levels his critique of pastoral care. Pastoral care should not only be socio-politically aware but also committed to justice and liberation for the voiceless, marginalised and oppressed (Pattison 1994:9).

The church in Lesotho has a long legacy of caring *for* people with disabilities. for which missionaries, priests and pastors take credit. Disability and people with disabilities are only occasions for non-disabled clergy to sanctify themselves, and this mentality has not been erased. Though there has been a paradigm shift in terms of the church's understanding of itself as a communion, it is still immersed in the past in terms of praxis, and thus in need of constant liberation and reformation (*reformanda*).

What was said about the church's need to undergo *kenosis* can also be said about pastoral care, which has been described by Clinebell (1966:14) as an instrument through which the church stays relevant to human need and relationships. As the operational hand of the church, pastoral care, taking a cue from the church itself, should also undergo a *kenotic* process. It has to free itself from imprisonment within its own Western essentialist selfhood, individual and a-political stance, and engage the world in loving service (Lartey 2003:175-176). This will facilitate the liberation of pastoral care and its immersion in the daily struggles of the people it serves. Only when it is liberated can it in turn liberate.

A liberated pastoral care is apt to address itself to economic, political, cultural and human environments, most of which have colonised people into what Mbembe (2001:14) calls a "never-ending process of brutalization" against others and oneself. Such a liberated and liberating pastoral care can then cease to be an activity *for* and develop into an activity *with*.

In the disability discourse all are capable of taking positions of polarization. Disabled and non-disabled can be perpetrators and can also be victims or witnesses in the face of brutalization (Mbembe 2001). This makes it necessary to be constantly predisposed toward conversion, liberation and mutual transformation with respect to disability. This transformation and liberation is made possible by what Heshusius (1994:17) calls a 'self-other relationship', which forms the basis of caring *with*.

### **7.3.3 Relational and ethical pastoral care**

Within this paradigm of caring *with*, emphasis shifts from care as a special preserve of caregivers to care as a practice which results from the interaction of both caregivers and care-receivers. This is what Sevenhuijsen (1998:147) calls a 'caring solidarity.' Because care is communal, it is interpersonal and can only be negotiated between all participants.

A model of pastoral care in the context of disability as envisaged by research participants cannot only be brought at random to people with disabilities for consumption. This resonates with a powerful expression among disability activists, "Nothing about us without us." Jack, Tsili and Reg argue that any programme that is meant for us without our involvement is bound to fail. Unfortunately, some traditional models of pastoral care have aligned themselves with old ways of interpreting disability, which is where disability is seen as a case for charity, repentance, healing and normalisation. In such a situation, pastoral care and counselling serves to address presumed disability as a punishment for sin (Church of All for All 2003:#16). This is where people with disabilities are viewed as service receivers and others as service providers. People with disabilities cannot give, but can only be given; they cannot do, only be done for. This way of doing pastoral care evokes prescriptive ethical practices (Kotzé 2002:13), where only a certain section of society has access to divine treasures and dominant truths, while others can only depend on them.

The evacuation of such a paradigm is not only a justice and ethical issue it is also a theological one. It subverts the notion of sharing and participation so central to both church as communion and participatory ethical practices. The ethical pastoral care adopted in this research is situated within the paradigm of church as communion, where participation of all and sharing by all within the remit of each one's talents, are central. This is what Kotzé (2002:17) calls 'participatory ethics', which requires ethical consciousness situated in the participation of all, especially those who are usually marginalised and silenced. "*Because we belong one to the other, we have to care for one another,*" said Reg. This belonging and connectedness which resonates well with the metaphor of the church as body, is a constant

reminder of what Heshusius (1996:131) calls, “the larger participatory consciousness of the ‘hermeneutics of connection’, where the self and the other are seen, not as separate entities, but as an ontological and epistemological unity.”

### **7.3.4 Accountable pastoral care**

*“We are all human I guess. Over and above we are Christians and members of the body of Christ,”* said Reg., and what logically follows from this assertion is that members are members one to the other. The whole body owes it to each member to live, and each member owes it to the other members to be itself. On the basis of this analogy, each member of the body is accountable to each other and the whole body depends on the responsible response of each member to survive. De Saint Exupéry (1943:58) argued that taming is not the end, but members should assume responsibility for what they have tamed. Taming is about establishing ties, which when established render the need for each other necessary. Because I now know the other, accountability becomes meaningful.

Jack recalls the question that God asked Cain, “where is your brother Abel?” (Gn 4:9). That question is rhetorical and implies that Cain was supposed to know where Abel was. It was an accountability question, as Cain was accountable to Abel and vice versa, because they belonged to each other. In a similar vein, believers belong not only to the same human family but also to the same Christian family. As Ackermann (1998:91) wrote, relationships are by nature reciprocal and they are, therefore, accountable. Elsewhere she wrote: “We are bound in relationships that claim responses that make us accountable and, in our very accountability, bonds of relationship are forged, strengthened and expanded” (1996:45).

Though believes are members of the same body of Christ, and brought together in a bond of communion; though they cannot be members except in relation to others; though they can neither be fully independent nor fully dependent; their relations have been defined in terms of members of the body of Christ, some of which were more abled than others; better than others; more holy than others, and more whole than others. That has indeed blinded them to the belief that they are all God’s creation and have all been created in the image of God, and that they are interdependent, whether black or white, able or disabled, male or female, short or tall. Accountability can only make them whole and healed. Ackermann (1998:91) articulates the point thus:

The healing we require is one which combines both rigorous accountability to our different communities and histories with a reaching out across differences to 'the other', seeking collaboration in the cause of healing, and being prepared to be vulnerable yet actively contributing and concerned citizens.

This also applies to abled or non-disabled persons.

#### **7.4 CONCLUSION**

At the beginning of the chapter I set out to thicken the unique outcomes gleaned from conversations with research participants, as part of a deconstructive process that would eventually lead into a creation of an alternative disability story. What emerged was that disability is a fluid and unstable category. It is subject to historical, cultural, societal and individual determinations. Almost all these determinations are skewed in favour of societal values and norms that regulate disability as a monstrous, sub-human, sinful product of ancestral wrath, deserving of rehabilitation at best and obliteration at worst. The definitions, models and policies that societies construct about people with disabilities serve the interests of institutions who constitute them as objects of power relations over which they have little control (5.1).

The participatory approach adopted in this research journey has made possible the "coming into voice" of people with disabilities. Their lived experience as a result has been privileged. In the process, the taken-for-granted knowledge claims which have assumed truth status through performative repetitions, have been subverted. Thin descriptions that have always accompanied people with disabilities are giving way to more life-giving stories. The model of a church as communion, with participation as its overriding feature, has emerged as a local voice. It linked well with both biblical images of the church as the body of Christ with different members, with each member playing his or her role in the edification of the body. It also connects well with the traditional African notion of *ubuntu*, with belonging, solidarity, mutual responsibility and participation as its defining features. Within such a church, the common categories of dependence and independence give way to interdependence.

However, in conclusion, the church understood as communion is constantly called to a *kenotic* acknowledgement of pain, which is a common feature of a community made of humans who are prone to sin. They are therefore called to constant communion through *metanoia*. Such communion has to be truly incarnate in the life experiences of everybody, especially those previously marginalised. In this case, these are people with disabilities. The theology and consequently the pastoral care that emerge from the metaphor of church as

communion are foregrounded in participation, interdependence, liberation of all, accountability and transformation that unfold as in a journey.

## CHAPTER 8

### A REFLECTION ON THE RESEARCH JOURNEY

The examined life is a good thing  
Not always an immediately happy thing but  
an unavoidably important thing  
(Frank 2005:968)

#### 8.1 INTRODUCTION

This research journey has not been my journey alone, but is better called my journey within our journey. It is a journey which carries within it different voices, or as Frank (2005:968) puts it, these different voices “came together in some shared time and space and have diverse effects *on each other*.” In this final chapter, these different voices reflect on their participation in this research journey. First, I reflect on the research process, especially on how it has impacted on my way of doing things as a researcher and pastoral therapist. Secondly, participants in this research journey are allowed to share their experiences of how their lives were impacted by this process. Thirdly, contributions that this research journey has made to the field of practical theology and pastoral care are discussed. Lastly, I make suggestions on the possibilities that this research journey has opened up for future exploration and action.

#### 8.2 MY REFLECTION ON THE RESEARCH PROCESS

In this section I engage in dialogue with myself, and listen to that dialogue as I question the undercurrents and musings of that voice. My social location and ways in which it contributed to the tension felt as I evacuated the familiar territory to inhabit the new one which was as yet not very clear, will be interrogated. When I started this journey, I had specific aims and objectives in mind, though they were shared with research participants. I will look back to inquire whether what I set out to achieve has indeed been achieved. The twists and turns of a journey, in terms of decisions made and reviewed, will also be reflected upon.

##### 8.2.1 Reflections on my reflexivity

I came into this research as a product of the histories, perceptions and prior knowledge systems which played a part in forming me as I now am. My conduct, interpretations and representations became lenses through which I read the research stories (Etherington 2007:601). Making transparent those values that would eventually influence the research

process and its outcomes constitutes reflexivity (see 2.5.2.2 c), defined by Etherington (2007:601) as:

... a skill that we develop as therapists and researchers. It enables us to notice our responses to the world around us, to stories, and to other people and events, and to use that knowledge to inform and direct our actions, communications, and understandings.

Reflexivity required of me ethical sensitivity to the beliefs, cultural contexts, and positioning within power relations, in society and in research relationships. I had to be constantly on my guard not to privilege my voice over those of the research participants. As Etherington (2005:306) suggests, the 'expert' discourse tends to silence the voices of people whose ways of knowing are different from one's own. Even that could not be achieved without much effort.

I came into this research with preconceived ideas of what research should be. I thought that even where I had to interview people it was my responsibility to interpret the story and very selectively leave out information which in my opinion did not harmonise with what I wanted to achieve. I had to keep reminding myself whose knowledge systems these were (Kotzé 2002:8), for whose purpose they were constructed and who stood to benefit from them. But the temptation to impose my own ideas did not readily go away.

My own social location was also problematic in its relationship to that of the participants. I was a university lecturer and one of the participants one of my students, whose assignments and scripts I had to mark. I thought this constituted a power imbalance that would undermine the need to relate on equal terms with them as subjects in this research journey. The other participant was female, while I was male, within a society where power valences between the two sexes were skewed in favour of males. In addition I was a member of the board of the institution where she belonged. One happened to be a student at a deaf school where I once acted as a principal in the early 90s, though she was now married. The other one had consulted me on one or two occasions because he was doing his research toward an MA in Disability Studies, though it was after I had asked him to be part of this journey. As I talked with research participants I was conscious of the discomfort that my position in relation to theirs brought about. I was conscious of the differences between myself and them and they seemed noteworthy. I was not in the class or category of the disabled whereas they were.

When I inquired as to what it meant to them that I would be conducting this research with them, they assured me that they would freely participate without any qualms. Despite Jack's (2009) reassurance: "*your power does not take away my power and never will,*" I could not

shirk the potential power and boundary issues inherent in some of the relationships (Etherington 2007:603). Even as I remained a lecturer and a member of the board and somebody who could be consulted, this did not mean that I was the expert and the research participants ignorant. I needed to remember that expert local knowledge was equally valid (Etherington 2005:306). The research participants were the experts of their own bodies and experiences. No matter how much research I may have done on disability issues, their experiences were unique and only they understood them better. In the area of individual disability experiences mine was not an authentic voice (Grobbelaar 2006:299).

The adoption of what Grobbelaar (2006:299) calls wisdom of ignorance allowed me to be curious and to recognise that the encounter of my own understanding of disability and theirs created a new meaning and understanding (Etherington 2005:306). My earlier assumptions regarding disability issues and people with disabilities were challenged when Reg (2009) said to me, "*though other people tend to pity me I do not pity myself.*" Their experiences with different public and private institutions were a revelation I could not have undergone had I not participated *with* people with disabilities in the manner in which I did. I could not have realised that even though I was categorised among the non-disabled, I had my own limitations which the so-called people with disabilities did not have. This was because, as Frank (1995:23) wrote, "I was not thinking about them and their stories, I was thinking *with* them.... To think *with* a story is to experience it affecting one's life and to find in that effect a certain truth of one's life".

The knowledge claims emanating from the philosophy and theology that were taught to me left very little option for me to think about God differently. God was perfect, omnipotent, omniscient and, in keeping with the principle of *simili similem parit* (the like generates the like), could not be associated with people with disabilities. How could they be images of God when they were not perfect? My philosophy, so I thought, had sufficiently prepared me to make sense out of these. I was convinced that nothing made better sense, and it was the most logical thing to think about God in this way. I assumed I had acquired expert knowledge about God and was an authority (Kotzé 2002:8) on these issues through my formation.

However, immersion in postmodernist theory allowed me to critique my thinking and practices, opening up possibilities for me to revisit the meaning of biblical notions of *kenosis* and incarnation in the light of the experiences of people with disabilities. It made me reconceptualise, in the light of the stories of people with disabilities, *imago Dei*. The encounter between my story and theirs changed my life in very profound ways, confirming Etherington's (2005:305) insights that people are continuously changed by their stories.



The dilemma of evacuating this familiar territory of knowledge, with its features of certainty, objectivity and perennality, evoked in me a feeling of precariousness. I was however consoled by the belief that a journey of migration reflects features of uncertainty and openness, which I had to face with courage. In that uncertainty lay possibilities for the discovery of the previously unthinkable.

## **8.2.2 Reflecting on the research process**

In this section I set out to reflect on the different stages of the research process, from finding participants to deconstructing together the dominant disability story and co-constructing an alternative story. This was a research journey, of which the twist and turns, detours, disappointments, affirmations and transformations were an intrinsic part. When I now temporarily exit this journey, I am not the same person that I was when I set out on it, for journeys have a transformative dimension. The latter does not come by only through acquiring new knowledge but also by the process of self-reflection initiated by such a journey (Kvale 1996:3).

### **8.2.2.1 Twists and turns of a research journey**

My change of the topic after six months into its exploration was motivated by a realisation that there was so much to tell about disability and yet only a fraction of it had told (Martin 2007:49). This resulted from a series of conversations between an ITD master's and doctoral group of Lesotho and learners with disabilities at one of the high schools in Maseru, during our practical internship. It was an inter-disability conversation (Kotzé 2011) between the abled and the disabled. It was indeed a visceral moment that set in motion a journey that would engage all of us who took part in it, but it was also accompanied by the uncertainty: "If I keep on changing topics will I ever finish and how will I be sure that I have the right one?" Being the first major piece of research of its own kind in which I had engaged I had no prior experience to which to refer. Conscious of the limitations of time, I felt vulnerable and helpless, but the reassuring words of my supervisor made me realise that uncertainty has a positive side, namely that it was part of the precariousness of this journey.

The ambiguity of responses from some of the pastors whom I had invited to become part of this journey was a disappointment that I had to contend with. Despite the many persuasions and pleadings that I made with one, the process never took off. With the other, after much postponement of our meeting, the circumstances that occurred in the parish made it difficult for any open and fruitful conversation to take place. Despite having explained what I thought were potential benefits for all of us in engaging in this research, my ethical imperative was to

respect the right of choice not to engage at all, or the right to withdraw at any point (Etherington 2007:603). Though their voices could have enriched the lives of all who took part, this had to be accepted as a setback.

### **8.2.2.2 Participation of the research participants**

My choice to position myself within a participatory action research approach was a deliberate political and ethical one. Participation is about sharing and co-production of knowledge, and has dialogue as its central feature. It is an atmosphere or attitude which, according to Buber (1958:46), is characterised by I-Thou as opposed to I-It. Through participation, a space was created for participants to share their experiences and information (Park 2001:81). Our conversations and discussions on this report was, in their words, *a revelation*. Tsili confessed that this manner of doing research was “*quite unique and interesting... the participatory dimension of the research that you committed yourself to at the beginning was not just tokenistic but it was so real.*”

The dialogue that engulfed us as we shared the time and space, brought about change in all of us. My questions and observations during our conversations, as they said, made them reflect more on some things that had assumed truth status. As I listened to their experiences I was challenged in my assumptions not only about disability and people with disabilities but also about issues of life and faith (Berger 2004:79). Our dialogue interrupted a monologue which would have finalised either myself or people with disabilities. For all of us, disability became an opening to unfinalised new possibilities of being (Frank 2005:969-970). In this sense, Frank’s (2005:968) words that “research does not merely reports it *instigates*” had resonance. The instigation led to self-reflection to each of us who took part in this research journey, and this in turn led to change.

Despite the success that I believe I achieved with respect to participation, there is a feeling of “it could have been better”. This confirms Epston and White’s (1990:15) claim, that “people are rich in lived experience and only a fraction of this experience can be storied and expressed at any one time.” If we had had an opportunity to go into the focused groups perhaps it could have been different. If all the pastors had agreed to join us in conversations the story would have been richer.

However, the question remains, did the research lead to knowledge that is translatable into action which would transform people’s lives? This is discussed in the next section.

### **8.2.2.3 Participatory action for transformation**

This research aimed at knowledge production for transformation (2.4.2.2), and as action research focused on social change and change informed by reflection involving all participants. For Reg, there was still more to do in raising awareness and advocacy:

*Conventions, statements and policies have been made. It is time for action. I have been in this institution for quite some time but some students with visual impairment have achieved things and improved the lives of others. This research has forced me to reflect and be more aware than I was. I feel that as early as now I feel the need to talk on radio about issues of disabilities. I feel the courage to organise a workshop for Senators and Parliamentarians.*

(Reg 2010).

My invitation of people from different categories of disability to talk to the students was praised by Tsili and the others as doing it “Jesus’ way”: *“He started small with twelve disciples but eventually transformed the entire globe. We will through these small and seemingly insignificant steps transform Lesotho.”*

The inter-disability conversation between people with disabilities and a small group of students was not only praised by Tsili, it was also an educational experience for the students, as they reported that it had changed their earlier perceptions about people with disabilities. They had thought people with disabilities did not know anything and they depended on others for almost everything. Now they were beginning to think that they might have limitations which people with disabilities do not have. They were echoing the words of de Saint Exupery (1943), tamed by that meeting. After many indifferent interactions we became significant to each other for the first time.

### **8.2.2.4 Deconstructing the dominant disability story**

The aim of this research was collaborate in deconstructing oppressive ways inherent in dominant disability discourse, and to co-construct an alternative pastoral disability narrative. Though the research participants knew very little about the theory of deconstruction, they did manage to practice it in our conversations. For instance, they were able to identify the beliefs and the practices that supported the problematic disability story. The associations evoked by the notion of inclusion, rehabilitation, and the disability–sin and disability–abnormal binaries, were isolated and the problems they engendered for all of us were exposed not on behalf of people with disabilities but by people with disabilities themselves. My decision not to go into

the details of what the research journey set out to achieve through complex terminology, worked in my favour. I neither had to mention that this research was about deconstruction nor did I have to explain what it is. That simplicity of approach made communication much better than it would have been and dissipated the power and expert knowledge that is often held in the researcher's role (Etherington 2007:604). When I confirmed with the research participants the analysis and findings, particularly in Chapter 7, and intimated to them that what we had done was called 'deconstruction', they then asked me about it. My answer to them was, "*what you have done.*"

### **8.2.2.5 Local theology removed from the controversy of the academia**

My formation in Catholic theology had as one of its covert objectives apologetics which consisted in defending what adherents regard as the 'true Catholic faith' against 'apostates.' Orthodoxy in Catholic circles ranked higher than orthopraxis, and saying things rightly and correctly was more important than doing things correctly. In the course of this research, I struggled to come to terms with some of the expressions that I read about for the first time in literature, for example the expression "A Disabled God", the title of a book by Nancy Eiesland (1994). It was quite brusque for my sensitivities when I first saw it and it did not fit within the ontotheology in which I was brought up. These represented resistances in the face of uncertainties of the future, common of journeys of migration. As with the fleshpots of Egypt, growing up in certain environments deny one the opportunity to imagine possibilities outside the familiar, the certain and the fixed.

Again, however, such discomfort only served to enhance my awareness, as it generated pertinent questions that I together with the participants asked. Jack (2009) grappled with one, "*if God is perfect and whole and we are imperfect, unwhole and sinners through and through, who created us? If everybody else is created in God's image, in whose image are disabled people created?*" These were deep theological questions, paradoxes demanding seriously thought out responses. When Maki (2009) said that "*to be different is godly*" she said something that orthodox theology would regard as bordering on heresy.

These powerful utterances represented theology from below "that is grounded in the challenges and fulfilments of ordinary life and its ordinary concerns rather than in the controversies of the academy" (Grobbelaar 2006:310). The research participants had no academic certificates of theology to display on their walls but they had pertinent responses to life's challenges resulting from the experiences with their bodies. These answers were not from the books or encyclopaedias but from their bodies and from their hearts. They

confirmed Eiesland's (1994:49) view that for persons with disabilities, the body is the centre of political struggle. This is their starting point for doing theology.

The above reflections are subtle expressions of resistance against unjust and unethical practices shaped by dominant religious discourses masquerading as Christianity (Kotzé 2002:10). When sharing her reflections on the godliness of difference 'Maki said, "*I hope I will not be suspended from church for saying the kind of things that I said.*" What becomes clear from her statement is that the hegemony of truth has been instituted without participation of certain sections of society and that the latter's voices have therefore been silenced (Kotzé 2002:12). Her assertion reminded me of how I too had been colonised into believing that certain so-called 'truths' about people with disabilities were eternal and unchangeable, and therefore said the last word (pronouncing them dead) about people with disabilities. My openness to the dialogue with research participants helped challenge the monologues about disability and people with disabilities (Bakhtin 1984:58-59).

Throughout this research, there has been a temptation to understand this research as being about disability as if it were the only topic, but since I regard it as a relational notion it was not about the research participants alone but also about me, and how disability fits into a larger story of my own life as a person, researcher and therapist. Frank (2005:967) writes, "one story calls forth another... and my voice always contains the voice of others for each voice is formed in an ongoing process of anticipation and response to other voices." My story of disability is permeated with people with disabilities' stories and it is a response to these as much as theirs are a response to mine.

It makes sense, therefore, to say that we are journeying together, with no question of one (researcher) being more in this journey than others (research participants). As I reflect on how this journey impacted on my life, the reflection in the research participants is further instigated. It is like a dance where each partner's movement makes whole the movement of an entire dancing partnership. The movement of one is important for the movement of the other. My reflection without the reflections of the research participants, therefore, would not make any sense. This would turn what was destined to be a dialogue into a monologue.

It is for this reason that the research participants deserve space and time to reflect on how their participation in the research journey made a difference to their lives.

### 8.3 REFLECTIONS OF PARTICIPANTS IN THIS RESEARCH

This research journey has been an engagement of the researcher and research participants in their own struggles of becoming (Frank 2005:968), providing an opportunity that set all on a road to a change of life (*metanoia*). Any conversational engagement involves an exchange of voices and ideas which can lead to both unsettling questions and life changes (Eide & Kahn 2008:200), through dialogue (Frank 2005). Where there is no dialogue there is monologue and monologue means death (:968). Becoming is change in another way, with both an indication that there is life and where there is life there is dialogue (Bakhtin 1984:58). Where there is dialogue there is no room for only those who are strong and whose voices are fully grounded, but there is also room for those who are usually marginalised and silenced (Kotzé 2002:18-19). I now focus attention on ways in which this participatory and dialogic research journey has influenced, in a transformative way, the lives of the research participants. This was a way of deconstructing my own power and being ethical.

Our reflections were guided by the three questions open to further expansion by research participants and discussed under the sub-headings that follow.

#### 8.3.1 How has it been for you to be part of this research journey?

*Jack: This research journey created a space for me to talk about my own experiences in a world where nobody seemed interested in me and my experiences. It gave me a sense that 'at least someone is going to listen and perhaps give volume to my little or even silenced voice'.*

*'Maki: From the beginning there was a sense in me of being chosen amongst others whose experiences I share. Though it was clear that I was not representing them, I could not shirk that feeling that may be whatever I say will affect them in a way, for good or for worse. I must say that it was quite liberating and enriching to be part of this research journey, for me personally and hopefully for others who were indirectly affected by it.*

*Tsili: This research found me in my own research journey. It has enriched my research acumen and capacity. It never occurred to me that I would be able to talk to students who are not part of my responsibility. But that you invited me to talk to students – in the course of your research – about experiences of disability was a removal of barriers around disability issues.*

*Reg: I have had a rare opportunity of reflecting seriously about issues of disability in general and my own disability in particular from the point of view of culture, politics and*

*religion. People are afraid even to ask question relating to our disabilities. When you intimated to me that you wanted to research with me about my disability I felt so liberated and I saw this as an opportunity for growth together as people of God.*

Bakhtin's (1984:58) claim that where there is dialogue and participation there is life and vice-versa, is borne out by the above reflections. The words used, such as growth, liberation, enrichment, voice giving are all paradigmatic of life characterised by dialogue and participation.

### **8.3.2 In what ways has this journey impacted on your lives?**

My conversations with research participants regarding the impact of this research journey on their lives revealed the following:

*'Maki: I did not often talk about my disability with my mother. This research has occasioned the sharing of perspectives from both of us. I now know what I, at first, only assumed. The voice of my mother has called for a reflection on my part about what it might mean for non-disabled people to have people with disabilities as members of family, relatives or friends. I have learned that anger may not necessarily be a bad thing as we were made to believe and that it may be a motivation for more positive action.*

*Jack: The recollection of some of the things that happened to me early in my life sort of contributed to my healing. I seldom go back to such memories. I have always pondered on them and many of them had been classified in my mind as painful memories. But talking about them has been some form of catharsis. I can even laugh about them now. Your remark about the power and the creativity in me that made me challenge people at the library and what that power could do to overcome other obstacles in my live, made me think. It has actually softened my resolve to stay away from church. I am actually considering going back to church. I am thinking about ways in which I can challenge fellow congregants and pastors to view disability in a different light and perhaps make it easier for us to participate fully and consciously in worship.*

*Reg: Some of the conversations we had have forced me to think about what I could have done better to improve the conditions of other people with visual impairment in this institution (National University of Lesotho). And I am thinking I could have done better. I am on radio quite often but I seldom talk about disability in general and experiences relating to visual impairment in particular. Since we started this journey lots of ideas on how best we can intensify awareness campaign have kept on flowing. It has made me reflect more about what*

*it means to be the church. Is it not providence that at the same time that you invited us to this research, Bro. Mat (deacon at the Catholic Cathedral) also organised meetings with us on how best we can participate in Liturgy? At our church I can see more good things coming.*

*Sam: I am hopeful that something good will come out of this research. It would have done me a lot of good to meet with my pastor and to share with him experiences of living with speech and hearing impairment and what it means to be part of the church that does not make an effort to hear us in our own language. But my wife tells me that there are some signs of developments and I am hopeful that something good will happen.*

*Ken: I am happy that you talked to me. What are you going to do with this information? However I am happy that the Prime Minister will know about this.*

*Rev. Frank: I had this knowledge and this experience about how the decision of my daughter affected me. Talking about it is a different story. As I talked I also reflected. As you talked and also asked questions you made me reflect more on what it meant to me to journey through that experience. I now better understand Apostle Paul's conversion experience. I can also relate with the experience of Israel in its journey from Egypt to the land that they only knew as a promise. I can now say conversion is not a ride in the park. It is a struggle. I have also realised the value of not judging or making conclusions about people on the basis of their alleged limitations. My question was how will this couple be able to survive in this highly competitive world when my son-in-law cannot hear or speak? Now I can say the resolve of my daughter has made it possible for me to discover something that would have otherwise remained hidden from me about people with disabilities especially people with hearing and speech impairment.*

*Maki's mother: I have never thought that my daughter and others like her may not be viewing themselves as abnormal and, therefore, in need of cure. I have thought about this and I am still thinking about what it could mean.*

The above reflections confirm the thesis of Frank (2005:968), that reflecting upon life is a good thing though it is sometimes fraught with struggles and challenges. They are stories of struggle as participants evacuated their painful though familiar territories of fixed identities and associations. The questioning of that familiar led to a "greater sense of connection, a fuller sense of meaning, and... A greater sense of comfort with who we have chosen to be and how we act in our lives (Boler 1999:197). I concur but also add that when it is done it yields the kind of results that we hear from the research participants. This research conversation has not only instigated self-reflection it has also been an invitation to *metanoia*,



and change of life. It was a talk that instigated a process that changed lives (Frank 2005:968).

### **8.3.3 How do you see the world differently with regard to disability as a result of this research journey?**

*Tsili: I appreciate myself better. I have had the opportunity to say to others how I viewed life and the world and they told me how they thought about me and others of my own kind. When you invited me to address your students I felt, as I talked to them, that there is a possibility of moving from the diametrically opposed to those who though different belong together.*

*Reg: A road to conversion begins with an insignificant little step. In the area of disability perhaps I should scream first because I am the one who feels the pinch and that will call for a response from others instead of waiting for those who are not disabled to scream first because their experience is not my experience. Their experiences may be such that they do not demand a scream.*

Reg's reflection here is evocative of Brueggeman's (1978:21) primal scream, to say that things are not right (1.13). It recalls the scream of Israel that reminded God of the covenant with Israel. It is that relationality embodied in the covenant that reminded God of God's responsibility toward the other that was Israel. Welch (1990:135) concurs that transformation starts when that primal scream becomes an expression of the pain felt. The primal scream of Israel under the burden of Egyptian slavery set Israel on the road towards liberation and transformation not only of their lives but also of their relationship with God.

As a result of this research journey Jack (2010) feels much less angry. As he says,

*I had made up my mind that my disability was a private issue; an issue between myself and my body; between myself and my family. Other than that there is no use talking about it because nobody seems to care. All one can do is to fight and fight to get things done and changed. How long will I fight alone, I always said to myself. Now I know I am not fighting alone.*

Rev Frank (2010) shares similar sentiments:

*To me people with disabilities were batho ba sa itekanelang (unbalanced people) nothing less nothing more. Today I know better. I could also be unbalanced because I do not know their language. I had not opened my mind well enough to participate in the world of talents, such as those that my son-in-law have, that even the so called people with no*

*disabilities do not have. Today I see the world differently not only with respect to people with disabilities but also to other people.*

Rev Frank's reflection above confirms the words of Bakhtin (1984:58) that we often spy upon people's lives, which results in analysing, describing and defining them finally, with no other prospects remaining.

The inclusion of the research participants' reflection in this research journey was not only demanded by the participatory nature of the research, but was from the point of view of the researcher the best thing that could have happened to him and to the research participants. It was not merely paying lip service to collaboration and participation, but also taking a stance against prescriptive ethics (Kotzé 2002:13-16), which have things concocted elsewhere for people and only to be served to them without their involvement. Throughout this study I have constantly reminded myself of the following questions:

Whose knowledge?

Who benefits from it?

Who is silenced?

Who suffers as a result of this knowledge? (Kotzé 2002:8).

These questions have guided us, myself and the participants, toward a collaborative and dialogical construction of the text that I now present. We can therefore conclude that the knowledge and the care that resulted from this study is liberative (7.3.1.1), relational (7.3.1.2), participatory (7.3.1), ethical and accountable (7.3.1.3). It has established that we are a communion (7.2.1.1), who belong together and are able to care for each other through dialogue, for in monologue there is only death. In dialogical relationship, where there is participation and *ubuntu* (7.2.2.1), one takes responsibility for the other's becoming (Frank 2005:967). When one is oppressed we all feel the effects of that oppression. In that context, therefore, one's liberation cannot leave others unaffected.

I believe that the research knowledge and praxes that have been created in this research journey have been a collaborative endeavour, which has made a contribution to the field of practical theology and pastoral care, particularly in the deconstruction of dominant disability discourse and co-construction of a preferred disability story. These contributions are a matter for the next section.

## **8.4 CONTRIBUTIONS AND CHALLENGES TO THE PRACTICAL THEOLOGICAL AND PASTORAL CARE FIELD**

The sections that follow represent contributions and challenges that this research journey has brought to the field of practical theology and that of pastoral care. Using the narrative metaphor, I set out to deconstruct the long legacy of a dominant disability story in church and society through participation with research participants. From the scaling off of the dominant disability story emerged the different and preferred disability story. This is the story about the church as communion, where we all participate as a *koinonia*. Such a church, because it is still a pilgrim church, is fallible, sinful, worldly and weak (Tutu 1983:108), and is therefore in need of constant conversion (*metanoia*). It is grounded especially but not exclusively in, and nurtured by, the theologies of interdependence, *botho*, embrace, and of a journey where possibilities are always open for further transformation and better care *with* one another. The pastoral care that comes out of this *koinonic* and participative church is ethical, relational and accountable. It loathes prescriptions where people have no “say in the ‘truths’ that are supposed to shape their lives” (Kotzé 2002:16).

### **8.4.1 Legacy of church and society in constructing the body**

Like Stiker (1999:viii) I argue that history is a continuum of effects in which one epoch’s beliefs continue to inform the practices of succeeding generations, particularly with respect to the disabled body. Contemporary perceptions about disability and people with disabilities have been influenced, in significant ways, by the ancient Mediterranean world. Not only do bodies become social scripts onto which are written societal values (Viviers 2005:799), they also become representations of society such that “watching the body becomes the same thing as observing society” (Berquist 2002:11). The next sub-section looks into the dynamics and implications of the construction of a disabled identity.

#### **8.4.1.1 Social construction of a disabled body**

What I have been able to discover through this study is that a body is a social construct and that the Judeo-Christian world, taking a cue from the Greco-Roman culture, has influenced the contemporary Western world’s perception of disability and a disabled body (Barnes 1997:4). As Wilde (1966:1019) argues, much that is modern in many people’s lives is owed to the Greco-Roman and Judeo-Christian cultures. For instance, the manner of regularising the body was inherited from these cultures, and, more specifically, the missionary legacy of most of the churches in Africa has left a lasting impression on the understanding of disability and people with disabilities. The sin-disability interface lives on to this day, but there is also a

compassionate dimension of the church's treatment of people with disabilities that assumes the "disability as occasion for charity" perspective. The sin-disability interface combines with the cultural interpretations to shape Christian cultural disabled identity that is now prevalent in Lesotho.

Through language, practice and ritual, a particular type of body was created, typified and legitimated to act as a measure for other bodies, known as a regulatory body. Within the Greco-Roman and Judeo-Christian culture it had to be whole, male and have godlike features, and if it did not meet these standards it was regarded as abnormal, impure and sinful. The disabled body was such a body, by regulation relegated "to the liminal realm of anti-structure or dis-order" (Viviers 2005:800). This perception, albeit assuming different forms, is still very much alive in society today.

Though the general fate of the disabled people has been characterised by marginalisation and misery throughout history, the instability and fluidity of the notion and the experience of disability has stubbornly refused to succumb to the pressures of homogenisation, or what Stiker (1999:viii) terms "passion for sameness". A careful reading of the history of disability, especially Western Christianity, bore testimony to this (Covey 2205). Not all disabled or unwhole bodies were despised, then or today (Viviers 2005:801), but rather disability has remained unstable and dependent on socially generated interpretations (Stiker 1999:ix). Church and society continue to construct bodies and disabled bodies in different ways, whether through models, policies, laws or practices, the interrogation of which, and the resultant unstable and unfixed disabled body, are other contributions offered by this study.

Apart from yielding results to the effect that disability remains a very fluid concept, their effects have alienated people with disabilities from society, from the institutions that are supposed to embrace and serve them, as well as from God.

#### **8.4.1.2 Politics of power in disability discourse**

The process of normalisation of or regularising the body was fraught with political ramifications, implying the binaries of the regulariser vs. the regularised, the normer vs. the normed upon; and the namer vs. the named, with power valences skewed in favour of the first members of these binaries. Through the above process of naming their (people with disabilities') experience of disability is invaded to their detriment. Those named, normed and regularised as the 'other' become marginalised and objectified, and are subjected to someone by control and dependence (Galvin 2003:150). The binaries sustain the discourse

and so become very powerful political tools to further “set up a symbolic frontier between the aberrant and the normal” (Galvin 2003:154).

These power politics play themselves out, in very subtle ways, in the public domain in Lesotho. The education sector views and constructs disabled learners as those that need to be included as if there is a regularised centre, “a prefabricated, naturalised space” (Graham & Slee 2007:278) into which all should be included. In the health and welfare sector the language that is used is resonant of the medical model, which views people with disabilities in pathological terms. They are viewed as sick and have to be subjected to medical scrutiny and rehabilitation. The legal sector also views them through the lens of rehabilitation and resettlement, in a scenario that is reminiscent of the situation of the lepers in the biblical tradition, when they were quarantined and made to go through the process of rehabilitation. It was only after this process that they could be resettled or reintegrated into society.

The language that is used serves to construct the disabled people as the ‘other’ and those who do not belong who have to migrate from the unacceptable state to the land of the normal, but not without undergoing some ritual. In the church they are for the most part still objects of charity, a situation where everybody but they themselves know what they need. They can be dispensed from participation in worship because they are different and sinful, and perhaps a constant reminder to others of their vulnerability and transience. The above provide a base-line for a critical practical theological reflection on the impact and ethical implications these religious and social ideologies have on the lives of people with disabilities and on society and church.

#### **8.4.2 The results of a pastoral reflection on disability models, policies and practices**

The participatory pastoral reflection on the policies and practices resulting from the above analysis reveals that the models of disability can and do represent systems of power that exert control over the lives of people with disabilities. Unless such ideologies are subject to some critical interrogation they become oppressive to people with disabilities.

##### **8.4.2.1 Pastoral reflection and the disability models**

The medical model of disability, with its normalising tendencies, continues to legitimate the authority, power and expert knowledge of professionals, while on the other side depriving people with disability of control over their lives. Even under its new modern guise of a community-based rehabilitation programme, the medical model remains under the control of professionals.

The social model, meanwhile, despite its service to people with disabilities in the political realm, does not operate through participation and involvement of people with disabilities. Its elitist outlook denies it an important component of doing *with* which would ensure that the plurality and heterogeneity of lived experience of people with disability were given its rightful place. The policies and practices that often result from embracing and adopting these disability models have generated knowledge systems that do not serve the interest of people with disabilities. The models' non-participatory stance silences those who were supposed to have a much larger stake. These are people with disabilities whose knowledge and voice is more authentic than those of people who have no expertise on issues of disability. They feed on prescriptions that render them unethical (Kotzé 2002:15-16).

#### **8.4.2.2 Ushering in the participatory model of disability**

It is this inadequacy that has prompted a proposal for what we have termed a participatory model of disability. The participatory model is not only sensitive to and in dialogue with the lived experiences of people with disabilities, but it also matches the motto of people with disabilities, "nothing about us without us." This model is a contribution to the field of disability studies in that it challenges the monopoly of the medical and the social models on disability. It is also a reflection that involved participation by people with disabilities, and can therefore serve as an important tool for policymakers in not only reviewing their current policies and practices but also in interrogating models that are concocted somewhere only to be presented to people with disabilities in a different context.

The participatory model further represents a more ethical and accountable model, founded on participation by disabled people with their unique experiences given their rightful place. The participatory model also contributes to the field of practical theology and that of pastoral care. In this regard, Disability Studies represents a social system or ideology which provides a context and occasion for critical theological reflection. What happens to people with disabilities within the ambit of social ideologies and models has serious political ramifications, for the personal is the political and the political has theological implications. Practical theology and pastoral care have constantly to reflect on and speak to a context within which the church is called to proclaim the word (de Gruchy 1994:11). That context embraces fields of social sciences, sociology, politics, psychology and disability studies, with which practical theology has to engage in dialogue.

The participatory model further links up with the metaphor of church as communion, where all, though different, are members of the same body, namely the church. It is from such a

metaphor that the local theology of *ubuntu*, the theology of embrace and the theology of interdependence emerge to nurture the same church. As such, the participatory model not only challenges social models and ideologies but also religious and Christian traditions, with respect to forces that tend to exclude under the guise of remaining true to the gospel and to authentic human endeavours. This paves the way for a pastoral care model that rejects caring for and is sensitive to the lived experiences of people with disabilities in their own contexts. It further liberates pastoral care from the “captivity of its self-hood in terms of origins” (Lartey 2003:176), so that it can liberate those on both sides of the disability divide.

The above reflection has served to achieve the first and the second aims, with associated themes already overlapping into the third aim of this research journey. The participatory model of disability proposed by this study resonates with the metaphors of a disability friendly church that are resulting from a deconstruction of a dominant disability discourse and a co-construction of a preferred pastoral disability narrative.

#### **8.4.3 Dominant disability story scaling off and an alternative story emerging**

The title of this research, relating to deconstructing disability discourse within Christian cultural narratives in Lesotho, suggests that the end to which this research is geared is deconstruction. However, deconstruction itself is not about ‘destruction’ but about subverting taken-for-granted realities and practices to render visible their biases and prejudices (White 1992:121). One of the aims of this research was to examine and lay bare the machinations of the oppressive dominant disability discourse and to collaboratively create an alternative story that would be more inclusive, relational, ethical and accountable. I now provide a résumé of the incapacitating ideas that emerged from the research participants and fed the dominant disability story in the Christian cultural context.

##### **8.4.3.1 Culture as context for the scaling off and emergence of alternative story**

The dominant perception in culture has long viewed ancestors as police, who remain vigilant and catch their culprits as soon as they trespass. This analogy for explaining the ancestor’s role in society (Landman 2007:344) trapped many people into a false belief. When people were suffering, it is because the ancestors were offended and showed it by either taking it out on the sufferers or withholding their protection (sleeping). This contradicted a positive perspective of the ancestors that they were benevolent and showed interest in the welfare of their families. As Jack asked, “*how could they prey on my miseries when I or anyone in my family had done something wrong? Why can’t the cause be something other than ancestral wrath?*”

#### **8.4.3.2 Public institutions as the context for scaling off and emergence of alternative story**

With respect to people with disabilities, various public institutions in Lesotho have adopted the nomenclature of abnormal, special, as opposed to normal and non-special. The latter, therefore, have to be rehabilitated in order to conform to the norm and be worthy of inclusion. The uncritical adoption of the notion of inclusion implies the idea of centres, which in Derrida's (Powell 1997:21-22) view tend to exclude. It implies that there are those who have been part of the inclusion who do not need to be included, while those who had been excluded for reason of their difference, abnormality and specialty need now to be included.

Reg's powerfully deconstructive statement that "*each one of us is special in a way*" shows that the term 'special' had assumed a rigid and dogmatic status which denied it the chance to participate in the emerging new meanings hidden in the word (Caputo 1997:8). The same applies to the uncritical use of the term 'abnormal', which survives only because it has an antonym. The normal, as Stiker (1999:viii) argues, "begins with our acceptance of the norm as a controlling principle", but the question remains: who determines what is normal and what is abnormal? From the findings of this research, the answer seems to lie very much with Kotzé (2002:8), namely: those who have power and knowledge and use it in unethical ways to oppress and silence others.

This study, through the lens of post-structuralist and social constructionist frameworks, has been able to discover the dynamics of power and knowledge at play in the binaries which support the dominant disability discourse in the various public institutions in Lesotho.

#### **8.4.3.3 Christianity as a context for the scaling off and emergence of alternative story**

Within the Christian context, some knowledge systems had assumed "the truth status" and had become unquestionable despite their debilitating effect on the life of the church. People with disabilities are associated with the sinners at worst, and the miserable at best, whose needs can only be met by the compassionate non-disabled people. The latter can only care for those who cannot care or do things for themselves, such as the disabled. Because of their sinfulness, which exposed them to disability, the disabled can only be incorporated back into the fold of the holy ones through repentance and healing by being prayed for. Jesus' answer to the question of the man who asked, "who had sinned that, this man was born blind?" was an indictment against those who associated sin with disability. It broke down the religious prohibitions which were a characteristic feature of the Israel of the Old



Testament. With this confounding of the traditional conception, the dignity and the right of the disabled to “partake fully of religious and social life are recognised” (Stiker 1999:35). It is this detail that reminds Christians of the call to a sharing of the life that Christ has obtained for them through his death and resurrection. Jesus’ mission was to make possible participation in the relational (Trinitarian) life of God, which for believers is characterised by deep communion through affirmation of differences.

#### **8.4.4 The alternative story emerging**

Deconstruction should lead to the emergence of an alternative non-dominant story. My conversation with research participants not only facilitated the taking apart of the ideas that supported the dominant disability story, but also sought out stories of identity that will help people to break from the influence of a dominant story (Morgan 2000:14). These stories were followed through and thickened, and the results of that process summarised below; realigned to the larger picture that emerged from this research journey and their contribution to the field of practical theology appreciated.

##### **8.4.4.1 Metaphors of a disability friendly church**

The metaphor of church as *koinonia* emerged as the most important for the research participants. The other biblical notions, such as *kenosis*, *metanoia* and incarnation not only serve to foreground this central metaphor they also evolve around it. The reflection on this central metaphor generates the theologies that are disability friendly which in turn nurture it.

##### **a) A metaphor of church as communion**

In a church and society characterised by fragmentation, alienation and exclusion, no other idea would express better what the research participants longed for than communion. It did not come as surprise that the research participants referred to the notion of family as a place of belonging, fellowship, participation, sharing and communion. The metaphor of the church as communion was therefore better placed to challenge the fragmentation, alienation and exclusion that had continued to characterise the lives of people. Another reason was its susceptibility to be aligned to other ideas, such as *ubuntu*, *kenosis*, *metanoia*, interdependence, embrace raised in our conversation with research participants. Of particular relevance to this research is *koinonia*’s propensity toward the features of participation, which has equally been underlined as key in deconstructing the dominant disability story.

What Stiker (1999:viii) calls “passion for sameness” has been at the origin of the oppression, rejection and exploitation of people with disabilities through history. The refusal to appreciate that difference is not to be dreaded but rather a benefit to be cherished, has made life for people with disabilities what Jack (2009) called “*hell on earth.*” Communion, where participation of all is possible, presents itself as an antidote to a situation in which all are different, with no sense of purpose or unity, or all are so united that their differences are reduced to nothing. Communion creates a scenario where the self-other; I-thou held together in deep kinship, “dance in the silence of dark – no movement to be seen or music to be heard – a search for participatory consciousness that will create their own music and become a healing movement” (Kotzé 2002:4). However, the dance is carried out not by a universal I-thou but by the I-thou embedded within a specific context which will give that participatory consciousness its unique features.

Within the context of Lesotho, the embracing of the church as *koinonia* would certainly yield results that are responses to burning questions and issues that have been raised by people in Lesotho. Disability as a social construct assumes and expresses the values of a society within which it is experienced. It is in this connection that the biblical concept of incarnation becomes relevant. Through incarnation, God takes flesh not only in the human condition to commune with humankind, but also in the different human bodies. The above claim that incarnation has made possible for God to be at home in various cultures, heritages and bodies (7.2.1.3), then falls into place. As Tutu (1983:108) stated:

The Church divine is holy and without blemish and the temple of the Holy Spirit and custodian of saving truths... It is fallible, sinful, worldly and weak insofar as it is made up of sinful, worldly and weak human beings... It is the school of saints and the home of sinners and contains within itself the tensions of that which is in the world but not of the world. It has the same tensions that exist within the individual Christian who has died and was buried with Christ and has been raised and is ascended with him and yet experiences the tussle between the old and the new Adam in his everyday life.

#### **b) The church as *metanoic* communion**

The human dimension in the church as *koinonia*, therefore warrants a need for conversion and healing of its members. Members, because of their sinfulness, often fail to live up to the demands and responsibilities of communion, a failure that expresses itself in the fragmentation, alienation in all its facets, anger and silencing of some members. Conversion, as Navone (1989:36) argues, “is the event and process of overcoming this failure to assume one’s responsibility toward God and neighbour”. Within the context of disability it is

necessary to amend for the wrongs meted out to others if they are to live up fully to the demands of communion, as *metanoia* is an integral part of a life of a covenant community. When communion and love are duly shared between believers and God, and between themselves, it is in what Navone (1989:39) calls 'generous self-giving' (*kenosis*). The theologies of interdependence, embrace, *ubuntu* and a journey flow from the *koinonic* and participative church and they further nurture it.

The participatory model, with its links to the metaphor of the church as *koinonia*, represents a major contribution to the field of practical theology and pastoral care. It is within such a church that liberative, participatory and ethical pastoral caring *with* becomes possible. Within such a church, what Stiker (1999:viii) calls "The love of difference" becomes the source of life, for although different members, members belong to the same body. No part of the body can tell the other they are of no use, for each member has a role to play in the building up of the body.

#### **8.4.4.2 Obstacles to the church becoming a *metanoic koinonia***

The idea of a church being a *koinonia* is clear enough, but unless it is accompanied by concrete and practical actions it remains a mere utopia. When further asked how best these noble theological ideals grounded in the gospel can be achieved, the research participants noted that this journey was fraught with immense challenges. Below are some of those challenges and obstacles as they were articulated by them.

##### **a) New ideas looked at with suspicion**

*"As far as I can remember, the church has always been defined in terms of durability; custodian of traditions. This kind of understanding makes it very difficult for new ideas to be embraced with openness. Instead they are looked at with suspicion,"* said Jack (2010). When asked about the possibility of a disabled person becoming a priest in the Catholic Church, he said, *"not in my lifetime. That would be quite a radical innovation."*

Jack's response immediately reminded me of two things: firstly, Yves Congar, among many theologians whose ideas were looked at with suspicion, only to be recognised with time as a Cardinal in the Catholic Church; secondly, my friend, a priest, who upon seeing the title of the book of Eiesland, *The Disabled God*, asked what kind of books I was reading. A reflection upon the above incidents suggests that the Catholic Church should be open to new ideas. They may not like them but they can nevertheless be appreciated for what they propose. The questions of my friend the priest took us back to our own years of

philosophical and theological formation. According to the philosophy and theology that we studied together at the seminary, an imperfect God was unthinkable. We were taught that God was perfect then and forever, and that was one immutable truth among the many which any person changed at his/her peril. Anything different would be looked at with suspicion in the church, because of a dogmatic obsession with sameness which has marginalised and oppressed not only people with disabilities but anybody who seeks to dissent from the norm (6.3.5).

**b) The metaphor of church as hierarchy still dominant**

*The clergy are the most difficult to change  
May be it is because they are protecting the truth*  
(Jack 2009)

Though there has been a paradigm shift in terms of the metaphors of the church, many minds adhere to the past. The dominant metaphor within both Protestant and Catholic theology is currently that church is a communion, but people are still crying for the fleshpots of Egypt. They are feeling nostalgic about the metaphor of church as hierarchy, where the clergy occupy the highest part of the ladder, giving out instructions; in charge and in control, a value much treasured by Western discourse (Kotzé 2002:18). What Pryce (1996:21) calls “weight of hierarchicalism” tends to overshadow the most important dimension of communing and interaction between the different members of the church. It renders obsolete the ‘taming’ of de Saint Exupery (1943), where the need for each other is key. To tame is to establish ties, while sitting a little closer every day to the one to be tamed is part of the process that achieves the results. The question is whether taming is possible within the metaphor of the church as hierarchy.

**c) The church as an impenetrable fortress**

After many failed attempts at convincing his pastor about the advantages of having him as a research participant, Sam used sign-language (signed) to say, “*the clergy are an impenetrable fortress.*” This image comes in the face of a God who chose to come to earth in real flesh and blood (Tutu 1982:27). God could have chosen to come as a spiritual being but chose to come in human form, thus revealing an intention to be accessible rather than aloof. The church incarnate, through its members (priests and laity), has to be accessible and close to the experiences of the people.

#### **8.4.4.3 Concrete ways of doing participation**

Though living a life of communion is fraught with challenges, especially because it is “a mixed bag of saints and sinners” (Peterson 2005:226), the research participants were full of hope for a better future for all in church and in society. I now propose concrete and practical ways that the Church can participate with people with disabilities.

##### **a) Doing it Jesus’ way: From dogmatism to theology of relationships**

Christ cared so much about people that he dared not withhold a hand when called for, even in the face of legal strictures. In that way he transformed and fulfilled the law, leaving an example that it was not sacrifice that he needed but mercy (Mt 12:7). His ministry focused mostly on those who needed him, especially the rejected, marginalized and social pariahs. To them he represented a God who revolutionised religion, from being a fossilized observance of legal prescriptions to a personal and relational entity.

When Jesus called Levi, a tax-collector, to be one of his apostles (Lk 5:27-32); dined with Zaccheaus (Lk 19:1-10) and mixed freely with the “scum of society” (Tutu 1982:28) he was turning upside down the religious dogmatism of the time. He was on the lookout for the ‘other’ and to be involved with the real ‘other’, not as others painted them. It was indeed a major shift from the common theology of laws and regulations under the custodian of the powerful few to a theology of the ‘other’, “who seldom benefit from the ethics of discourses created and entertained by the powerful or knowledgeable” (Kotzé 2002:18). Clinging to what people believe to be perennially true about God, Jesus and the church, something which is common in dogmatism, “can only limit a fuller understanding of what is actually possible to know of God” (Cornwall 2008:189). Indeed, that clinging has led to a belief that “a single present or historical reading” of the “disabled other” tells the whole story of God which becomes valid for all times and places. It is this clinging that Jesus’ way of practicing religion challenged successfully, albeit, at a heavy personal price.

This, I argue, is a challenge to all who have to carry on the ministry of Jesus. We have to critically examine our own structures and theologies, which might serve as barriers to the life of true discipleship to Jesus, on a constant basis (Swinton 2000b:158), but a shift from religion as a set of doctrines and rules, to religion as a personal encounter, has implications for the ways in which the church conducts its affairs. One such implication is that the church as a community of believers is called to *kenotic* and attentive listening.

**b) Listening attentively and *kenotically***

Within the context of communion, where the ties have been established and there is a need for each other (interdependence), listening is a *sine qua non*. That listening requires a *kenotic* disposition in order to be conscious and aware of the other and to be present to him/her. When Jack and Sam quit the Church, it was because, as they said, “*our voices were not heard and our needs were not met.*” *There was no feeling of God-with-usness in church.* They felt that their views were not valued as members simply because of their alleged differences. Yet to be listened to, particularly with attention, is to be heard as an individual who is unique. Arendt (1958:8) asserted, “we are all the same, that is, human, in such a way that nobody is ever the same as anybody else who ever lived, lives, or will live.”

The seemingly little gesture of a new deacon at the Cathedral of our Lady of Victories became a key to the treasures that were hidden under the rubble of the worshipping church. A little research that he conducted with people with disabilities at the Cathedral opened possibilities for more attentive listening. It became an occasion not for routine celebrations but for experience of religion as a personal encounter. This research led to a series of meetings between the deacon and the group of people with disabilities who are worshipping there. There was, as Reg (2010) later said:

*a feeling of being where I belong, in a family, a body of Christ, where I could be myself even at my very worst. It did not end there. It led to one of us, visually impaired people, read in church something that changed the perceptions and attitudes that people had about people with disabilities. The church became aware. I can bet that some of those people who attended that service are the people who are responsible for formulating policies and laws at government level and that experience could not have left them untouched.*

When asked what inspired him to take interest in people with disabilities in this manner, when no deacon or pastor before him had thought of doing so, the deacon said: “*I just thought about how it might be if people with disabilities were given more attention in church. That idea has haunted me since then.*” Despite the challenges discussed above (8.4.4.1 c)), that meeting of the deacon with the “real disabled others” opened a wide array of relational possibilities. It was a shift from a disembodied and abstract theology common to theological departments and seminaries, with no face or voice to an embodied theology with a face and voice (Creamer 2003:62).

In my conversation with the deacon, we both identified with how the centralisation of the dogmatic theology learned from the seminary closes our minds to the relational theology that emerges from meeting the other and talking with the different other. It makes our life on earth, like that of the fox which hunts chickens and is in turn hunted by men, monotonous. Within such a scenario enmity is created, which can only be challenged by “taming” the other (de Saint Exupery 1943). Taming brings about interdependence (needing each other) without wiping out the differences. When the other has been tamed and ties with him/her established, the meeting of the hearts becomes possible. Under such circumstances it becomes very difficult to kill someone known to you; someone whose heart you have met; someone you have established ties with. This meeting of the hearts with people with disabilities, and this awareness, let me to change the topic and to pursue a research *with* people with disabilities. This meeting of hearts with people with disabilities and this awareness opened to Rev Frank treasures that would have otherwise remained hidden and left him with dogmatic competence, albeit devoid of ethical competence. It let him create space for dialogue between himself and the previously marginalized.

**c) “If the seminary can be aware and produce more similar disciples”**

After being invited to one meeting between the deacon and people with disabilities at the Cathedral of our Lady of Victories, I chatted with Reg about the prospects of this encounter. He said in response, “*if the seminary can be aware and produce more disciples like the deacon then we would have covered much ground within a short time.*”

The chat was later followed by a much more serious conversation on what could be done to make disability inform theology (Anderson 2003:1), and to help the seminary integrate ‘welcome’ in its curriculum (Birch 2003:23). Seminaries are not there as part of the mandate of the interested denominations, but because:

theological schools are in the business of providing for and equipping the ministries of the whole people of God. If, on reflection, a portion of God's people have been pushed to the margins, denied full access, or left out altogether, then we have failed at our task

(Birch 2003:24).

The seminary can and should become a place of involvement with the incarnate God who engages with life. The church, through its ministers, can do the same without fear of losing its identity. God shared his love through Jesus who became a man for others. The church in a similar vein should be the salt and light of the earth. It has to get involved *with* and minister *with* the real other. This conviction should be impressed in the minds of the ministers of the

church, but there is no better means of convincing them than through their seminary and theological formation.

## **8.5 SUMMARY OF RESEARCH FINDINGS**

Deconstruction of the dominant disability story was central to the investigation carried out in this research. The aim was to discover, through participation with people with disabilities, ways in which society has been responsible for the construction of dominant disabled bodies and how such constructions assumed reality status that affects people with disabilities in adverse ways. The social constructionist framework has been used to examine culture, traditions and religions in order to identify ways in which language and discourse combine to create social construct out of identities.

The social construction of people with disabilities is fraught with political ramifications. Through symbols, language and practice, both in church and society, politics of power play themselves out and are often skewed against people with disabilities. The application of the ideas of Foucault and Derrida in particular have helped to reveal the often glossed over power dynamics inherent in the regularisation and naming of the disabled body.

Deconstruction, as employed in this research, went further in identifying and taking apart the beliefs and convictions that sustain the dominant disability story, as well as following through unique outcomes as they emerged from our conversation with research participants. The church, culture and public institutions in Lesotho constituted a context within which a dominant disability story was constructed and deconstructed, and an alternative, relational, inclusive, responsible and accountable story co-constructed.

What has emerged from this research is that, indeed, disability is a social construct. It is subject to historical, cultural and societal determinations. It has therefore remained a shifting and unstable category, refusing to be homogenised. Though it remained, in the main, a negative category, in some cases it was viewed in positive terms, deserving therefore of compassion and charitable treatment. This tension continues to characterise relations in church and society between people with disabilities and those who claim to be able-bodied in our day. Through language, rituals, models, practices, policies and laws we develop, bodies in general, and disabled bodies in particular, continue to be constructed.

Exploring the beliefs and ideas that sustain the construction of a dominant disability story has also facilitated the emergence of an alternative story that is relational, inclusive, responsible and accountable. The participation of people with disabilities in the creation of



an alternative story facilitated the emergence of what has been proposed in this research as a participatory model of disability. Not only will it assist as a tool for use by policymakers not only to review current policies on disability but also to interrogate models that are often invented elsewhere and presented to people in pre-packaged forms.

This participatory model of disability links up well with the metaphor of a church as communion. Within such a church the voice of every member, particularly that of the previously marginalised, is taken seriously. Within such a church one is a member not by virtue of being able-bodied or disabled, but by virtue of faith in Jesus. It is a church where interdependence, *ubuntu*, embrace and healing are the key features.

## **8.6 SUGGESTIONS FOR FURTHER ACTION AND RESEARCH**

The focus of the study was a deconstruction and co-construction of dominant disability narratives. This was setting a plot that would attract what contributed toward the development of that plot and leave out what did not. The lenses used to read the story further limited the scope of this research journey. It is my belief that a journey is an open-ended enterprise, as was our research journey. It had at some point to end, but the end of one journey is the beginning of another. In the following paragraphs I reflect on some of the stages of the journey that were not analysed in the thesis, but which could however be considered for further action and research.

### **8.6.1 Faces of poverty, HIV and AIDS and disability**

From conversations with research participants, local voices on the experience of living with disability emerged. These voices matched the social location of the selected research participants. I am under no illusion that the voices of people with disabilities included in this research journey represent all categories and experiences of every person with disability in Lesotho. The individual research participants chosen for this research were either employed or studying. Though they face challenges common to people with disabilities, they cannot be said to represent all the faces of disability, particularly the poor and the unemployed. Some categories of disability are more marginalised than others, and their chances to succeed in the labour market are very bleak. People with speech and hearing impairment seem to be more disadvantaged. Their integration into mainstream education has not yielded results in their favour. Lack of teachers with knowledge of sign language at all levels of education is one of the greatest obstacles. A study with research participants in different social locations would have yielded different results, which is an issue for further research. The epidemic of HIV/AIDS and disability is an important one and deserves more attention as research

participants intimated in our conversations. The Situational Analysis on HIV/AIDS and Disability in the Kingdom of Lesotho by Ntlatlapa (2007) reveals that very little is known about the condition in Lesotho, as there is virtually no research in this area and very few organisations empowered or confident enough to work with various categories of disabled people. They are therefore rendered vulnerable to HIV infection.

### **8.6.2 “If we had had the focused groups things would be different”**

I had envisaged a scenario of coming together as research participants at some point in our research journey, however the different programmes and commitments of the research participants did not allow for such. Conducting individual interviews had its own advantages, especially given that not all in the group spoke the same language and that some would need translators every time we met. I still feel that group interviews would have expanded, affirmed or even challenged stories from other research participants. The outcome, I believe, would have been richer.

The meeting that I was invited to attend, between a deacon and a group of visually impaired individuals at the Cathedral of our Lady of Victories alerted me to the benefits of discussing things as a group. When I asked the group about how it benefited them that they were now talking their issues as this particular group, said the response was, *“it is only when we come together that we realised we had common concerns and aspirations.”* One of them had shared with the group that he had been on the verge of quitting the Church but now was determined to persevere. This confirms Salmon’s (2007:985) view that, “group interviews give additional support, encouragement, and an increased sense of safety and trust in an interview with a researcher who was previously unknown”. This conversation between people with disabilities among themselves can only serve as a starting point and not as an end itself. Awareness is brought about through interaction between the disabled and the non-disabled, as in that way they cease to be the sinful other, the sick, the abnormal or the one to be rehabilitated, and they become the one I know, I journey with and the one I care *with*.

### **8.6.3 The missing voice of the pastors**

The desire expressed at the beginning of this research journey has been that pastors should be part of this research especially for the voice of authority that they represent. Winning their confidence, to become part of this research journey has not been an easy thing. Their level of understanding, denominational position and suspicion about research, made it difficult to access their authentic voice. I could sense the reluctance coupled with discomfort that

accompanied their questions when I invited them to become part of the journey. One willingly offered to share his experiences as both pastor and father-in-law. The one who was willing had an experience to share. His experience of the disabled other changed his dogmatic disposition and his ethical values. The previously “batho ba sa itekanelang” shifted to “I may equally be disabled for not being able to speak their language.” As a result of this encounter and experience, he cannot anymore ignore or disregard the voice and the face of people with disabilities because now he knows and is aware. For the rest of the pastors the opportunity was missed.

I still feel that the dance is not complete without their participation. It would have been interesting to journey with them as they struggle to balance the need to teach what the church believes and the challenge of the reality of the experiences of disability from the research participants. The theology from that struggle would have enriched not only this research journey but all of us who took part in this research journey. When Reg said that the church ought to be both the teaching church and the listening church, he was deconstructing the understanding that the pastors only are the teachers and channels of God’s grace and the people (laity) can only listen. The *koinonic* church is called to listen and to teach. It is called to constantly listen to God’s word and to the groans and the joys of God’s flock entrusted to its care. I owe it to myself and to the research participants to pursue this detail beyond the finalisation of this study. Only in this way can theory be challenged by praxis and the latter subjected to critical reflection for the enhancement and improvement of the traditions in new contexts.

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## **APPENDICES**

### **Appendix A**

#### **A DECONSTRUCTION OF DISABILITY IN CHRISTIAN CULTURAL NARRATIVES: A PARTICIPATORY PASTORAL STUDY**

##### **INFORMATION SHEET FOR RESEARCH PARTICIPANTS**

I wish to thank you for your interest in this project about the stories of people with disabilities and their deconstruction thereof. The suitability of the terminology as well as the aims of the study will be negotiated at our first meeting. I will also, with your permission, be inviting, a significant other person (a parent, carer, as the case may be) as well as your pastor to journey with us.

Please read this information sheet carefully before deciding whether or not to participate in this research. If you decide to participate, I thank you. If you decide not to take part, you will not be disadvantaged in any way for deciding so.

##### **The Aims of the Research**

This research is undertaken as part of the requirement for a doctoral degree in Practical Theology – with specialization in Pastoral Therapy. The aims of the research are as follows:

- a) To trace the evolution of disability in both Christian and Sesotho narratives
- b) To analyse the impact of the pain caused by the long hegemony of able-bodied theology
- c) To deconstruct together with the research participants oppressive ways inherent in the dominant story of disability and co-construct more life giving ways of inclusiveness in the light of a 'migration of identity' metaphor.

##### **Participants needed for the study**

Six people with disabilities will form the core of this research. They will tell their stories and share their experiences of living with disability. Parents and carers will also be invited to journey with us and acknowledge the impact of the long hegemony of dominant disability story. Pastors of the research participants, because of the 'authoritative voice' they represent, will also be invited to become part of the journey. The last two groups will be included with the permission of the research participants.

**What will be required of participants?**

Should you agree to take part in this research, you will be asked to give consent for the use of the information obtained during meetings and sessions in the research. If you decide to take part in this research, you will be expected to meet at times agreed between yourselves and the researcher. After each meeting you will receive a summary of the session on which to make comments, corrections and feedback. The summary will be in Sesotho. The report will, however, be written in English.

**Free participation**

You are free to withdraw from this research project at any time without any consequence to you.

**Confidentiality**

The information obtained during the meetings will be used in the project and will be available to my supervisor for comments and discussions. If you prefer not to have sessions put on audiotape, notes will be preferred during meetings. This information will be stored and locked up in a filing cabinet and will be disposed of after the completion of this research.

**Results of the study**

The intention is to publish the results of this research in different forms. Details of names and places will be hidden under the pseudonym of your own choice if you so wish. You will also be availed a copy of this research if you so wish.

**Questions of participants**

If you should have any questions or concerns to raise before, during or after the research, feel free to contact me at the following number:

Cell: + 266 63016969

Or my Supervisor Dirk Kotzé at the Institute for Therapeutic Development:

Tel: +27 12 4606704

This project has been reviewed and approved by the Department of Practical Theology, Unisa and the Institute for Therapeutic Development.

## Appendix B

### DECONSTRUCTING DISABILITY IN CHRISTIAN CULTURAL NARRATIVES CONSENT FORM FOR RESEARCH PARTICIPANTS

I have read the information Sheet concerning the research project and I understand what the project is all about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage. I know that:

1. My participation in the research project is entirely voluntary.
2. I am free to withdraw from the project at any time without any disadvantage.
3. I am aware of what will happen to my personal information at the completion of the project; that the information will be kept confidential and that raw data that the project depends on will be retained for three years after which it will be destroyed.
4. I will receive no payment or compensation for participating in the study.
5. All personal information supplied by me will remain confidential throughout the project.
6. I am aware that Paul's supervisor will read the material.

I ....., therefore, give consent to be interviewed and the interviews be tape-recorded. I understand that the tape-recordings will be transcribed and used for material for a doctoral thesis. I agree that I do not have to answer any question that I choose not to answer.

I understand that my name will not be used, but a code name or pseudonym will be given and that confidentiality will be maintained. I also agree that, after consultation with me on the interpretation of what has been said on the recordings, the transcribed recordings may be used for the thesis.

.....  
Signature of participant

.....  
Date

.....  
Signature of witness

.....  
Date

**Appendix C**

**A DECONSTRUCTION OF DISABILITY IN CHRISTIAN CULTURAL NARRATIVES: A PARTICIPATORY PASTORAL STUDY**

**CONSENT FORM FOR CO-RESEARCH PARTICIPANT**

I am in agreement with the aim of the study as described and explained to me.

I agree that my story be used during discussions of the research participants in my presence as well as in my absence.

I agree that I shall have access to the summary notes of the discussion and that I shall have to respond to these.

I understand that I reserve the right to alter or delete any information about me that I may wish not to be included in the report.

I prefer that the following pseudonym be used for the purpose of the discussion:

.....

OR

I prefer that my own name (as indicated below) be used during the discussion.

.....

.....

Signature of participant

.....

Date

## Appendix D

### Research interview guide questions for participants

1. Please tell me about yourself (i.e name, family background etc).
2. Would you tell me about your relationship with your form of disability (when it started, family reaction to it, how it was explained in terms of its causes, your beliefs about it).
3. Please tell me about your own understanding of disability or impairment.
4. Are there ways in which you may consider yourself more/less disabled than other people who call themselves non-disabled? How would you prefer to be identified in terms of your disability or impairment?
5. Please tell us about some of the painful things you experienced from society as a result of your impairment/disability. Tell us ways in which you coped/managed in such circumstances.
6. Can you share with us some experiences from school or work that shaped your life in both positive and negative ways?
7. Can you tell us about the good things you experienced from society as a result of your impairment/disability? Share with us what they meant to you.
8. Tell us your experiences about the church and disability/impairment and about going to Church. Would you say that the church is taking notice of you? Tells us what the church (Pastors, Priests, ministers of religion) still has to learn about ministering to people with disabilities in general and your form of disability in particular. What is it we can learn from the Bible about people with disabilities and ministering to them?
9. In what healthy ways can the so-called non-disabled people relate with disability and people with disability?
10. Tells us about the things that the so-called non-disabled people can learn from people with impairments/disabilities.
11. In what ways does the society (Basotho) treat people whom they perceive to be different?
12. Are you aware of any efforts made by the Government of Lesotho, through its different Ministries, or the Non-Governmental organisations (NGOs) to improve the lives of people with disabilities? Can you say what you wish the government or NGOs could do.
13. What stories do people with disabilities have to share with the so-called non-disabled people?

14. Is there anything that this research can achieve for all of us doing this research? Can you mention it if any.
15. Any other information you wish to share.