ACCESS TO HIGHER EDUCATION FOR STUDENTS WITH DISABILITIES IN SOUTH AFRICA: A TENSIVE INTERSECTION OF BENEVOLENCE, RIGHTS, AND THE IMPASSE OF THE SOCIAL MODEL OF DISABILITY

By

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ABSTRACT

The provision of support for students with disabilities in South Africa inadvertently finds itself at a tensive[1] intersection of benevolence, rights and the impasse of the social model of disability. The root of this tension partly emanates from the fact that, in comparison with the United States, the support structures for students with disabilities in South Africa are constituted by both benevolence and the rights approach, both of which coexist in a contradictory manner. The tension is exacerbated by the impasse of the social model of disability, which impedes the systematic provision of support for students with disabilities in the South African higher education system. This tensive intersection is unfortunately not yet obvious because of the seemingly subtle and uncritical belief in both the social model of disability and the legacy of benevolence and overlooking the context of a developing country. The transformation of our higher education system should break this deadlock by operationalising the social model of

[1] This adjective is not found in many dictionaries, other than the World Book Dictionary and Encarta Dictionary. It is seldom used and tension.

Preface

The subject of this thesis is to situate the provision of support for students with disabilities in South Africa in the context of rights, the social model of disability and benevolence. According to the central argument of this thesis, the provision of support is conceptualised in a contradictory manner, in terms of which benevolence, rights and the impasse of the social model of disability intersect. This intersection is contradictory, because the support for students with disabilities in South Africa seems to be rooted in benevolence, which cannot coexist with the discourse of disability rights, which in turn cannot be realised, because the framework of the social model of disability is at an impasse. This contradiction will be clearly explained and demonstrated in Chapter 10. However, before I commence the thesis, the following narrative provides some background to the personal journey of this essay.

In 2000, I was working for the Centre for Higher Education Development at the University of Cape Town, and I intended to present a paper on the subject of widening access to higher education in South Africa. In particular, I was interested in support programmes offered by some higher education institutions in South African universities. As I read through the literature, I observed that race and gender were the categories of interest for widening access to higher education in South Africa, with race taking precedence over gender. These categories were dominating the discourse of widening access to higher education in post-apartheid South Africa, and thus I felt that I would not be able to add much academic value if I were to write on race and gender issues.

resources and, moreover, have already implemented higher education policies of a more systematic nature for the support of students with disabilities.

The third factor was that this subject was largely a descriptive one, both in South Africa and in other countries. Contrary to the general subject of disability studies, the literature on access to higher education for students with disabilities had little analytical or sociological frameworks. The basic question seemed to be, what could be done for students with disabilities? It thus seemed to me that, from the beginning, the question of access to higher education for students with disabilities was a pragmatic one.

Although the subject of access to higher education for students with disabilities was largely descriptive, there was a fundamental difference in focus between South Africa and some developed countries. South Africa seemed to be concentrating on the assessment of needs, and learning from other countries to enhance the process of higher education transformation. Developed countries, in contrast, were assessing their past efforts, planning future strategies, and garnering resources to improve their existing systems of supporting students with disabilities.

The final factor was that South Africa shared some similar experiences with developed countries. One important similarity is that, since the 1980's, South Africa has been part of international campaigns that have been struggling against discrimination towards and oppression of people with disabilities. This means that it shares some of the socio-political and economic arguments on the rights of people with disabilities to enjoy citizenship. However, whereas developed countries are fighting for equal rights and advocacy within their context of improving the existing provision of support, South Africa is still fighting for the following: acquiring resources; recognising disability rights; and advocacy in the

disability and recognising our context as a developing country in pursuit of the transformation of higher education for diversity, excellence and equity.

The questions that the thesis asks are, if South Africa advocates for a social model of disability in its transformation of higher education, why is it that, after a decade of democracy, there is no disability policy in higher education? Why are disability support structures voluntary instead of obligatory? Why is disability in higher education one of the least important priorities?

In order to answer these questions, I conducted research through triangulation. The research methods involved were a literature survey, exploratory interviews, a national survey, and a comparative study of two American universities. From the literature survey, I connected the concepts of benevolence, rights and the social model of disability. The exploratory survey laid the foundations for the national survey, which indicated some of the problems faced by the disability support provider in higher education institutions (HEIs) in South Africa. The comparative study suggested some of the reasons for South Africa's problems and partly helped to suggest some recommendations.

The research found that South Africa was still struggling with balancing disability as an ideological entity and disability as a statistical entity. The debates on disability centered on the rejection of the medical model in favour of the social model of disability. The consequence of this polarised and exclusionary debate is that there is little consideration of the practicalities of redress, which would require recourse to the statistical entity of disability. Hence, even though the disability movement views disability as oppression, the way forward is blocked by an uncritical advocacy of disability rights and the social model of disability, and the realisation that our disability services still rest on assumptions of benevolence towards students with disabilities, rather than disability rights. However, even

when considering the discourse of these rights, it becomes problematic to translate them into real rights that are supported by legislation, changes of attitudes and funding.

The thesis concludes that the provision of support for students with disabilities in South Africa finds itself at a tensive intersection of benevolence, rights and the impasse of the social model of disability. It suggests that the only way to move away from and overcome this tension is to operationalise the social model of disability and to take into account our context as a developing country. The recommendations are that South Africa needs a national policy for students with disabilities and that it needs to balance disability as both an ideological entity and as a statistical entity too.

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Then I recalled that, in 1995 when I was an undergraduate student at the University of Cape Town (UCT), I had volunteered to read text on tape for blind students at the UCT Disability Unit. During my literature search, I had not come across any academic titles or current affairs debates on widening access to higher education for people with disabilities in South Africa. It was at this point that I decided to write a paper on access to higher education for students with disabilities in South Africa. My intention was to present a paper describing the existing provisions for students with disabilities. However, as my interest in the subject grew, I was presented with the opportunity to study towards a doctoral degree and so I decided to make this my thesis topic.

While expanding my literature search to other countries, I realised that there seemed to be four factors that both differentiated South Africa's experience from those of other countries, and also influenced my thesis. The first one was that, unlike most developed countries, South Africa was a nation in transition, an emerging democracy. The transition period necessitated the transformation of most state and private institutions, and higher education was one of the institutions that were undergoing such a process of transformation. While disability did not seem to be a visible part of transformation, I nonetheless thought of it as part of diversifying the student body, as was already happening with regard to race, gender and class.

The second factor was that South Africa was still a developing country in terms of resources and policies for the general support for people with disabilities, in contrast to developed nations, which had advanced systems of disability support and higher levels of financing the systems for people with disabilities in general and students with disabilities in particular. Developed countries, such as the United States, the United Kingdom, Belgium and Australia, have sufficient

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context of resource constraints and competing priorities in the transformation process.

These four factors shaped my thesis: Based on the first one, I was interested in researching on students with disabilities. From the second one, I realised that I needed to compare South Africa with some developed countries in terms of policies and resources. The third one presented me with an opportunity to conduct a more rigorous sociological analysis on the subject. The final one, in relations to the first one, encouraged me to explore the factors that might enhance or hinder access to higher education for students with disabilities, especially in the context of debates about benevolence, rights and the social model of disability.

Later, however, in the process of preparing the thesis, I discovered that, in 2001, the Foundation of Tertiary Institutions of the Northern Metropolis (FOTIM) had conducted a brief survey of its then 16 members to explore their disability services in order to assess whether there was a need for a disability project. FOTIM is now a consortium of nine public higher education institutions that network to discuss problems and solutions in higher education including students with disabilities. This brief survey is attached in Appendix D and, at the time of writing this thesis, FOTIM and the Disabled Students Office at the University of the Witwatersrand were to co-host a disability conference from 5 to 7 October 2005 at the University of the Witwatersrand. This conference suggests that FOTIM has indeed realised the need for a disability projects in its consortium. The findings of the FOTIM survey do not overlap with the central argument of this thesis because of the differences in methodology and scope between FOTIM's research and mine. Rather they serve as an indication that some work is being done with regard to higher education and disability in South Africa.

In summary, this thesis seeks to conduct a comparative analysis of access to higher education among students with disabilities in South Africa in the context of transformation. The purpose of this comparative analysis is to examine the South African situation and to show the possibilities offered by of a sociological understanding of access to higher education for students with disabilities in a country such as ours.

PART I

Background to the Thesis

CHAPTER 1

INTRODUCTION

(a) Thesis Argument

The argument of this thesis is that the future of the national provision of support for students with disabilities in the context of higher education in South Africa is inadvertently finding itself in a cul-de-sac, where benevolence, rights and the impasse of the social model of disability intersect in a tensive[2] manner. One way of breaking through the looming crisis is to replace benevolence with duty, to replace rights with real rights, and to examine the social model of disability in a critical manner. Central to the argument is that we need to understand the situation in South Africa in the context of a developing country, which faces both national imperatives and global pressures. Chapter 10 will elaborate and illustrate the general argument of the thesis.

The thesis seeks to answer the following questions: If South Africa is promoting a social model of disability in its higher education transformation, why is there is no disability policy in higher education? Why are disability support structures voluntary instead of obligatory? Why are disability and higher education the lowest priorities?

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[2] This adjective is not found in many dictionaries, other than the World Book Dictionary and Encarta Dictionary. It is seldom used and tension

(b) Key Terms

I am investigating the position of South Africa with regard to disabilities in terms of three key terms: benevolence, rights and the social model of disability. I have chosen these three concepts because they run through the literature on disability studies both implicitly and explicitly. I use the word benevolence to refer to what Johnstone (2001:7) calls the legacy of philanthropy which is associated with the alms house, the industrial revolution and asylums or what French (1994:7) refers to as the philanthropic model of disability, which portrays people with disabilities as helpless and in need of charitable care. The understanding of the concept of rights, as used in this thesis, falls within the discourse of the United Nations' (1948) Universal Declaration of Human Rights. I furthermore refer to second generation rights (social and economic) in which students with disabilities claim the right to higher education within the social justice framework, and reject the needs based approach. In terms of the social model of disability, disability is perceived as a social category that is produced by social barriers within relations of power and in particular within the capitalist mode of. In summary, then, the aim of this thesis is to position the South African disability support system in higher education in terms of benevolence, rights and the social model of disability.

(c) Background

The transformation of the South African higher education system from one that was racially divided into one that is unitary, non-racial and non-sexist has received considerable attention in the academy and in South African politics. For example,

Cloete, et al (2002) are the editors of a book that does not only consider transformation policies and practices in the South African higher education system, but also with its relationship to globalisation. Cooper and Subostzky (2001) provide statistical evidence of the transformation of the higher education student body according to race and gender and the intersection of both during the democratisation period. Kruss (2004) reports on the development and structures of private higher education in South Africa and elsewhere. Agnélil-Carter (1998) compiles articles on strategies of helping students from previously disadvantaged background to cope with curriculum demands.

Although much attention has been given to higher education issues, such as funding frameworks, changing student bodies, curriculum development, institutional cultures, governance, globalisation and the socially reconstructive role of higher education, little attention has been paid to access to higher education for students with disabilities in South Africa. After an extensive literature search on this topic, the only organisation that seems to be directly interested in the subject is the Foundation of Tertiary Institutions of the Northern Metropolis (FOTIM), which I mentioned in the preface.

Looking at the international literature, it became clear that the subject was indeed being extensively studied in developed countries, such as the United States, the United Kingdom, Canada and Australia. Nonetheless, the available literature seems to be limited to three areas of study. The first consists of descriptive and evaluative reports on the availability and provision of support for students with disabilities. The second concerns the actual experiences of students with disabilities in post-secondary education. The third area of study looks at the perceptions of the academic community with regard to disability and the participation of students with disabilities in higher education institutions. For example, Hurst (1998) provides research articles on the existence of support

services for student with disabilities across countries in the developed world. Pfeiffer (2001) has conducted a comparative study of support services for students with disabilities in Massachussetts. Shevlin, Kenny and McNeela (2004) document the experiences of students with disabilities at two Irish universities. The latter also point out that, in the area of research on the experiences of students with disabilities, the focus is on specific disabilities rather than on general problems.

Given such scant interest in access to higher education for students with disabilities in South Africa, I thus decided to study the subject, as I will explain in the next chapter on methodology. Research material on higher education and disability elsewhere is helpful in indicating how far other countries have gone in terms of supporting such students. Other institutions of higher education in South Africa could easily replicate such research. However, my observation is that, although such research is indeed possible here, a macro view of the position of the South African system in this regard would be more revealing than a simple description and evaluation of services or an isolated analysis of the experience of students with disabilities in selected institutions.

In trying to research this position, it became evident that there was very little material upon which to build a systematic study in South Africa. The best possible way was to study South Africa's systems of disability support in relation to systems in other countries. After some thought, I chose the United States, because federal law entitles students with disabilities to specific services, whereas no such provision or anything approximating it exists in South Africa. I also refer to other developed countries to highlight South Africa's position.

(d) Chapter Outlines

This thesis does not follow the typical outline of introduction, methodology, findings, discussion and conclusion. This is because it drew on various sources to create a certain analytical argument, which was best structured into four parts with sections as chapters. Part I provides the background to the thesis, and includes this chapter and Chapter 2 on methodology. Part II is a conceptual analysis, which focuses on the concepts of benevolence, rights and the social model of disability in three separate chapters (Chapters 3 to 5). Part III describes the legal frameworks and actual support provisions for students with disabilities in the United States (Chapters 6 and 7) and in South Africa (Chapter 8). Part IV illustrates the argument of the thesis by linking benevolence, rights and the impasse of the social model of disability (Chapters 9 and 10) and concludes the study (Chapter 10). The following sections describe the chapters in detail.

PART I

Chapter 2 explains the methodology and provides the philosophical assumptions underlying the study. It also describes the research design, the data collection methods, the data analysis and the limitations of the methodology.

PART II

Chapter 3 analyses the problem of the relationship between disability and society. As such, it is not a series of definitions of disability, but rather an overview of the relationship between disability and society. The chapter tries to unearth and develop the idea of benevolence, which is part of the central argument of the thesis. It also tries to understand the social model of disability as a relational model that has resolved the relationship between disability and society. The

primary purpose is to explain the use of the social model of disability in disability studies and in this thesis in particular.

Chapter 4 discusses various critiques of the social model of disability. These critiques also try to lay part of the foundation for the central argument of my thesis, with regard to the tensive intersection of benevolence, rights and the social model of disability. It focuses specifically on the impasse of the social model of disability as discussed in contemporary disability literature. At a later stage in the thesis, I will show that this impasse is also partly present in South Africa.

Chapter 5 describes the theoretical, practical and rights approach frameworks within which people with disabilities receive education. It describes the changing paradigms about the education of people with disabilities, and outlines the medical model of disability in the education of disabled South Africans. It also tries to develop frameworks within which students with disabilities can receive support in higher education by comparing the situations existing in the United States , Britain, Canada and Australia. Thereafter, it problematises the notion of rights in disability studies. The chapter primarily tries to show that, whereas disability rights run across all contemporary paradigms and practical frameworks in the provision of support to students with disabilities, they (disability rights) are academically underdeveloped concepts, which cause tension in themselves. This argument introduces the tensions that exist in the Human Rights discourse, and investigates how they affect the provision of support to students with disabilities in South Africa.

PART III

Chapters 6 and 7 introduce and describe the system of disability support in the United States. Chapter 6 describes the legal framework, whereas Chapter 7 outlines the key achievements in that country since the creation of disability

support services in state funded colleges and universities, and specifically describes the contemporary provision of support at Boston University and Harvard University. The United States is a good point of comparison for this thesis because of two reasons. Firstly, it has a long official history of disability support in higher education: In 2003, the United States celebrated its 30th anniversary of officially providing for its students with disabilities. The University of Illinois at Urbana-Champaign, which is the first university in the United States to provide support to students with disabilities, has been doing so for 57 years as at 2005. Secondly, as I will suggest in Chapter 10, the situation in the United States provides some useful lessons from which South Africa could learn.

Chapter 8 describes the legal and policy frameworks that protect disability rights in South Africa by looking at some of the relevant education policies and other policies since 1994, i.e. after the election of the first democratic government. The primary purpose of the chapter is to indicate that even though South Africa does not yet have a national policy on the provision of support for students with disabilities, some protection for disability rights does already exist. However, it will also indicate that such rights do not guarantee the provision of support for students with disabilities.

PART IV

Chapter 9 is devoted to a descriptive investigation of the actual South African support system. It begins by describing how the disability support services began in the 1980's. It then analyses some of the national survey data to explain how such support is being provided in the South African higher education environment. The descriptions in this chapter are used in Chapter 10 to compare the South African situation to that of the United States. The aim of this comparison is to juxtapose the two countries' experiences.

Chapter 10 summarises the important issues raised in Chapters 3 to 9, and then presents and illustrates the argument of the looming cul-de-sac, in which benevolence, rights and the impasse of the social model of disability intersect in a tensive manner. The primary aim of this chapter is to indicate that, in the context of a developing country like South Africa, the experiences and priorities are different to those in developed countries such as the United States. Moreover, facing the challenges of global pressures complicates this difference in terms of both the impacts and responses to globalisation.

Finally, Chapter 11 concludes the thesis by summarising the main points, making some important recommendation, and indicating the limitations of the thesis.

CHAPTER 2

METHODOLOGY

(I) Introduction

The purpose of this chapter is three-fold: the first purpose is to present the philosophical assumptions underlying this research; the second is to describe the applied research strategy for this study; and the final one is to describe and discuss the specific research techniques that were used in the research leading up to the thesis. The philosophical assumptions are important because they help one to "recognize that 'knowledge' is determined by the way you frame a research problem and the strategies that are used to obtain, analyze, and interpret information" (DePoy and Gitlin, 1998:26). The philosophical assumptions and the description of the research strategy and techniques help the researcher to reflect on the process, and to defend and justify his or her methods not as best but as necessary for the research question (Clough and Nutbrown, 2003).

The philosophical assumptions in this research are partly derived from a positivist approach in as far as collecting survey data for the Council for Higher Education (CHE) survey was concerned, partly interpretivist in the literature review, and lastly applying a structural materialist approach in deciding on the units of analysis. Briefly, positivism is a theory of knowledge in philosophy. It emphasises empirical and observable knowledge, and rejects metaphysics and theology as being inadequate and illogical. Interpretivism emphasises human construction and understanding of phenomena. Lastly, structural materialism is a philosophical approach, which argues that the only thing that exists is matter and its qualities. In this research, then, I have (in accordance with the positivist approach) collected data that is observable and verifiable. Moreover, I have focused on

macro structures and thus taken a macro view of higher education institutions, in accordance with the structural materialist approach.

The research strategy used herein is triangulation. As such, it is a combination of an exploratory study, a literature survey, a Council on Higher Education (CHE)[3] survey research, two case studies and interviews. The exploratory study, which was conducted in 2001, investigated what was available in South Africa in terms of the provision of support for students with disabilities. I used the literature survey to build the thesis' core argument on the impasse of benevolence, rights and the social model of disability, and to illustrate key historical developments in South Africa and in the United States with regard to students with disabilities. It also provided a conceptual analysis and background to both countries' situations. The CHE survey research was conducted at South African universities and technikons[4] in 2003 to identify and report on the existing situation in these institutions. The case studies looked at two American universities (Boston University and Harvard University) in April and May of 2004. The following techniques of data collection were used: documentary sources for conceptual analysis and background with regard to the provision of support for students with disabilities in both South Africa and the United States; mailed semi-structured questionnaires with regard to the CHE survey; and unstructured interviews for the case studies.

In accordance with the above, this chapter thus comprises six sections. The first is a discussion of the philosophical assumptions underpinning the research methods. The second makes a case for choosing the survey method, the case study method and the documentary materials method. The third section discusses

[3] The Council on Higher Education (CHE) is a statutory, independent advisory body for the Minister of Education.

[4] Technikons in South Africa are now called universities of technology, as some are currently merging with some universities and also forming what are called 'comprehensive universities'.

the research strategy and explains the units of analysis, sources of data, data collection and data analysis. The fourth explains the theoretical framework underlying the thesis, the fifth looks at the ethical considerations, and the final section delimits the study.

(II) A Positivist Approach to Survey Data

Clough and Nutbrown (2003) argue that research methods are often erroneously polarised into positivist, interpretive or critical theory. They suggest that social researchers should not be guided by choosing strictly one of these three philosophical traditions, but that they are faced with alternatives and strategic decisions regarding the research question. Quoting Denscombe (1998: 3), they agree that in social research, the researcher should consider six issues, namely, relevance; feasibility; coverage; accuracy; objectivity and ethics, and additionally interest and motivation "because research projects become part of the life of researchers and it is important that any research 'grabs' the researcher sufficiently to sustain them throughout the study and all its triumphs and disasters!" (Clough and Nutbrown, 2003: 15).

Similarly, Brayant (1992) indicates that, whereas philosophical assumptions have value for sociological research, sociologists are not necessarily required to follow philosophical distinctions strictly. He suggests that sociologist should be able use philosophical assumptions if these are helpful and that they should also construct their own philosophical arguments instead of religiously sticking to what philosophers have proposed. Social research and social theory should therefore be underpinned by an ontology and epistemology that is justifiable in the context of a particular social inquiry. In summary, as Lazarsfeld observes, "Philosophers of science are not interested in and do not know what a work-a-day empirical research man does. This has two consequences: either we have to become our

own methodologists or we have to muddle along without benefit of the explicating clergy" (Lazarsfeld, 1960:470).

Even though Clough and Nutbrown (2003) and Brayant (1992) make excellent points about the need for flexibility in research design, they also indicate that it is necessary to locate research within a particular or combination of traditions and methods of inquiry. This makes it easier for the researcher to be reflexive by questioning his or her approach in conducting research. Locating one's research within particular philosophical categories allows the researcher to explain how the research question and the research context justify the choice of philosophical assumptions and research methods.

The survey research is primarily located within the positivist assumption albeit only in its data collection methods. It is not based on empiricism, which claims that 'truth' is only verifiable through the senses. Positivism is a philosophical doctrine that ranks the primacy of empirical evidence of phenomena over superstition and speculation. The French philosopher August Comte advocated this way of thinking by suggesting that intellectual reasoning has progressed through three stages, namely, theological, metaphysical and positive. "In the theological stage, human science is at its most primitive, awash in religious superstition ... in the metaphysical stage the gods are replaced by impersonal force of gravity and charge ... the third stage and final stage is the positive stage in which the metaphysical forces are done away with in favour of common sense observational concepts" (Klee, 1997:29).

The positivist doctrine argues that social phenomena can only be reconstructed through scientific knowledge of what is observable. Logical positivism went so far as to argue that only logical and mathematical truths could be established to produce the positivist model of scientific theory presented in formal language (Klee 1997).

In sociology, positivism as a philosophical doctrine and as a sociological outlook has a pejorative connotation of seeking to establish a social science research agenda that is similar to the natural sciences, in which there is a tendency to establish absolute truths and propositions of universal laws of nature. Positivism has been associated with evolutionary theory and a naturalistic treatment of social phenomena. Modern sociologists point out that, methodologically, positivism has failed to unify sociological knowledge and has also failed to achieve consensus in social reconstruction.

While the philosophical debates about the merits and demerits of positivism are beyond the scope of the thesis, the influence and translation of positivism into social research methods is nonetheless important to consider. For sociological research, the positivist approach is not necessarily a worldview but a philosophical basis for gathering data. Research methods that are underpinned by positivism are generally quantitative and qualitative methods and, in this case, we have used the survey method, historical evidence and interviews to collect verifiable data.

Quantitative research methods are underpinned by a positivist argument that knowledge is experienced, and that it can thus be categorised and quantified. Such methods include experiments, surveys, content analysis, and existing statistics (Neuman, 2000:34-35). However, as I have stated above, choosing quantitative methods of the survey data collection does not mean explaining phenomena in terms of a natural scientific model. Rather, the research uses a conceptual analysis of the intersection of benevolence, rights and the social model of disability.

(III) A Case for Surveys, Documentary Sources and Case Studies

(a) Surveys

Part of the thesis – as Chapter 9 will show in detail – was a survey of South African universities and technikons. Surveys are a form of data collection and data analysis. A survey is "any enquiry which collects pieces of information by whatever method, over a range of different cases, and arranges the information about those cases as variables; variables therefore must have the property of providing one unique code for every case ... the common strategy is to consider the relationship of the variables" (Marsh, 2003:95). Neuman adds, "Survey researchers sample many respondents who answer the same questions. They measure many variables, test multiple hypotheses, and infer temporal order from questions about past behaviour, experiences, or characteristics" (Neuman, 2000:250).

In this research, we have used the CHE survey to cover all thirty-six existing South African institution of higher education. The purpose was to begin to collect empirical data on the status of support for students with disabilities in universities and techniknons throughout the country. However, the CHE survey collected only limited data on what was reported, by means of mailed questionnaire, by officials at the universities and technikons. It targeted key informants at each of the 36 higher education institutions, who provided data on this topic within the limits of their knowledge and understanding of the process. Thus, although the CHE survey did target all higher education institutions in South Africa, it did not cover a wide sample of respondents who could provide broad and detailed information in each higher education institution.

Surveys, which have a long history, dating back to 17th century Britain, have evolved into big private enterprises, now make use of complex computerised methods (Neuman, 2002; De Vause, 2003) and have been subject to criticism. De

Vause (2003: 7) has categorised the relevant criticisms into three, namely, philosophical, technique-based and political. In the philosophical category, surveys are criticised for: failing to establish causality; unable to derive meaningful social action; ignoring human consciousness; failing to consider context; being rigid and empiricist; and failing to recognise that some things are unquantifiable. In the technique category, surveys are criticised for being too restricted by highly structured questionnaires and being too statistical and reducing phenomena to mere numbers. In the political category, surveys are criticised for being manipulative in claiming knowledge and furthering the ideologies of those who are in control.

Although we understand the shortcomings of surveys, the CHE survey was primarily exploratory and descriptive, and claims no causality or explanation of human action and consciousness. The survey questionnaire did not only contain pre-coded questions, but also some unstructured questions. Moreover, it was the first of its kind in South Africa that was designed to help the process of higher education transformation rather than to pursue the ideologies of those in control. In fact, it could be argued that it would partly help the political goals of marginalised people with disabilities to access higher education in South Africa and also help the government to understand the current situation in that regard.

In trying to illuminate the debate rather than defending surveys, Marsh (2003) argues that it is incorrect to reject surveys simply because of their association with positivism. She states that the ways in which researchers collect, analyse and report survey findings makes such researchers susceptible to a positivist charge. Moreover, drawing conclusions from survey results is similar to the positivists' concepts of phenomenalism and nominalism, which are out of favour in sociology. She argues, instead, that surveys cannot offer conclusions but rather processes which could be uncovered by theory and tests.

In agreement with Marsh (2003), this thesis does not use the survey to come to any conclusions. Instead it is used to obtain a descriptive profile of the current South African situation, both empirically and conceptually, and to identify the tensions that exist. Moreover, as I have stated above, the survey has a positivist assumption only in so far as it draws on empirical data rather than on empiricism, which claims that there is no knowledge outside experience or observation.

(b) Documentary Sources

A large and substantial part of the study used both primary and secondary documents to build the thesis. The primary documents that were used were written by Kathy Jagoe at the time when she established the Disabled Students Programme (DSP) at the University of the Witwatersrand in the 1980's. In Chapter 9, these documents partly introduce some background into the actual experience of support provided to students with disabilities in South Africa. These documents were not memoirs, historical accounts or diaries. They were pieces of information that had been obtained before and after the establishment of the DSP. Some documents were proposals to potential sponsors, whereas other documents were progress reports to sponsors.

Although these documents seem to claim that the DSP was the first establishment of its kind to provide support services for students with disabilities in South Africa, one cannot verify this claim from such documents or even claim that they present a complete history of the establishment of the DSP. Finnegan and Thomas (1993) indicate that documents are a process of production and that they cannot be taken at face value because they are produced in certain circumstances for particular purposes. Prior (2003) also explains different texts as discourses, which should be analysed because documentary sources are discursive. Jagoe's documents are no exception. Their goal was to outline the problems faced by people with disabilities and to raise funds for the

establishment of the DSP. In this thesis, her documents are only used to highlight the concept of benevolence rather than to offer a history of the DSP *per se* or to do a discourse analysis or content analysis. They are also used to provide some background into the provision of support for students with disabilities in the South African higher education system.

Other documents that were consulted were secondary data from government publications, research reports, academic books and research papers. These documents were used mainly to understand general disability issues, to understand contemporary debates and development in disability studies, and to prepare for the interviews and the survey. In addition to the interviews and the CHE survey, the literature also helped to compare the overall systems of disability support of South Africa and the United States respectively, with reference to other countries too.

Secondary documents were used particularly in this chapter and in Chapters 3 to 9. Chapter 3 examines the relationship between disability and society with the intention of highlighting the role of benevolence and introducing the social model of disability. Chapter 4 evaluates the social model of disability by discussing the literature on the merits and demerits of this model. It is in this chapter that I point out and investigate the impasse of the social model of disability. Chapter 5 uses literature and official documents to link disability and education in general and to develop such a framework for higher education in particular. It also discusses the issue of disability rights. Chapter 6 describes the legal framework for the support of students with disabilities in the American higher education system. Chapter 7 partly uses secondary literature to provide key selected historical events in the development of the American system, whereas Chapter 8 uses official documents to describe the South African policy framework in relation to disability support. As I have already mentioned, Chapter

9 uses Jogoe's documents to give some background on the South African situation.

Of course, not every document, report or book on disability studies was consulted. Instead, the focus was on those that seemed relevant to the direction of the thesis. Even the selected secondary sources are subject to the same limitations pointed out by Finnegan and Thomas (1993) and Prior (2003). More so than other documents, the selected South African government policies are taken as written policies rather than as implemented policies. Their limitation is that they often reflect what should be done rather than what has been implemented. In the absence of policy implementation, it is difficult to evaluate the situation with greater insight than if the policies were already implemented and evaluated. Thus, the arguments are based more on the written policies than on the actual practices, as will be seen in Chapters 8 and 9.

(c) Case Studies

Another part of the research methods in the thesis are two case studies of Boston University and Harvard University respectively, conducted while I was at Harvard University during the first half of 2004. In this research, a case refers to a single-element subset of a population rather than a conceptual class with some properties (Abbot 2000:53). The purpose of these cases was to explore ways in which they translated Section 504 of Rehabilitation Act of 1973, which looks at the provision of support services for students with disabilities in the American higher education system. Moreover, the cases would offer some lessons and insights for disability support in South Africa. Such case studies are termed "instrumental case studies" (Stake, 1995:3) because they are used to understand and help other situations. In this case, I needed to understand the different ways in which support was provided in the United States and how these might be of use in understanding the South African system.

In terms of case selection, Stake (1995) indicates that case study research is not the same as sampling research, but is framed by a purpose to understand a case. With instrumental case studies, some cases are more helpful than others in order to maximise what one can learn. Moreover, the selection also depends on the resources that are available to the researcher. In the case of this research, I chose Harvard University for two reasons. Firstly, as part of my Spencer Foundation Scholarship, I was eligible to conduct part of my research in one of six designated universities in the United States. Harvard University was my choice because of its unusual decentralised system of support for students with disabilities. The second reason was that it is a very wealthy institution and that its provision of support seemed to approximate the ideal disability support service. The reason I chose Boston University was that, contrary to Harvard University, it has a centralised disability support system, though it too is a relatively wealthy institution. Both these institutions will also highlight the differences between South Africa and the United States.

A limitation of my selection of these two cases is that I could have researched some poorly resourced universities and colleges in Massachusetts. However, the purpose of this study was not to compare American institutions but rather to learn how those that have resources provide support services and what we can learn from them. Although such comparison is outside the scope of the thesis, it would nonetheless have been interesting to know how higher education institutions in the United States that have less resources coped with providing disability support in the context of their Section 504 of the Rehabilitation Act of 1973 This could also be a lesson with respect to the general lack of resources for disability support in South African institutions of higher education.

(IV) Research Design

(a) Units and Sub-units of Analysis

After an extensive search on the availability of support for students with disabilities in South African higher education, I did not seem to find research or an indication of documented support service structures at higher education institutions. As a result, in 2000 I did an initial email 'survey' of most universities and technikons in South Africa to ask them if they had support services for students with disabilities. I asked three questions: Do you have a disability unit? If yes, what services do you provide? If no, why is there no disability unit?

As some replies came in, I realised that my questions were based on the assumption that other universities and technikons either had a similar separate disability service structure to that of my university or had no such structure. It emerged that not all institutions had a separate disability unit, but also that some did provide support within different structures. Moreover, it also emerged that institutions had different modes of support services for students with disabilities.

These differences in terms of structure and services led me to do an exploratory study in 2001. In that study, I conducted face to face unstructured interviews with six higher education institutions in both the Western Cape and Gauteng provinces. I chose these two provinces because I was based in the Western Cape, and because Gauteng was another province that seemed to have most institutions running disability services from which I could gather some relevant information. Moreover, in both provinces I also visited higher education institutions that either had not replied to my initial email 'survey' or those whose websites indicated nothing about disability services.

Before embarking on the six visits, I called the six higher education institutions to identify the relevant person to interview and secure an appointment. During the

interviews, I asked questions on four categories, namely, the existence of policies with regard to providing support for students with disabilities; the structure of the support unit; the functioning of the support unit; and the types of services available. The choice of categories was influenced by both the need to gain a general understanding of disability support services in South Africa and by reading some international literature on support for students with disabilities.

From the international literature review and this exploratory study, I realised that South Africa did not have a national policy to support higher education students with disabilities. Moreover, some institutions said that they had an institutional policy, whereas others said that they did not have one or that it was still being drawn up. This led me to make national policy and legislation my first sub-unit of analysis. This choice was motivated by knowing that the United States had legislation in place that entitled students with disabilities to *legal rights* of support services in federally funded institutions.

The second sub-unit of analysis was the existence of institutional policy on the provision of support for students with disabilities. This was motivated by the observation that not every higher education institution in South Africa that provided support for students with disabilities said that it had a disability policy. Moreover, at that time (2001) countries such as the United Kingdom also had no national policy or legislation that provided specifically for students with disabilities, and yet most higher education institutions had formal policies in this regard.

The third sub-unit of analysis was the structure of support services. The variations in the support structures at each higher education institution, which emerged from my exploratory study, warranted a need to find out how these support services were created and organised; what services they offered; how the structure functioned and what resources were available for running them.

In 2003, the email 'survey' and the exploratory study grew into a national survey mentioned above, which was commissioned and paid for by the Council on Higher Education (CHE) via the Department of Education. The research was conducted under the auspices of the Centre for Higher Education Studies[5] at the University of the Western Cape. Colleen Howell and I undertook the research. Combining the CHE survey and the exploratory study, there are three sub-units of analysis in this thesis. They are:

1. The national legislation or national policy that provides for the support of students with disabilities.

2. The institutional policies that guide the provision of such support for students with disabilities on campus.

3. The structures of support services and the services they offer.

From the literature review and the exploratory survey, it was clear that the United States and other countries have long-established provisions for students with disabilities and that South Africa can learn from these. I therefore decided to make the study comparative in terms of the three sub-units of analysis, by using the South African and American systems of providing support as units of analysis. The unit of analysis is thus the entire system of support for higher education students with disabilities, which consists of the three sub-units that I have identified above.

While I was at Harvard University, I read some documents on the American support system and what Boston University and Harvard University were actually doing in terms of this, and I also conducted interviews at the two institutions. At

[5] During the CHE survey, the Centre for Higher Education Studies was known as the Education Policy Unit (EPU).

the Boston University Disability Centre, I conducted one interview session with the director, his deputy and one co-ordinator. At Harvard University, however, I conducted six separate interviews. Five of those were at five schools with their disability co-ordinators and one was at the Admissions Office with a disability co-ordinator. The schools were the Graduate School of Public Health; the Graduate School of Education; the Graduate School of Business Administration; the Law School; the Disability Resource Centre, which services Harvard College and the Faculty of Arts and Sciences.

(b) Sources of Data

Data for this research came from both primary and secondary sources. Primary data came from informants during the exploratory study interviews in 2001, the CHE survey in 2003, the case studies interviews in 2004 in the United States, and one source on the establishment of the Disabled Students Programme at the University of the Witwatersrand in Johannesburg. This primary data helped to answer – at least in part –questions around the background of disability support in South Africa during the exploratory study at the six institutions and then in more detail in the CHE survey.

A very significant part of the data, however, came from secondary data sources. These were derived from the literature survey, which included research projects, books, government publications and higher education institutions' websites and governments' websites. This secondary data helped to define defining concepts, to guide the analysis, and to clarify the core argument in the thesis on the intersection of benevolence, rights and the social model of disability. In particular, secondary data sources have helped me to contextualise the survey findings within the South African situation, comparing this to the United States and other countries. All chapters, except Chapters 1, 10 and 11, draw significantly on secondary data.

(c) Collection of Data

Data was collected through the following research techniques: mailed semi-structured questionnaires as part of the CHE survey of South African universities and technikons; primary documents on the establishment of the Disabled Students Programme at the University of the Witwatersrand; open ended interviews during the exploratory study; open ended interviews with some staff members of the Boston University Disability Centre and members of staff in the disability services at some schools at Harvard University; international and South African secondary data on access to higher education for students with disabilities and disability issues in general.

Survey Questionnaires

As part of the CHE survey, questionnaires were mailed to all South African universities (21) and technikons (15). According to Neuman (2000: 271-272) the advantages of a mailed questionnaire are that it is the cheapest and that it can reach a wide geographical area. Moreover, to some extent it avoids bias by eliminating interviewer bias and also allows the respondent to check or verify records or information when it is necessary. However, Neuman also points out some disadvantages, which include low response rate; incomplete questionnaires; poor responses on open ended questions; difficulties verifying whether the respondent was serious and honest, and that he or she was the only person filling in the questionnaire.

In the case of this research, the mailed questionnaires had the same advantages as those listed by Neuman (2000). The questionnaires were mailed to all higher education institutions across the country, and respondents were at liberty to fill in the questionnaire. However, the difficulties listed by Neuman (2000) were also evident when the questionnaires were returned. Firstly, not all questionnaires were returned. The response rate was 66% (of the 36 institutions), which

according to Payne and Payne (2004) was above the typical rule of thumb of 33% in general or 60% if the research is relevant to the respondents. Secondly, some questionnaires were incomplete and some open ended questions were not clearly answered. In this regard, however, there were follow-up face to face interviews because respondents were also requested to fill in their names and contact details. Thirdly, the question of verification did not pose a problem because the respondents included their names, contact details and employment positions. This CHE survey will be discussed in Chapter 9.

During the design of the survey, a woman from an organisation of people with disabilities initially participated. However, she could not continue participating because her organisation was not happy with the fact that she used her working hours to participate in the CHE survey design. As I later mention in Section (III) of Chapter 11, the absence of the voice of people with disabilities was regrettable, because it could have improved the research design in terms of its construction and including relevant additional question. Moreover, as I will indicate in Chapter 4 on the impasse of the social model of disability, emancipatory research is necessary in order to include the voices of people with disabilities in disability research.

Unstructured Interviews

In 2001, I undertook an exploratory study of some South African universities and technikons. The study adopted a two-pronged approach. Firstly, I sent emails to all the higher education institutions, asking the following three questions: (a) Do you have a disability unit or services for your students with disabilities? (b) If yes, what types of services to you provide? (c) If no, what other means to you have to support your students with disabilities? Secondly, I visited four higher education institutions in Gauteng and two in the Western Cape to conduct some exploratory interviews. Most of these interviews were conducted at institutions,

which provided disability services. This was a conscious choice as it enabled me to gather information from actual disability service providers.

During the first half of 2004, I used face to face unstructured interviews at both Boston University and Harvard University. At both universities, I was trying to understand how these institutions had effectively translated their legal obligations to provide support for students with disabilities under Section 504 of the Rehabilitation Act of 1973. An unstructured interview format was suitable for such exploratory questions.

For both the exploratory study in South Africa and the American study, I used the free format method and recorded the interviews. This method was helpful because I was trying to explore what the institutions were doing. The interviews were "conducted, approximately, like natural conversations between people. They are often tape recorded for a later full analysis" (Wilson, 1993: 5).

Even though these unstructured interviews helped me to probe and understand the issues better, Wilson (1993) indicates that free format interviews do actually have a structure because the interviewer is exploring a particular issue. In this instance, I was not just interested in finding out everything about disability support services in higher education. I was interested in the three above mentioned sub-units of analysis, namely, national legislation or national policy, institutional policy guidelines and disability support structures and their services. Moreover, Wilson (1993) also indicates that in face to face interviews there are issues of personal reactivity and power relations. He states that characteristics, such as gender, race, and age could affect the way in which respondents answer questions. In my experience, I observed only one case during one of the interviews, in which the respondent was very reluctant to give answers. Instead, he was more interested in the capacity in which I was researching. He thought that I was appraising his disability unit, and only relaxed when I again explained

that I was a student and that the purpose of the interview was to conduct research for my PhD thesis.

Another important aspect to consider in interviews is retrospective data and the possibility of forgetfulness on the part of respondents. Baddeley (2004) and Menneer (2004) investigate this aspect. Baddeley demonstrates that memory is a reconstructive process and that if respondents are asked to discuss past events, then it is likely that they will provide a partly distorted account. Menneer agrees with Baddeley's argument and identifies specific techniques that social surveys should use to minimise the errors from respondents.

The problem of memory reflected the possible limitations of the interviews in both the exploratory interviews in 2001 at some South African universities and technikons and the ones conducted at Boston University and Harvard University in 2004. In both sets of interviews, respondents relied on what they knew and remembered since working in their respective disability support structures. The information that was recorded was limited to their memory and level of understanding. The best possible way to have received better data was to have interviewed every person who has ever worked in each disability service structure since its inception and to read all documents ever written by and about that service structure. In terms of time and resources it would have been impossible to conduct such an in-depth study in 38 institutions (36 in South Africa and 2 in America). Moreover, my study was more interested in gaining a broad overview of contemporary methods of supporting students with disabilities, even though a detailed historical dimension would have provided better insight than a once off data collection.

(d) Data Analysis

The CHE survey data was analysed in 2003 using the Microsoft Excel pivot tables. Responses from structured questions were entered as nominal scales of 0's

and 1's to indicate negative and positive responses respectively, and computed into descriptive statistics in tables and graphs as presented in Chapter 9. Responses from open-ended questions were analysed and sorted into categories. We initially reported the data descriptively for the CHE in a separate report. I then further analysed the data for the purpose of the thesis as shown in Chapter 9.

The purpose of such further analysis was to see if I could find the following data sets: Firstly, I wanted to identify the relationship between the availability of disability services and the type of institutions. Secondly, I wanted to see if there was a relationship between organisational structure and the number of services. Thirdly, I was trying to give plausible explanations for the constraints faced by the disability service units. Fourthly, I was trying to outline some advantages and disadvantages of regional mergers for the provision of disability services. Finally, I highlighted the problem of lack of a statistical profile of students with disabilities in South Africa.

The sub-units of analysis that the CHE survey focused on for each higher education institution, were institutional policy and the structures of support services and the services these offered. The aspect of institutional policy focused on the existence and nature of disability support policy. The aspect of support services focused on curriculum flexibility; types of services; students with disabilities profile; funding of services; constraints; networking and future plans.

I used a tape recorder for the interviews and transcribed these for the exploratory study. The CHE survey focused on the same aspects as the interviews of the exploratory study. The exploratory interviews were used to build an initial understanding of the topic. The CHE survey and the follow-up face-to-face interviews filled the gaps in the survey. My colleague, Colleen Howell, conducted these interviews 2004 but I did not use the data from them as it was incorporated

into the descriptive CHE report, which I read and indirectly used as part of my thesis.

I conducted interviews at Boston University and Harvard University in order to understand how the two American institutions translated Section 504 of the Rehabilitation Act of 1973 into practice . I was specifically interested in obtaining the following data: the process of recruiting prospective students with disabilities; the types of services provided; the cost and funding of the services; the limitations of the legislation and how these often caused conflict between the students with disabilities and the universities.

As noted above, secondary data in the form of literature, research projects and official documents formed a very significant part of data collection. Data from these sources was analysed according to interesting categories, such as key historical illustrations of support provided to students with disabilities in South Africa and in the United States. Such data was also analysed to extract national legal and policy provisions and to identify the assumptions underlying the different systems of disability support services. Most importantly, it was also used to understand the concepts of benevolence, rights, and the social model of disability, which are the central theme of the whole thesis.

(V) Theoretical Approach

This thesis is undertaken within a social creationist approach to disability. According to Priestly (1998), the social creationist approach understands disability as a product of social barriers and the material relations of power. This approach has both materialist and social aspects because it sees disability as a material product of socioeconomic relations. The social creationist approach should not be confused with the social constructionist model of disability or the social model. The social creationist approach explains how individuals interact to

construct reality. In the case of disability, this approach explains what meanings society gives to disability and its symbols. The social model of disability explains disability as an ideological entity and as a struggle against oppression. Within its argument, the social model of disability shows that society constructs disability, and creates barriers, which warrant struggles for disability rights.

Oliver (1990) proposed and popularised the social constructionist approach based on the experience of people with disabilities in Britain. Oliver (1990) shows how a system of ideas and a mode of production have throughout history produced numerous identities of people with disabilities. Making use of history, anthropology and sociology, he demonstrates the impact of social ideas on institutional practices with regard to people with disabilities, even though he does not focus on higher education institutions *per se*. He recommends a social theory of disability, which "must be located with the experience of disabled people themselves and their attempts, not only to redefine disability but also to construct a political movement amongst themselves and to develop services commensurate with their own self-defined needs" (Oliver, 1990:11). In the first chapter of his book, *The Politics of Disablement*, he outlines how disability has been defined and how different definitions have influenced the way in which people with disabilities are perceived. In the second chapter, Oliver outlines how disability is a cultural construct and how factors such as the size and mode of the economy, and values and beliefs influence the constructions of identities such as the "disabled". In Chapters 3 and 4, Oliver argues that the changing ideas and practices towards people with disabilities have also been influenced to some extent by the rise and development of capitalism in Western countries. For example, the idea of individualism under capitalism has influenced how disability was seen as an unfortunate individual's problem that had to be medically defined and to some extent taken care of by state intervention. In the last three chapters, he offers a critique of the construction of disability and proposes a counter-

hegemonic strategy of fighting against these ideas through social movements of people with disabilities.

In the context of this thesis, institutions of higher education are viewed as part of structures within the capitalist mode of production. Oliver (1990) argues that the capitalist mode of production has marginalised people with disabilities as being unfit for work; it cannot be ignored that part of the purpose of higher education is to produce a professional workforce, which, if we accept Oliver's contention, is largely non-disabled. Higher education institutions are thus part of exclusionary structures that have denied access to people with disabilities for a long time. For example, the report of the Great Britain Colonial Office (1948) on blindness in British Africa and Middle East territories states, "A defect of much education for the blind is that it produces youngsters who can pass examinations ... but who are useless as competitive employees and whose only destiny is sheltered employment" (Great Britain Colonial Office, 1948: 49). The office recommends vocational education instead of higher education, and suggests professional training only for "outstanding" individuals. Similarly, Topliss (1975) writes about the provision of education for people with disabilities in Britain and assumes that the natural progression from schooling is employment and not higher education. Stodden and Whelley also indicate, "Postsecondary education has been described as, 'America's traditional gateway to the professions, more challenging jobs, and higher wages' (U.S. Department of Education Strategic Plan, 1998-2000). Yet persons with disabilities have often experienced limited access to and success in postsecondary education, resulting in poor employment outcomes" (Stodden and Whelley, 2004: 6). In the case of South Africa, the Community Agency for Social Enquiry found that, in 1999, of the approximately 2.5 million people with disabilities, 88% were unemployed (Silver and Koopman 2000: 16). It is on the basis of this contention, that access to higher education for students with

disabilities is explored here within the social creationist approach to disability, which emphasises the relationship between disability and society, as will be explored in the next chapter.

(VI) Ethical Considerations

Every respondent in the CHE survey, the exploratory interviews and the case studies interviews understood the purpose of the research and gave their consent. During the planning phase Colleen Howell and myself decided that the South African respondents and their higher education institutions should remain anonymous because we thought that not all institutions might be comfortable to reveal their situation in terms of providing support for students with disabilities – or not. Moreover, what the respondents said about their institution may be held against them. However, the documents of Kathy Jagoe about the University of the Witwatersrand are open to the public, and hence I was free to openly quote from and reference them.

The case of the American institutions was different, because research on the institutions' providing support for students with disabilities is public knowledge. Most of the research on American higher education and disability give both the names of the universities and the names of the respondents. However, for the purposes of this thesis, it was not necessary to give the names of the American respondents, because the aim was to highlight the process rather than their views.

It is in my understanding that the subject of the research question was not a sensitive one and that we made every effort to ensure anonymity where necessary and at the same time to avoid losing relevant data.

(VII) Demarcations of the Thesis

This study is the first of its kind, being an exploration of a macro view of the situation around the provision of support for students with disabilities in South Africa, by applying the concepts of benevolence, rights and the social model of disability. These concepts were chosen in part because they often either implicitly or explicitly appear in the literature in disability studies. Moreover, they seemed relevant for exploring disability and higher education in the South African context. The thesis does not propose any strong new theory but works within the social creationist disability approach to provide a perspective from South Africa, particularly in terms of disability and higher education as a neglected area.

Moreover, this study does not investigate the daily experiences of students with disabilities in South Africa or elsewhere. Rather, it researches the process of providing support for such students. It is also not primarily descriptive of the process but instead analytical in terms of the legacy of philanthropy, disability rights and the impasse of the social model of disability. A particular limitation, although a positive one, is that the thesis does not encompass disability issues in general, such as welfare, but only focuses on higher education in South Africa, as compared to that of the United States.

PART II

Conceptual Analysis

CHAPTER 3

UNDERSTANDING THE RELATIONSHIP BETWEEN DISABILITY AND SOCIETY

(I) Introduction

This chapter tries to illustrate the relationship between disability and society as it is discussed in selected Western literature on disability. This chapter is not intended to be a history of disability and nor a series of disability definitions. Nonetheless, it does illustrate this relationship from the biblical period (Old Testament) to contemporary arguments about disability rights and the social model of disability. The analytical framework within which the relationship between disability and society is to be understood is DePoy and Gilson's (2004) Explanatory Legitimacy Theory. This theory argues that definitions of disability are mediated by three interactive elements, namely, description, explanation and legitimacy. That means that disability is physically described, explained or interpreted by some ideology, and based on the explanation that society judges or responds to give it legitimacy of either acceptance or rejection.

There are three reasons why this chapter is relevant to the thesis. Firstly, it tries to indicate that, to a large extent, the 'positive' societal response to disability in Western thought and practice has been based on benevolence, charity or what Johnston (2001) refers to as the philanthropic legacy. It is a paternalistic benevolence, in terms of which particular members of society assume custody and responsibility for the welfare of people with disability to an extent that it becomes a pattern for most disability service to be established by benevolent individuals instead of disability being part of mainstream services. Such

benevolence in industrial societies is characterised by charity and welfarism, which Coleridge (1993) argues, is disempowering because it allows people with disabilities to be controlled by non-disabled people.

Secondly, the chapter also explains that, in Europe, the education of people with disabilities initially began as initiatives of benevolent individuals who wanted to take care of people with disabilities. Similarly, as Chapters 7 and 9 will show with regard to the United States of America and South Africa respectively, it appears that even support services for students with disabilities in higher education appear to have been started by individuals instead of mainstream institutions in society. They were based on benevolence instead of on individual rights. This notion of benevolence will be explicated further in Chapter 10 to show how it tensively interacts with rights and the impasse of the social model of disability.

Thirdly, the chapter also suggests that the social model of disability could be understood as evolving out of this long-term historical process of the relationship between disability and society with reference to existing literature on histories of disability. Thomas (2004), for example, also reminds disability studies of the relational aspect of disability and society, an approach that we shall follow throughout this thesis.

Even though this chapter will present selected histories of disability in Western societies, the notion of such histories has three very important shortcomings that need to be stated before exploring the relationship between disability and society. The first shortcoming is that there is very little material on society's response to disability in developing countries. For example, there is some literature on certain African countries, which primarily argues that disability has traditionally been understood in superstitious terminology, although this varies according to cultural context. For example, Avoke (2002) suggests, "For instance, among the Nchumuru people in the Volta Region of Ghana, it was strongly believed that

disability was a result of evil spirits, ghosts and powers of sorcery brought on families as a result of offences that they have committed" (Avoke, 2002: 773). Similarly, writing about Somalia, Tomlinson and Abdi (2003) explain, "Although most clan families support their disabled members, families have been known to hide disabled children away from the local community, and also to receive little help or sympathy from others. One reason for this is a traditional belief that 'demons'" caused disability (Tomlinson and Abdi, 2003: 914). They also state that war and mine injuries are more acknowledged than congenital disabilities.

The second shortcoming is the reliability of evidence in the histories of disability. Bredberg (1999) argues that this evidence comes from sources that are often potentially unreliable, because they might be anecdotal rather than descriptive or attitudinal rather than experiential or based on institutional records rather than on actual practices. She also cautions against presentisism through which historical disability material is interpreted by contemporary standards of knowledge.

The third shortcoming is the western Eurocentric approach in disability history. Bragg (1997) demonstrates that the medieval Celtic and Old Norse literature do not indicate disability as a typically pitiful and marginalised category, which is how it is reported in European disability studies. Miles (2001) also indicates that part of the disability history in Asia has been distorted by European understandings of disability. He also indicates another shortcoming, viz. that evidence of disability in Asia is not as straightforward as it is portrayed in literature, but that it, too, is rather characterised by different meanings.

(II) Explanatory Legitimacy Theory

As mentioned above, according to DePoy and Gilson's (2004) Explanatory Legitimacy Theory, there are three interactive elements that have characterised disability definitions across historical periods. These elements are description,

explanation and legitimacy. The purpose of the Explanatory Legitimacy Theory is to demonstrate the interaction of the three elements in order "(a) to provide an organized framework for analyzing and testing how social, cultural, intellectual, and related trends intersect to shape and dynamically change categorical understandings and subsequent value-based judgments of and responses to groups of humans and (b) to advance guidelines for professional change and social action" (DePoy and Gilson, 2004: 4).

Description refers to what is considered usual and unusual human activity, appearance and experience. It also has two dimensions, namely, typical/atypical and observable/reportable. The first dimension of description has two diametrically opposite concepts (typical/atypical). Typical activity, appearance and experience are the expected course of everyday life in specific contexts. The atypical, in contrast, are infrequent and considered abnormal. "For example, typical walking for an adult would consist of a two-legged gait that follows the alternating advancement of each leg, with heel strike proceeding to strike. Atypical walking might involve the use of crutches for ambulation" (DePoy and Gilson, 2004: 5).

The second dimension of description distinguishes between observable and reportable phenomena. These dimensions can best be explained by the classical distinction between quantitative and qualitative research methods. An observable phenomenon can only be known by the senses as espoused by quantitative research methods that are underpinned by positivism and its claim to objectivism. A reportable phenomenon is experienced by an individual and thus cannot be observed, but known only by inference. It is recognised by qualitative research methods, which are underpinned by subjectivism and its claim to interpretation.

Explanation is the second element in understanding disability definitions according to the Explanatory Legitimacy Theory. DePoy and Gilson do not say

what they mean by explanation, but rather imply it in their examples. "To explain is to account for change in one phenomenon (variable, thing) with changes in another phenomenon or set of phenomena (variables, things)" (Carter, 2004: 5). This element explains the causes of disability from different perspectives. For example, as will be shown later, medical-diagnostic explanations of disability are different from social explanations of disability.

The final element of disability definition in Explanatory Legitimacy Theory is legitimacy. Legitimacy refers to the way in which society judges and responds to disability. Legitimacy is used to "explicate the primacy of judgement about acceptability and worth in shaping differential definitions of disability and in determining community, social, and policy responses to those who fit within diverse disability classifications" (DePoy and Gilson, 2004: 6). Legitimacy makes the final judgement on disability and directives on how society should respond to people with disabilities.

The interaction of description, explanation and legitimacy works as follows: disability is perceived by describing what is disabled and what is not disabled; then society explains the causes of that disability based on certain beliefs; the description and explanation of disability are at the same time value-laden so that judgment could be made as to how society should respond to such disability. According to DePoy and Gilson, this means that a given definition of disability in a given context and time can be analysed through its description, explanation and legitimacy.

The following sections give a historical overview of disability in trying to illustrate the relationship between disability and society, with reference specifically to western European society. At the end of each sub-section, the three elements of the Explanatory Legitimacy Theory will be applied by using the literature on disability from antiquity to the 21st century.

(III) An Historical Overview of Responses to Disability

(a) Disability in Religious Texts

Braddock and Parish (2001) say that there is evidence of physical impairments in prehistoric times even though "documentation of the treatment and life experiences of people with impairments during the earliest periods of recorded history is extremely limited" (Braddock and Parish, 2001: 14). They proceed to illustrate that the Bible offers some clues on how disability was conceived and responded to in that period. They indicate that the Book of Leviticus (19:14) provided the first legal protection for deaf and blind people. They suggests that, paradoxically, the Book of Deuteronomy (28:15, 28-29) warns that if people did not follow God's commandments, then they would be afflicted with madness, blindness and confusion of mind. Moreover, disability was also perceived as ominous.

To illustrate the position of people with disabilities in the Old Testament as outcasts, Rieser (2002) quotes the Book of Leviticus (21:16-20), which pronounces, "And the Lord said to Moses none of your descendents throughout the generations who has a blemish shall draw near, a man blind or lame or one who has a mutilated face or limb or a limb too long, or a man who has an injured foot or an injured hand or a hunchback or a dwarf, or a man who has defective sight or itching disease or scabs or crushed testicles. He may eat the bread of his God, both of the most holy and of holy things, but he shall not come near the veil or approach the altar, because he has a blemish, that he has a blemish, that he may not profane my sanctuaries'" (Rieser, 2002: 128).

Stiker (1999) explicates the biblical contradictions on the status of disability by deconstructing both the Old and New Testament texts that refer to disability. He

also begins by referring to the Book of Leviticus to show that the Old Testament treated disability as unclean and abnormal. The story of Job and his suffering from leprosy is illustrative of the impurity of the disabled and the fact that people with disabilities were not permitted to attend certain social settings, such as the Temple and communal meals. "Those whose skin is afflicted and are examined by the priest, and, if the symptoms are found to be those of leprosy (or of a serious disease of the skin), he must deliver a judgment of 'unclean'. The priest functions here as a specialist who determines whether there is actually an impurity or not. This impurity entails a physical seclusion from the social group, which required, if a cure were to be sought, a purification ritual. The ritual was very precise and complex and permitted rehabilitation and re-entry into ordinary life. The prohibition that weighs on the leper is legal, that is provided for, codified, and not moral – but it is no less an exclusion from the group" (Stiker, 1999: 25).

Abrams (1998) comprehensively illustrates the meaning of perfection in Jewry canonised texts from the Torah[6] to the Talmud Bavli.[7] She illustrates that, in Judaism, the required priestly perfection in the Temple was necessary because the Temple was a zone of interaction between God and humans in which the priest mediated. This zone of mediation was so dangerously holy, moreover, that it required priestly and ritualistic perfection: "The symbols of the sacrificial cult – the offered animals, the incense, the physically perfect priest of unblemished lineage in his special garb, and the dangerous sense of holiness and the concomitant restricted access to the inner precincts of the Temple – formed a coherent system of meaning" (Abrams, 1998: 8).

Abrams (1998) also shows that this priestly perfection was extended to society through rituals and metaphor. By implication, people with disabilities under

[6] The first five Books of the Bible (Genesis, Exodus, Leviticus, Numbers, Deuteronomy).

[7] One of the rabbinic writings.

Jewish Law were not allowed to be priests or participate in the Temple because it was a holy place in which the unclean (disabled) would die if they dared to trespass. Some of the texts implied, "being physically whole is metaphorically equivalent to being wholly righteous, so physical imperfection is equated with imperfect righteousness. Thus a state of one's body serves as a metaphor for one's inner state, [and] any blemish or disability may attest to a person's inner blemish" (Abrams, 1998: 68).

The *r'ayon* mitzvah exemption also exemplifies the extension of the physical perfection to the Israelite when it proclaims, "All are obligated to appear [at the Temple on festivals] except a *cheresh*[8], *shoteh*[9] *v'katan*[10], a hermaphrodite or an androgyne or women and slaves who have not been freed or the lame [man] or the blind [man] or the old [man] or the one who cannot go up [to the Temple Mount] on his feet. Who is [considered] a *katan*? Anyone who cannot ride upon his father's shoulders and go up from Jerusalem to the Temple Mount. This is the opinion of the School of Shamai. But the School of Hillel says, 'Anyone who is unable to hold his father's hand and go up from Jerusalem to the Temple Mount, as it is written... (Exodus 23:14). (M. Hagigah 1:1)'" (Abrams, 1998: 50).

In Islam, too, there are levels of the religious and the ethical as expounded by Stiker with regard to the Old Testament. The religious level in Islam texts regards disability as the deliberate will of God to test one's faith (Turmusani, 2003). The fundamental element is the belief in Quadah and Quder[11]. Disability can be associated with either good or evil, depending on what is believed to be the cause of the disability. For example, "blindness is perceived to be an act of God and

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[8] "Most often, persons with speaking and hearing disabilities, typically since birth; less often, persons with hearing disabilities only", (Abrams, 1998: 215)

[9] Mentally disabled or mentally ill (Abrams, 1998: 152)

[10] Children/minors (Abrams, 1998: 152)

[11] This is the belief in the preordination of good and evil and to absolutely accept God's decree thereof.

more divine power is attributed to the blind person... Deafness and 'retardation' are seen as an act of God with negative implications" (Turmusani, 2003: 52). Similarly, the Prophet Mohammed instructed his companions to flee from a leper as they would from a lion (Turmusani 2003: 53).

At the ethical level, however, Islam teaches caring and helping without discrimination. Consequently, people with disabilities are pitied, as they face the test of their faith by God, but they are not to be outcasts. Nonetheless, this does not mean people with disabilities have enjoyed the same social position as non-people with disabilities in both old and contemporary Arab societies. Attitudes towards people with disabilities depend on how particular disabilities have been understood. For example, blind people have been treated with mysticism, because it is believed that blindness is God's holy intervention and because some blind people could recite the Qur'an. "On the other hand perhaps because Arabs have always attached the greatest importance to verbal communication, deaf people are rarely mentioned in Arabic literature and seem to be confused with idiots" (Turmusani, 2003: 52).

Whereas Judaism of the Old Testament legally and ritualistically prohibited disability, its offshoots, the New Testament (Christianity) and Islam, differed on the matter. "Without denying the global connection between evil (and misfortune) and sin, Jesus quite decisively breaks the connection between disability and individual fault. But, otherwise, he does not seem to allude to the justification of religious prohibition that affects the impaired. The practice of Jesus the Nazarene is relief and cure" (Stiker, 1999: 33).

Stiker explains what seem to be the contradictions with regard to disability within the Old Testament and between the Old and New Testaments. Judaism, Stiker reckons, is a system with two levels, namely, the religious and the ethical. The religious level defines what is integral or natural. It differentiates between the

divine and the profane; the natural and the cultural; and it separates what is natural from aberrant for the ethical level. The ethical level then situates these differences at an individual level or at the level of daily experiences. In terms of such a system, that which is disabled is unclean and not integral or natural at a religious or spiritual level. At the ethical level, then, disability is situated in a way that shows physical distance from religious function; as a result, people with disabilities faced exclusions, such as interdiction from the Temple and being prohibited from partaking in meals with others. In other words, the fact that the Old Testament makes contradictory statements about disability could be explained by the functioning of the system of Judaism, which intersects the primary religious level with the secondary ethical one. This system transformed disability into something that was unnatural and outside the integral. However, according to the ethical level, people with disabilities were at the same time 'innocent' and could be cured by God's power. Their place in society was thus situated as far as possible away from what signified cleanliness, Godliness and the integral until they were cured and 'clean'.

The religious prohibition of Judaism was dismantled by the teaching of Christ in the New Testament. Stiker argues that in the Gospels of Jesus Christ in the New Testament, the ethical is primary. There is no division between the sacred and the profane. What *is* sacred is the fellowship of God with humans. A good heart is primarily what the New Testament requires of human beings, and [the fight against] evil is the responsibility of all humankind. Jesus did not exclude the disabled but, in fact, invited them into the Temple and cured others, despite much admonishment from the keepers of the Jewish law. "The God-relationship no longer entails religious prohibitions, just the opposite; it excludes only the wicked heart, only the wrong that comes from within. But, then, at the same time, and this has hardly been emphasized either, we find ourselves facing a problem that is extremely difficult to assume: our relationship to disability, our relationship

to abnormality, depends entirely on ourselves. There are no longer any dictates… The Gospels disturb, deconstruct, sow panic, and become a source of instability" (Stiker, 1999: 36).

According to my understanding, the application of the three elements of Explanatory Legitimacy Theory (description, explanation, and legitimacy) explains the definition of disability in the Old and New Testaments as follows: Disability is described as an abnormality such as leprosy, blindness, deafness and madness. The explanations of disability are religious ones. The Old Testament explains disability as a consequence of sin and at the same time emphasizes the power of God's miracle to cure the disabled. At the ethical level, disability also reminds human beings to be compassionate towards the disabled while they are facing their punishment from God. The response was thus to exclude people with disabilities from religious functions while showing general compassion towards them. The New Testament does not explicitly explain disability or allude to its prohibition. Rather it uses disability to remind people that what matters is what is inside (i.e. the heart) and not what is external, and that salvation starts with a good heart. Jesus went further to mention that those who were poor and disabled would be the first in the Kingdom of God, i.e. before those who are rich or healthy. In this way, the New Testament emphasised the legitimacy of including people with disabilities in religious functions and responding to them with compassion. The inclusion of people with disabilities, though, as Stiker observed, left the relationship between disability and society unresolved.

(b) Impairment and Deformity in Ancient Greece

There is no definition of disability in ancient Greek discourse. Edwards (2000) gives two reasons for this. Firstly, "Greeks had not reached the level of abstraction in perceiving a category of physical disability in which people were *a*

priori banned from carrying out certain roles and expected to fulfil others", (Edwards, 2000: 36). Secondly, "permanent physical disability was not part of the realm of Hippocratic medicine, and partly as a result of this, the Greek vocabulary for physical disability appears vague, at best, to the modern eye" (Edwards, 2000: 36).

The absence of such a definition does not mean there were no physically impaired people in ancient Greek societies. Greek mythology and literature provides some evidence of people with deformities and impairments (Garland, 1995; Braddock and Parish, 2001; Edwards, 2000). However, according to most writers, it seems that evidence about the experiences of people with impairments in ancient Greece is insufficient to make any conclusive analysis. Quoting Edwards (1997), Braddock and Parish (2001) reiterate: "The consequences of physical handicaps varied according to the context and to the individual. Without a codified notion of able bodied on [the] one hand and disabled on [the] other, people were not automatically assigned one category or the other on the basis of medical diagnosis or appearance. We see a few instances in which people with physical handicaps were banned *a priori* from certain roles. People with disabilities in Greek society were integral to the society. There's no indication that people with physical handicap in ancient Greek world identified themselves or were identified as a distinct minority group" (Braddock and Parish, 2001: 16).

Edwards (2000) suggests a community model of disability. This explains physical disability as a cultural construct, which has no inherent meaning and is not associated with any *a priori* prohibition, but can be recognised from the community's assignment of roles. In other words, it refers to the relationship between an individual's role and his or her physical ability. "The degree to which one is able to fulfil the tasks of membership in the community determines the degree of one's physical ability or disability" (Edwards, 2000: 35). In fact, men

who were permanently injured from the wars were regarded as dauntless and seasoned veterans, and could continue to work in the military. The greater the fulfilment of community roles, the less disability was relevant.

Edwards (2000) also demonstrates that there was support for people with impairments in ancient Greece. Economic support came in the form of a dole or pension. However, having an impairment did not automatically guarantee a dole. The impaired individual had to convince the Council and prove that the impairment prevented any form of self-sufficiency in the community. Although evidence is sparse, it also suggests – according to Edwards – that taking care of the impaired was a family duty and not that of the public.

Although there is no conclusive evidence on the treatment of people with physical impairments and weaknesses in ancient Greece, there is a suggestion that classification and discrimination did occur. For example, Stiker (2002) demonstrates, drawing on some of Plato's writings, that some mentally ill people were stoned, spat on and shunned by the public in Athens. He mentions that madness was assigned to three categories: "ritual madness, poetic madness and erotic madness" (Stiker, 2002: 44). Common madness was admonished and subject to punishment, whereas prophetic madness as exemplified in oracles was honoured. To illustrate this point, Stiker (2002) quotes Plato in *Phaedrus* as saying, "when grievous maladies and afflictions have beset certain families by reason of some ancient sin, madness has appeared among them, and breaking out into prophecy has secured relief by finding the means thereto, mainly by recourse to prayer and worship, and in consequences thereof rites and means of purification were established' (Stiker, 2002: 44). In the *Republic*, Plato postulated an ideal state's response to disability as follows: "It [the state] will provide treatment for those of your citizens whose physical and psychological constitution is good; as

for the others, it will leave the unhealthy to die, and those whose psychological constitution is incurably corrupt it will put to death" (Plato, 1897: 173).

The social significance of physical impairment in ancient Greek is interestingly edifying when the notion of teratology and infant exposure are introduced. Deformed infants were killed in ancient Greece through a process called exposure. "The exposure of deformed infants means taking them outside the settlement of an unknown location and letting them expire in a hole in the ground or drown in a course of water" (Stiker, 2002: 39). Physical impairment in adults did not, however, call for exposure. Exposure was practiced when the deformity was considered monstrous or far from the natural appearance of the human body, the '*terata*' (Stiker: 2002: 39). Interestingly, blindness, deafness and mental impairments were not considered deformities in ancient Greece. They were simply regarded as weakness. Infanticide was regarded as a form of atonement to the gods and not execution or a ritual sacrifice, as it might be understood in contemporary Western value judgements. Monstrosity was perceived as an expression of anger from the gods. In this way, infants who were subjected to exposure were returned to the gods.

According to Winzer (1997), the killing of infants was also practiced in ancient Rome. Under the mandates of the Law of the Twelve Tables, the male head had authority over his descendents. He had the sole power of life and death over his family. "Any child under three who might someday become a burden on society was thrown into the Tiber by the father. Infants were also left to die in the sewers that ran through the streets of ancient Rome" (Winzer, 1997: 83).

The ancient Greek accounts of deformity and impairment might seem contradictory. However, Stiker (2002) systematises these accounts to show that there is no contradiction *per se*. He suggests that the Greek concept of illness could be understood as being influenced by both Hippocratic medicine and

mythology. Hippocratic medicine is based on the classification of diseases and physical illnesses and their medical cures. This influence is suggested by the emphasis on differentiating between certain kinds of madness, distinguishing between deformity and weakness, and perceiving medicine as a skill to cure diseases.

The mythological influence works at both the socio-political and magical levels. At the socio-political level, there is no room for disability as an abstract concept, and it also had no social or political significance. Hence, as Edwards (2000) explains, ability was related to community roles in ancient Greek and Stiker (2002) also suggests that exposure was a way of removing deformity from society and returning it to the gods.

At the magical level, deformity was assigned with a function for the human community. Stiker (2002) illustrates this point by analysing hermaphroditism. Hermaphroditic infants were exposed because the community perceived them to express the wrath of the gods. In Greek mythology, a hermaphrodite was a figure with both masculine and feminine physical characteristics. The figure was both a deformity and a magician. "[The] Hermaphrodite protects sexual unions and births. He/she is the figure of the impossible: androgyny. And androgyny is itself the figure of what is different, of what fuses. There is no longer man and woman; man and woman are the same, are identical. [The] Hermaphrodite wields a power over sexuality because she/he is not sexually normal. While at the concrete level of the everyday, the biological, the social , sexual anomaly is expelled and sent back to the gods, on the religious and mythic level (which is also the collective), the difference is sacralized and becomes the site of a power that has influence over love affairs" (Stiker, 2002: 62).

Returning to the Explanatory Legitimacy Theory (description, explanation and legitimacy), the first observation is that ancient Greek thought did not have a

description of disability or even an abstraction thereof. Instead, individuals were judged by the extent to which they could perform their roles. The main concern for the Greeks was deformity beyond 'normal' human resemblance. The second observation is that explanation of body differences was both religious and medical. Extreme deformities were attributed to the anger of the gods against the community as a whole and not just against the individual. Other deformities were 'medically' classified as impairments or weakness. Such descriptions and explanations justified the legitimacy of the community's response towards difference and impairment. For instance, monstrosity was described as a great aberration from human resemblance and explained by the wrath of the gods, and thus justified the community to respond by exposure. Similarly, blindness and deafness were not viewed as disabilities but weaknesses, and justified the community's response of making blind and deaf people an integral part of the community. Moreover, common madness was distinguished from prophetic madness and, because the latter was curable and indicative of oracularity, it was honourable and not subject to the physical abuse suffered by common madness. Impairments, differences or deformities were categorized, socialised and preternaturalised

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(c) Intellectual Stagnation during the Middle Ages

The Middle Ages did not change the uncertainties and contradictions in understanding disability. The instability of disability as already mentioned in the deconstruction of the New Testament persisted throughout the Middle Ages. On the one hand, demonic possession was believed to cause mental illness and

epilepsy. On the other hand, there is evidence to illustrate that people with disabilities in medieval times were indeed cared for and supported (Braddock and Parish, 2001). At best, the Middle Ages are marked as being the cradle of paternalism towards the disabled, the introduction of systems of charity and the rise of institutionalisation of the disabled (Braddock and Parish, 2001; Stiker, 2002; DePoy and Gilson, 2004). This would be the beginning of what Johnston (2001) refers to as the philanthropic legacy, which forms the basis of my argument on benevolence.

Although the Middle Ages did not have significant intellectual impact on understanding disability, Stiker (2002) discusses three medieval saints who shook this period with their ideas on disability. These are Zotikos, Saint Augustine and Francis of Assisi. Zotikos became a care giver to the sick and the disabled and founded a house in which to pursue that mission. He pursued his mission against the convictions of the emperor who believed in the classical world in which "all those whose body is ruined by leprosy and who struggle against disease which is called sacred he ordains to be driven from the city or even to be thrown into the depths of the sea" (Stiker, 2002: 74). Zotikos dismantles the Greek and Jewish tenets on disability and introduces the concept of charity towards the sick and the disabled into early Christian ethics and the Middle Ages.

Similarly, in Saint Augustine's view, deformities and monstrosities could be understood as being part of the global order of things, if deep insight was employed. In other words, the perception that deformity was outside the natural order of creation was because of limited employment of intellectual faculty. Similarly to the way in which Christ instructed his disciples, Saint Augustine, too, welcomed the disabled as part of society. Disability acceptance thus "becomes the touchstone for submission to a greater order" (Stiker, 2002: 77).

In practice, the ideas of Zotikos and Saint Augustine meant the provision of alms to the disabled and the poor, and their institutionalisation. Braddock and Parish (2001) enumerate some of the institutions that were established in the West for accommodating people with disabilities and organising alms for the poor and disabled. Stiker (2002) wisely warns that alms and residential institutions should not be confused with contemporary ideas of individual donations or giving small change to beggars. He emphasises that rich people in medieval times bestowed charity in substantial amounts of money, property or land. Charity was a highly esteemed system for the care and support of the poor and of people with disabilities. Hence, begging was not stigmatised. My emphasis in this thesis is that such benevolence has been a historical cornerstone of disability services in both public and private life.

The extreme version of Zotikos and Saint Augustine was St Francis of Assisi, who renounced wealth to live in poverty in the service of God and of the poor and the disabled. According to Stiker's analysis of St Francis' thinking, "the poor individual was no longer one to whom you gave alms but one in whom you recognized God, one who became like a living sacrament, like the sacred itself. There is no longer any sacrality outside the fraternal bond. And the fraternal relationship finds its highest expression in the relationship with the poor" (Stiker, 2002: 81).

Even though this understanding of disability in the Middle Ages was to some extent contrary to the beliefs of the classical world, it was not effective as an intellectual crusade. It still remained grounded in the Christian principle of the primacy of the ethical, in which the disabled person was accepted as part of society and his existence was regarded as God's way of instilling the ethic of care and love for salvation. It is no wonder that, as observed by Braddock and Parish (2001), attitudes towards disability during the Middle Ages remained mixed and

indecisive. As Stiker puts it, disability was "never truly excluded, for the disabled were always spiritually integrated; [nonetheless, they were never [socially] integrated, for they were always on the social fringes" (Stiker, 2002: 88).

(d) The Age of Enlightenment: Biology and Humanism

Enlightenment is underpinned by rationalism, that is, the exercise of reason as a primary basis of knowledge. According to Braddock and Parish (2001), this has two consequences for disability. The first one is that disability is no longer understood in divine order but in terms of material aetiology. In the second one, deformity, aberrancy and monstrosities begin to be described simply as impairments that could be classified or categorised in terms of aetiology, diagnosis, care and cure. In fact, the Enlightenment also started the professionalisation and medicalisation of disability (Braddock and Parish, 2001).

In 1605, Francis Bacon published *The Advancement of Learning, Devine and Human*, in which he "refuted the notion of divine punishment as a cause of mental illness. He suggested four lines of inquiry that would guide psychological research for the next three hundred years: studies of mental faculties and the interaction of body and mind, individual case studies, anatomical inquiry and post-mortem studies, and the interaction between society and the individual" (Braddock and Parish, 2001: 22). The education of the deaf and the blind established a concrete belief that sin did not cause disability as such; instead, disability was seen simply as disease with the hope of a cure. Schools for the deaf and blind consequently proliferated in Europe and in the American Colonies.

Medical specialisation and classification are evident in the classification and confinement of the mentally ill. Braddock and Parish (2001) describe Locke's distinction between intellectual disability and mental illness, and how it was

influentially applied to property law. Mentally people with disabilities were thus regarded as idiots who lacked reason. Intellectually people with disabilities were regarded as possessing reason but lacking the right configuration of ideas in their intellectual faculties. This is reminiscent of Plato's classification of madness, which I have outlined above.

The natural consequence of this was the proliferation of institutions for the mentally ill. In 1656, France established the Hôpital Général for the sick, disabled and poor. In 1714, England provided for the legal confinement but not treatment of the "furiously mad". Madhouses and prisons were merged into single facilities in what is contemporary Germany in the eighteenth century. In 1752, the first American general hospital was established to care for the mentally disabled. By this time, Europe had institutionalised all the mentally disabled, both the violent and the non-violent (Braddock and Parish, 2001: 25).

Returning thus to the Explanatory Legitimacy Theory, during the period of Enlightenment, disability was slowly becoming described as a clinical condition that could be cured through medical knowledge. Consequently, disability was explained by rationalism, which is based on the belief that facts are observable and can be attested to. The 'legitimate' response was thus to institutionalise people with disabilities with the intention of curing them. Moreover, blind and deaf people began to be educated, because it was believed that, contrary to biblical times, disability was not caused by sin.

(e) Nineteenth Century Normal Curve and Disability

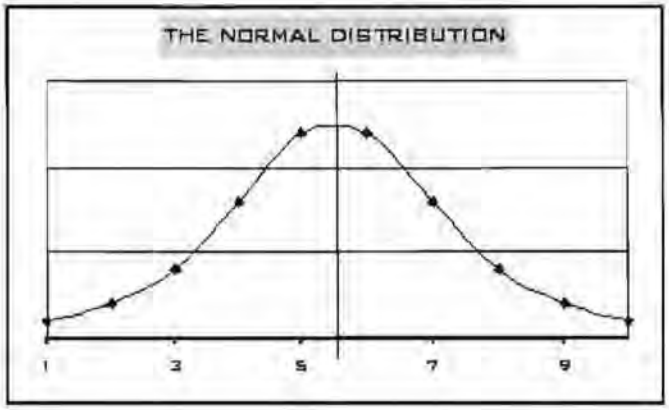
The relationship between disability and society in the 19th century still remained an unresolved issue. In the nineteenth century, however, disability is not just a consequence of sin and an object of compassion. It is an aberration of the

scientific average human being. The relationship between disability and society is not only unresolved but polarised, and the centre of the polarisation is occupied by the ideal average human being. As individuals approximate the norm, in other words, they become normal, and as they deviate from the norm, they become abnormal. Disability is thus understood by how far an individual approximates or deviates from the ideal average. It is not juxtaposed with sin or salvific compassion, but rather with the scientific ideal.

This ideal produced and was reproduced by the social quest for normalcy. "It was the French statistician Adolphe Quetelet (1796-1849) who contributed the most to a generalised notion of the normal as an imperative. He noticed that the 'law of error, used by astronomers to locate a star by plotting all the sightings and then averaging the errors, could be equally applied to the distribution of human features such as height and weight. He took a step further of formulating the concept of *'l'homme moyen'* or the average man. Quetelet maintained that this abstract human was the average of all human attributes in a given country" (Davis, 1997: 11).

The normal curve or the bell-shaped curve was developed mathematically in 1733 and used in 1783 to describe the distribution of errors (now known as the normal distribution). In 1809, it was used by Gauss to analyse astronomical data (Department of Statistics, West Virginia University). Today, it is commonly known as the bell curve and also used in human population statistics to show graphically where data typically lies in a given population or sample distribution. Figure 2.1 shows a typical normal curve:

Figure 2.1: The Normal Distribution Curve



The lower left and lower right areas of the curve indicate the least frequently occurring scores. The lower left area below the curve illustrates the least frequently occurring *lower* scores, whereas the lower right area below the curve end illustrates the least frequently occurring *higher* scores. The middle of the graph, which is the highest point of the graph, indicates the point at which most of the scores occurs. This thus indicates the average or typical scores, and the point at which the 'scientific' ideal of the 'normal' human *should* be. Anything further to the left approaches aberration from the norm, whereas anything further to the right approaches exceptionality or abberation.

The social significance of the normal curve was not simply to summarise the data in a normal curve, but to set apart the normal human being from the abnormal one in the 19th century. While the origins of scientifically determined normalcy can be attributed to the normal curve, Sir Francis Galeton conceptualised the scientific normal human being by introducing the first mental tests in the world in 1882, publishing his book *Inquiries into Human Faculty and Its Development* in 1883, and coining the word 'eugenics' (Fancher, 1985). Ushering in an idea that was to be echoed throughout the 19th century he stated, "The discriminative faculty of

idiots is curiously low; they hardly distinguish between heat and cold, and their sense of pain is so obtuse that some of the more idiotic seem hardly to know what it is. In their dull lives, such pain as can be excited in them may literally be accepted with a welcome surprise" (Fancher, 1985: 43). His mission was of course building on Quetelet's utopia in which he wrote "one of the principal acts of civilization is to compress more and more the limits within which the different elements relative to man oscillate. The more that enlightenment is propagated, the more will deviations from the mean diminish... The perfectibility of the human species is derived as a necessary consequence of all our investigations. Defects and monstrosities disappear more and more from the body" (quoted from Davis, 1997: 12).

Invariably, this was echoed throughout the 19th century, as Galeton, Quetelet and their disciples believed that intelligence was the primary condition for the excellent well-being of individuals. Intelligence determined life chances. The implication was that the disabled had no place in the upper and lower right regions of the normal curve of well being, neither physically nor spiritually. They were, simply put, abnormal, and thus scientifically set apart for the first time with no recourse to religion, myth and ethics.

As ideas of normalcy developed, the 19th century was also characterised by the further institutionalisation of people with disabilities, as had already begun in the 18th century. A particular feature of the institutionalisation of the disabled in the 19th century is the education of the disabled in institutionalised settings. Braddock and Parish (2001) describe the establishments of schools for the deaf and blind in Europe and America towards the end of the 19th century. Such schools were established first in Spain and France, then in other parts of Europe and finally in America

According to Braddock and Parish (2002), the first school for deaf pupils in the world was established in Paris in 1755 by Charles Michael De l'Epée. Samuel Heinicke established such a school in Leipzig, Germany, in 1778. In 1817, the American Asylum for the Education of the Deaf and Dumb was established; it later became the Gallaudet University and was chartered to confer college degrees since 1864. The first school for physically disabled pupils was established in Bavaria in 1832 by John Nepinak.

In England, the Elementary Education Act (Defective and Epileptic Children) of 1899 provided as follows: "Power is given to Local Authorities to ascertain what children, by reason of mental or physical defect, are incapable of receiving proper benefit from the instruction in ordinary elementary schools, but are not incapable of receiving such benefit in special schools or classes; and what children, by reason of severe epilepsy, are unfit to attend the ordinary elementary schools" (Faculty of Social Science, Rodboud University of Nijmegen). Thomas Braidwood established the first school for deaf pupils in Britain in Edinburgh, Scotland, in 1760 (Braddock and Parish, 2002).

As an example of the application of the 19th century normalcy, the education of the deaf was not a simple positive development but instead fraught with controversy, underpinned by the distinction between normal and abnormal. There had been a conflict of methods between so-called manualism and oralism. Manualists argued for teaching deaf people through signing, whereas oralists regarded signing as abnormal and inferior learning. "It was the Germans who in the mid-nineteenth century developed the theory of deaf education, whereby one must not only insist on training deaf children a spoken language by reading lips, but also use words naturally to express themselves... This theory held that a mode of thinking dominated by images, and allegedly encouraged by sign language, was inhibitory to the abstract mode of thinking that was considered

necessary to produce a cultured person. This was science and holism carried to unintelligent excess" (McCagg, 1989: 46). Nonetheless, oralism was pervasively applied for some time.

In fact, the education of disabled children itself was not simply regarded as learning and teaching, but as curative. The Germans referred to this medically curative pedagogy as *"Heilpädagogik"* (McCagg, 1989: 46). McCagg also says that, in Germany, the official academic discipline for teaching disabled children was called defectology (*Defektologiia*), which implied teaching 'defects' to cure them

Applying the framework of the Explanatory Legitimacy theory, disability, according to the normal curve, is an aberration from the norm. It is aberration from the normal population. In line with enlightenment, disability begins to be explained in rational terms. In this regard mental illness was equated with low intelligence. The response was the continuation of institutionalisation and benevolence of the philanthropists.

(f) Controversies of the 20th Century

The twentieth century could best be described as the era during which the perennial friction exploded between the normal human being and the abnormal one; the intelligent and the 'idiot'; the average and the 'dwarf'; the pedestrian and the quadriplegic; the optical and the blind; the auditory and the deaf; the verbal and the 'mute'. It was a century of three negations, namely, deconstruction, deinstitutionalisation, and desegregation.

(i) 1900's to 1970"s

The early twentieth century began as a period of growth for the eugenics movement. This movement believed in the idea of the wellborn and the

elimination of 'defects', which of course meant people with disabilities. A Chicago physician, Harry Haiselden allowed the death of infants, which he had diagnosed as "defectives" (Pernick, 1996). The US Supreme Court's case in *Buck v. Bell* in 1927 upheld the state's right to sterilise people with intellectual disabilities and, in 1933, Nazi Germany legislated its sterilization programme that was based on the one from the USA (Braddock and Parish, 2001: 40). In 1932, a New Jersey physician reckoned, " it would ... be conducive to racial improvement to sterilize even those feeble minded who do not necessarily fall in the hereditary group, since mental defectives tend to maintain inferior homes in inferior environments, and they quite generally rear their children in an inferior manner" (Pernick, 2000: 99).

The eugenics movement granted the ultimate power to the physician, viz. the power to determine who should die and actually perform the fatal procedures. I say this was the ultimate power because, for the first time in the history of the modern State, a citizen – the physician – outside the coercive apparatus of the State[12] – was allowed to kill without penal consequences. Whereas the nineteenth century began conferring power on the physician to have the final say in the well-being of a disabled person, the start of the twentieth century conferred on him the power to determine who should die and often perform killing procedures on disabled individuals. In antiquity, the disabled infant was killed by the *community* in order to be returned to the gods. In the twentieth century, in contrast, the disabled infant was killed by the *physician* in an attempt to efface disability, whereas the disabled adult was sterilized by the physician to preclude the propagation of people with disabilities in order to 'improve' the human stock. In Nazi Germany, Hitler's assertion exemplifies this power: "In this matter the State must assert itself as the trustee of a millennial future... In order to fulfil this duty in practical manner, the State will have to avail itself of modern medical

[12] The expression 'the coercive apparatus of the State' refer to the defense and security operations of the State.

discoveries. It must proclaim as unfit for procreation all those who are afflicted with some feasible hereditary disease or are the carriers of it: and practical measures must be adopted to have such people rendered sterile" (cited in Davis, 1997: 19).

The ways of thinking about, stereotyping and constructing people with disabilities during the first third of the 20th century are insightfully summarised by the Disability History Project as follows:

"People with disabilities are different from fully human people; they are partial or limited people, in an 'other' and lesser category. As easily identifiable 'others' they become metaphors for the experience of alienation.

"The successful 'handicapped' person is superhuman, triumphing over adversity in a way which serves as an example to others; the impairment gives disabled persons a chance to exhibit virtues they didn't know they had, and teach the rest of us patience and courage.

> "The burden of disability is unending; life with a disabled person is a life of constant sorrow, and the able-bodied stand under a continual obligation to help them. People with disabilities and their families – the 'noble sacrificers' – are the most perfect objects of charity; their function is to inspire benevolence in others, to awaken feelings of kindness and generosity.
>
> "A disability is a sickness, something to be fixed, an abnormality to be corrected or cured. Tragic disabilities are those with no possibility of cure, or where attempts at a cure fail.
>
> "People with disabilities are a menace to others, to themselves, to society. This is especially true of people with mental disability. People with disabilities are consumed by an incessant, inevitable rage and anger at their loss and at

those who are not disabled. Those with mental disabilities lack the moral sense that would restrain them from hurting others or themselves.

"People with disabilities, especially cognitive impairments, are holy innocents endowed with special grace, with the function of inspiring others to value life. The person with a disability will be compensated for his/her lack by greater abilities and strengths in other areas – abilities that are sometimes beyond the ordinary" (The Disability History Project).

Referring to Germany during the period after World War II, Hamilton observes, "Noteworthy are the ways in which the goals of postwar rehabilitation parallel the ideal of National Socialism: the suppression of deviant behaviour, education towards orderliness, cleanliness and discipline; and the measurement of a person's perceived usefulness to the larger society. To be sure, the actual physical liquidation of people with disabilities was no longer sanctioned after the war and the language degeneration had softened, but the drive toward normalization had survived intact" (Hamilton, 1997: 229).

(ii) 1970's to 1990's

The growing intensity of the power of the medical institution was not left unchallenged, especially in the second half of the twentieth century. A novel, unprecedented and momentous phenomenon in the history of disability was the reverberating voices of the people with disabilities from the last quarter of the twentieth century into the 21st century. To frame it within Foucault's terminology, the historically muted voices of the disabled in the hierarchies of knowledge unfolded the *archaeology* and *genealogy* of disability. "Archaeology is the method specific to the analysis of local discursivities and genealogy is the tactic which, once it has described these local discursivities, brings into play the desubjugated knowledges that have been released from them" (Foucault, 2003: 10-11). This

means that, for a long time, people with disabilities' knowledge about their conditions had no discursive space because their knowledge was subjugated by the medico-legal discourse. It is only now that such knowledges are desubjucated and thereby create a discursive space for the narratives and postulations of people with disabilities. People with disabilities entered the discursive space to challenge the disability discourses of the various periods, i.e.: the symmetry of sin and disability in religious antiquity; the paternalism of the Middle Ages; the medicalisation of the Enlightenment; the empiricism and normalcy of the 19th century; and the institutionalisation in the 20th century.

A significant development from the narratives and postulations of the people with disabilities was the emergence of both the social model of disability and the phalanx of the disability activists. The social model of disability was significant in two ways. Firstly, it was in fact the first significant paradigmatic shift since the New Testament. As noted earlier, Stiker (2002) observed that, while Christianity did not prohibit disability, it nonetheless left the relationship between people and disability unresolved. In the second half of the twentieth century, the social model finally resolves this relationship after about nineteen centuries of Christianity. The social model explains that disability is a consequence of society and not of the individual. In other words, people have impairments, which are different from disability. It is negative social factors that cause disability. These negative factors are stigma attached to impairments, the presentation and organisation of artefacts and technology[13], and a skewed distribution of resources in society. For example, the problem of a deaf person watching the news on television is not that she or he does not understand the news but that society has developed such technology to exclude deaf people. In this regard, I am referring specifically to the absence of captioning and signing in a television programme. Similarly, the issue is not that a person in a wheelchair does not visit a library, but that a typical library, even if it

[13] I mean technology in both its anthropological, social and technical meanings.

has an entrance ramp, aisles are too narrow for the wheelchairs and that the upper shelves are out of reach even for people of short stature. Moreover, as already mentioned, people with disabilities are often poor and the problem is not that they are voluntarily unemployed but that they are discriminated against in the labour market. In summary, then, although the impairment may be corporeal, the disability is primarily social.

I will use three themes to illustrate the development and tenets of the social model of disability. The themes are barriers faced by people with disabilities, the critique of the medical model of disability and the critique of the representation of people with disabilities. The first theme is the description of barriers that people with disabilities face in everyday life. This theme is constituted by narratives of people with disabilities and the descriptive and advocacy research by academics. This field is not yet termed the social model of disability in disability discourse. It is simply narratives, descriptions and advocacy, yet later in the history of disability discourse it proves to be seminal in the development of the social model of disability.

The first document to articulate the social model of disability was the *Fundamental Principles of Disability*, which was produced by the Union of the Physically Impaired Against Segregation (UPIAS) in Britain in 1976. The main thrust of the document was that it differentiated impairments from disability. According to UPIAS, "Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression" (Union of the Physically Impaired Against Segregation, 1976: 4).

Similarly, a good example of these beginnings is a book by Frank Bowe (1978) titled *Handicapping America*. He cogently introduces his book by stating: "There are in this country tens of millions of people who have difficulty hearing, seeing, moving, learning, controlling their emotions, talking. But all are people. Their disabilities are real, but so are their abilities. They are disabled, but they need not be handicapped. Yet we handicap them" (Bowe, 1978: ix).

Bowe (1978) continues by describing the obstacles that people with disabilities face. He identifies six barriers, namely, architectural, attitudinal, educational, occupational, legal and personal barriers (Bowe, 1978: 18-37). The first of these, architectural barriers, refer to the inaccessibility of buildings, transport and other facilities for people with disabilities. Attitudinal barriers describe prejudice, stereotypes and stigma against people with disabilities. Educational barriers concern the social systems misunderstanding of disability and ability. Occupational barriers comprise employers' aversion towards employing people with disabilities and income discrimination based on disability. Legal barriers are manifested by a failure to enforce disability laws and the paucity of disability lawyers. Lastly, personal barriers describe the cumulative effects of discrimination, which ultimately reduce the social status and life chances of a disabled person. Bowe concludes eloquently: "It is not charity or public assistance, it is not a welfare state, it is not perpetual childhood that disabled people seek but the opportunity to develop and apply their abilities to the furthest reaches of their potentials... We are beginning to understand that America handicaps disabled people. And we are beginning to realize that, by freeing abilities from the shackles of disability, we are rehabilitating not only disabled people but America itself." (Bowe, 1978: 225-226).

The second theme in arriving at a more complete understanding of the social model is its critique of the medical model of disability, which I alluded to above

as the power of the medical institution. The central tenet of this theme is that disability has been misconstrued as both a medical condition and an individual's tragedy that requires rehabilitation. Oliver (1990) cogently analyses part of the interview schedule of the 1986 survey of the Office of Population Census Surveys in Britain. The questions read as follows:

- Can you tell me what is wrong with you?
- What complaint causes your difficulty in holding, gripping or turning?
- Are your difficulties in understanding people mainly due to a hearing problem?
- Do you have a scar, blemish or deformity which limits your daily activity?
- Have you attended a special school because of a long-term health problem or disability?
- Does your health problem/disability mean that you need to live with relatives or someone else who can help look after you?
- Did you move here because of your health problem/disability?
- How difficult is it for you to get about your immediate neighbourhood on your own?
- Does your health problem/disability prevent you from going out as often or as far as you would like?
- Does your health problem/disability make it difficult for you to travel by bus?
- Does your health problem/disability affect your work in any way at present?

Source: Survey of Disabled Adults – OPCS, 1986, extracted from Oliver (1990: 7)

Oliver (1990) argues that the semantics and methodology of the survey are indicative of the medical model, which perceives disability as an abnormality attributed to the individual. As we have already noted previously, the survey questions are direct offshoots of the late 18th century biological determinism and the 19th century belief in the normalcy of the body. Oliver observes: "These questions clearly ultimately reduce the problem that disabled people face to their own personal inadequacies or functional limitations... It is hardly surprising that, given the nature of the questions and their direction that, by the end of the interview, the disabled person has come to believe that his or her problems are caused by their own health/disability problem rather than by the organisation of society" (Oliver, 1990: 7-8).

To further illustrate his points, Oliver turns the questions around and maintains that the interviewees should have been asked:

- Can you tell me what is wrong with society?
- What defects in the design of everyday equipment like jars, bottles and tins causes you difficulty in holding, gripping or turning them?
- Are your difficulties in understanding people mainly due to their inabilities to communicate with you?
- Do other people's reactions to your scar, blemish or any deformity you may have limit your daily activity?
- Have you attended a special school because of your education authority's policy of sending people with your health problem or disability to such places?
- Are community services so poor that you need to rely on relatives or someone else to provide you with the right level of personal assistance?
- What inadequacies in your housing caused you to move here?

- What are the environmental constraints that make it difficult for you to get about in your immediate neighbourhood?

- Are there any transport or financial problems that prevent you from going out as often or as far as you would like?

- Do poorly-designed buses make it difficult for someone with your health problem/disability to use them?

- Do you have problems at work because of the physical environment or the attitudes of others?

Source: Oliver (1990: 8)

Oliver's alternative questions as motivated by the social model are *a priori* a mirror image of the OPCS questions. Moreover, they are in fact a culminating subversion and almost a *coup de theatre* against the powerful conventions of understanding disability over almost two thousand years of the Common Era. There is no longer a symmetrical relationship between sin and impairment. Instead, what is normal and abnormal are the cultural constructions of society. People are not disabled because they are 'dwarfs', but because social organisation and stigma discriminate against people of short stature. Disability and society thus dysfunction in an oppressive relationship and, for the first time in the history of disability definition, reference to disability shifts from the individual as preordination to society as a structure that reproduces disability. Echoing these sentiments, Hevey (1992) reckons: "I think I went through an almost evangelical conversion as I realised that my disability was not, in fact, the epilepsy, but the toxic drug with their denied side-effects; the medical regime with its blaming of the victim; the judgement through distance and silence of bus-stop crowds, bar-room crowds and dinner-table friends; the fear; and, not least, the employment problems" (Hevey, 1992: 2).

The implication for academic research of the social model is that it necessitates a paradigmatic shift in methodology. Researchers need to be careful of the assumptions underlying their research techniques and how they treat disability as both a concept and an experience, i.e. as objectivity and subjectivity. The following table summarises Brown's (2001) implications of the social model of disability for research methods in disability studies:

Contrast of Disability Paradigms for Research		
Characteristics	*Old Paradigm*	*New Paradigm*
Definition of Disability	An individual is limited by his or her impairment	An individual with an impairment requires an accommodation[14] to perform functions required to carry out life activities
Strategy to address disability	Fix the individual, correct the deficit	Remove barriers, create access through accommodation and universal design, promote wellness and health
Method to address disability	Provision of medical, psychological, or vocational rehabilitation services	Provision of supports (e.g., assistive technology, personal assistance services, job coach)
Sources of intervention	Professionals, clinicians, and other rehabilitation services providers	Peers, mainstream service providers, consumer information services
Entitlements	Eligibility for benefits based on severity of impairment	Eligibility for accommodation seen as a civil right
Role of disabled individual	Object of intervention, patient, beneficiary, research project	Consumer or customer, empowered peer, research participant, decision maker
Domain of disability	A medical "problem" involving accessibility, accommodations, and equity	A socio-environmental issue

(Source: Brown, 2001: 157)

[14] In the context of disability studies, the word accommodation is used in the United States of America to refer to the support provision for people with disabilities.

The OPCS survey questions mentioned earlier, critiqued by Oliver, support Wood's (1980) International Classification of Impairments, Disabilities and Handicaps (ICIDH), which distinguishes between impairment, disability and handicap. In terms of Wood's classification, impairment is regarded as a psychological, physiological or anatomical abnormality; disability is classified as a restriction to perform tasks due to impairments, and handicap is the disadvantage in role fulfilment because of impairment or disability. Wood's classification was, however, rejected by disability movements because of its insistence that disability was caused by impairments (French, 1994: 13-14). The ICIDH was consequently replaced by the International Classification of Function (ICF), whose reference was impairment, activity and participation. However, it has been criticised for retaining much of the individualistic approach (Barnes and Mercer, 2004: 5-6).

It is interesting, though, to observe that, ten years after Oliver's critique of the disabling role played by society and its disabling language, the US Census Bureau questionnaire nonetheless contained similar language on disability in the 2000 Census. The following questions are excerpts from this questionnaire:

16. Does this person have any of the following long-lasting conditions?

a. Blindness, deafness, or a severe vision or hearing impairment?

b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?

17. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities:

a. Learning, remembering, or concentrating?

b. Dressing, bathing, or getting around inside the home?

c. (Answer if this person is 16 YEARS OLD OR OVER.) Going outside the home alone to shop or visit a doctor's office?

d. (Answer if this person is 16 YEARS OLD OR OVER.) Working at a job or business?

This observation indicates the need for continuous advocacy for the rights of people with disabilities. It also indicates some discrepancy between official discourse, grassroots activism and academic discourse, which often either support the official version or the grassroots activism.

The third and final theme in understanding the social model is its critique of social representations of people with disabilities in literary and artistic works and in the mass media. The central tenet of this theme is the critique of the stereotypical representation of people with disabilities as helpless and as objects of pity, summoning benevolence and charity from society. By implication, this would mean that people with disabilities are a burden and a drain on society. In this regard, I shall give three examples. The first one is the classic imagery of the poster child in telethons and disability charity events. The problem here is the relationship between charity and disability. The contention is that the advertisements of the multimillion disability charity industry have portrayed people with disabilities as helpless, poor and in need of alms. They evoke and reproduce the stereotypes of the personal tragedy of disability. "Real children with disabilities were paraded across the stage as objects of pity, while the amount of money raised was flashed on the television screen. The implication that somehow this money would be used to cure these particular children, and children like them, was misleading" (Fleischer and Zames, 2001: 10). Moreover, Fleischer and Zames (2001) argue that the image of the poster child also creates an assumption that there are no disabled adults, because disabled children either die young or are cured.

Longmore (1987) also describes how disability has been negatively portrayed on television and in films. He illustrates three associative categories with disability.

He identifies three categories associated with disability. The first one is how films associate disability with criminality. Referring to characters such as Quasimodo in *The Hunchback of Notre Dame*, Longmore states that "the most obvious feature of monster characterisation is their extremism. The physical disabilities typically involve disfigurement of the face and head and gross deformity of the body. As with the criminal characterisation, these visible traits express disfigurement of personality and deformity of soul. Once again, disability may be represented as the cause of evildoing, punishment for it, or both" (Longmore, 1987: 68). The second association is that of disability with either super-sexuality or asexuality. People with disabilities are either portrayed as being endowed with extreme lust or a total lack of sexual activity. Either way, there are always sexual undertones. The final association is that of disability with adjustment and acceptance. This drama typically involves a self-pitying and angry disabled person who receives a rude awakening, usually from a non-disabled person to stop feeling sorry and adjust to the situation. The implication is that the disabled person is isolated by choice and that they could live a meaningful live if they stopped indulging in self-pity. Such portrayals put the responsibility exclusively on the disabled person and are very silent of social attitudes towards people with disabilities and the daily obstacles that they face. Barnes (1994) also makes similar observations from British television.

The second example is the representation of disability in the mass media, such as television and the newspapers. Biklen (1987) uses a case to illustrate how newspaper journalists report and misrepresent a story on disability. He contends that such stories are never about disability rights or struggles, but rather an instance of tragedy, charity or overcoming disability. An apt example of this is the news article about Simazile Ntyikwe of Cape Town, South Africa. On November 14, 2002 the *Cape Argus* newspaper splashed the headline "*Bravest Man in Cape Town*" on the front page, accompanied by a picture that covered almost half the

page. The article was about Simazile Ntyikwe, a nineteen year old in a wheelchair, grinning with amusement. The article relates his tragedy of falling from a train platform and losing his legs in a train accident. It narrates the obstacles that he faces every day to go to school and moving around in his wheelchair. Typically, the article seeks to evoke a sense of pity, as it informs the reader that, when Simazile went for an entrance interview at a bridging college, "The interviewers heard with rising astonishment what obstacles he had had to negotiate just to turn up for the interview. They accepted him on the spot" (*Cape Argus*, 2002: 1). And the article finally eulogized Simazile for his determination in overcoming his disability and for winning a championship in wheelchair athletics.

To apply Biklen's criticism, the *Cape Argus* article did not contextualise Simazile's experience as a disabled person within the context of disability rights and advocacy. It presented the story from an angle of tragedy, pity, and charity. It leaves the reader to assume that Simazile was admitted to the college because the interview panel felt pity for him rather than because they judged him on academic merit. The article does not make the connection between disability and social status, even though Simazile lives in Delft, one of the poorest neighbourhoods around Cape Town, situated approximately 12 km from the conveniences of the City Centre. The closing statement of the article is the most revealing proof of a total disregard or ignorance of disability rights, when it refers to wheelchair access as a luxury: It reports, "Leaf [College] is negotiating to get him into a campus residence of the Cape Tech[nikon], where he will be able to get to the engineering block via a lift. What a luxury!"(*Cape Argus*, 2002: 1). The subsequent *Cape Argus* reports on Simazile's story praise acclaim the public and donors for providing financial support for Simazile and giving him the latest type of wheelchair. In the end, Simazile is no different from the poster child who is pitiful yet courageous in the eyes of the charitable public. The only difference is that Simazile's image is

disturbingly reproduced in the twenty-first century, at a time when such stereotypes are unforgivably intolerable in the disability rights movement.

The third example is the image of disable people in literature. Kent (1987) illustrates how some literary works portray disabled women as helpless, isolated and inferior. She also relates her teenage search for a disabled role model woman and her disappointment in finding few of these and in being flooded by negative images of disabled women amidst dazzling images of non-disabled women. She wondered, "What would have happened... if Juliet[15] had been blind? Would Romeo still have deemed her worthy of his love? Would Darcy[16] have appreciated Elizabeth Bennett's wit if she had had a disfigured face? Would Emma Bovary[17] have chafed under the yoke of married life if she had walked with a limp?" (Kent, 1987: 48). She concludes that disability has undermined womanhood in literature by emphasising the external beauty of womanhood.

Similarly, writing on the images of the disabled in several plays such as Anthony Sher's play *Richard III* and Charles Dickens' *A Christmas Carol*, Kriegel (1987) narrates parts of the characters. His main argument is that writers tend to perceive life from the angle of the 'normals' He observes, "writers like to think of themselves as rebels, but the rebellions they are interested in usually reinforce society's conception of what is and is not desirable. And most writers look at the cripple and the wounds he bears with the same suspicion and distaste that are found in other 'normal' ... The world of the crippled and disabled is strange and dark and is held up to judgement by those who live in fear of it" (Kriegel, 1987: 33).

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[15] Romeo and Juliet are characters from William Shakespeare's tragedy *Romeo and Juliet*.

[16] Darcy and Elizabeth are characters from Jane Austen's novel *Pride and Prejudice*.

[17] Emma is the main character in Gustave Flaubert's novel *Madame Bovary*.

From the above analysis of the social model of disability, it is apparent that it is a materialist perspective that is based on three levels with which disability is related to society, namely, the psychological, the immediate environment and the macro structure. It is materialist, because it regards disability as a social category that is produced and reproduced by society in daily experiences. It is underpinned by historical evidence, which shows that the shifting objectification of disability is not simply a matter of imagery and discourse, but that it has an effective negative impact on the daily experiences of people with disabilities. It also tries to explain the economic conditions of people with disabilities by arguing – as Oliver (1990) does – that the development of capitalism is linked with the marginalisation and discrimination of people with disabilities from economic life.

With regard to the first level, the psychological one, this suggests that individuals in society are in denial of the existence of disability. Moreover, they are in denial of the possibilities of being disabled by physical trauma or of giving birth to a disabled infant. They are also in denial of ultimately growing old and feeble and thereby becoming disabled. As Morris (1991) explains, "Our disability frightens people. They don't want to think that this is something that could happen to them. So we become separated from our common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity" (cited in Barnes and Mercer, 2003: 92).

The second level of relationship is between disability and the immediate environment. Narratives of people with disabilities abound with lived experiences of discrimination, stereotypes and inconveniences because of their disability. This relationship is expressed through stigma, ignorance or inaccessible facilities that are created and reproduced by people without disabilities. Hevey (1992), for

instance, describes during a seminar on changing negative images of people with disabilities, and he observes, "The non-disabled majority of workshoppers are bustling and keen, although the disabled presence – already small in the opening plenary – has been further divided into the workshops. The non-disabled-dominated workshop begins and is steered by a non-disabled 'facilitator' (given services free, old boy) who will orchestrate the not-so-hidden agenda... The disabled people will try to make interventions ... which will be softened up by the time these comments pass through the workshop facilitator's thick pen on the flipchart... The disabled people will meet together and the non-disabled people will meet together... The rest of the seminar, for disabled people will be a slow decline... The end will have finally come, and the non-disabled conference organisers will heave a self-satisfied sigh of relief at having prevented the disabled people present from 'hijacking' what should have been their forum" (Hevey, 1992: 9-10).

In defence of the link between sexuality and disability, Zola (1982) writes, "Our society does not like to picture people who are weak, sick, and even dying, having needs for sexual intimacy. It is regarded as unseemly. Yet my personal and professional observation has taught me to distrust this notion. The desire I believe is always there, but it is shunted aside, suppressed by fear. We do not express or even show our wishes, because we have learned that in our condition of disablement or disfigurement, no one could (or should) find us sexually attractive (Zola, 1982: 215-216). He concludes, "And where the chronically disabled are concerned, the research and clinical efforts are on compensatory techniques, ways to stimulate or simulate erections and ejaculations, ways to reclaim some weakened ability... But we can also touch, show and experience love in our fingers, hands, feet, tongues, lips, eyes, and ears, and in our words. The loss of bodily sensation and function... has made sexuality a natural place to

begin the process of reclaiming some of one's selfhood. But as the self is located in no single place, neither is sexuality" (Zola, 1982: 219).

The third and final relationship is between disability and the macro level of society. This relationship indicates that social institutions, services and sensibilities are oblivious of and discriminatory towards people with disabilities. Society is oblivious because it generally denies the existence of disability; even when it is aware of disability, it disregards, oppresses or marginalises it. Consequently, public and private policies, legislation and regulations discriminate against people with disabilities in both *de jure* and *de facto* capacities. Describing his struggle with the Social Security Disability Insurance in the United States of America, Longmore (2003) reckons, "The trouble was – and is – that disability related poor relief and social welfare have always operated on a foundation of false postulates about the nature of disability. The policies rest on the assumption that physical or mental impairments by themselves produce 'disabilities', limitations in social and vocational functioning... They give assurance that determination of eligibility for aid can be a fairly clear-cut process. Doctors and other professionals can reduce both impairment and disability to a set of numbers, numbers that will show objectively who qualifies to receive benefits" (Longmore, 2003: 238).

Writing about disability studies, Linton (1998) outlines twelve problem areas in the curriculum and representation of some disability studies. These faults basically summarise the problems encountered with the social model argument, with its central focus on disabilities studies as a crucial medium through which disability is understood, reproduced and debated. I summarise the problems areas identified by Linton in 9 point form as follows:

- Disability studies treat disability as an individual problem, which is exemplified by rehabilitation and special education. By implication,

the issue is to correct the corporeal and not the social aspect of disability.

- The emphasis on rehabilitation and special education indicates an overemphasis on intervention at an individual level rather than at the societal one. The aim is to cure the person and not the context that disables the person.

- Disability studies objectify disability as a metaphorical issue, problem or idea, and not as an experience. It problematises disability *per se* and not the social context of disability.

- The discourse of disability studies denies the voice of the disabled. Only professionals speak on behalf of people with disabilities and claim to know what people with disabilities think and feel.

- Empiricism dominates in disability studies and the qualitative experiences and expressions of people with disabilities are excluded. Disability is reduced to categories and numbers, with little or no to the subjective experience of disability.

- Disability studies tend to be essentialist and deterministic about disability. The essentialist part is individualised, as the disabled person is defined by his or her disability rather than abilities. The deterministic aspect is biological, which means that disability is simply viewed as a malfunction.

- Empiricism, biological determinism and essentialism have resulted in limited methodological ranges for disciplines within the humanities that investigate disability.

- There is a general marginalisation of disability studies in the humanities.

- Disability studies have for a long time made no distinction between impairment and disability. These terms have been used interchangeably to denote the personal tragedy of a disabled person.

The explanation of the social model of disability can best be summarised by referring to the Disability Rights Movement's slogan, "Nothing About Us Without Us". This is the slogan of the 1980's and Charlton (1998) reckons that the slogan has the following meanings: Firstly, the slogan makes one think about the implication of "nothing" in socio-economic and political contexts that impact on people with disabilities. Secondly, it emphasizes the inclusion of people with disabilities in decision making about their lives, and their need for self-determination. Thirdly, it is an epistemological break with the past and a necessary precedent for the liberation of people with disabilities from oppression and exclusion. Fourthly, it encompasses concepts such as rights, independence, empowerment, independent living and integration of people with disabilities. Finally, it indicates an unstoppable resistance to oppression.

Returning to the Explanatory Legitimacy Theory, we can thus establish that the element of description **in** the 19th century and in the first half of the 20th century is clear. What is described and defined as disabled is that which does not lie below the highest region of the normal curve. The explanations for differences are constructed in the scientific discourse. People's well-being is primarily explained by their genetic traits and, to a lesser extent, good nurturing. Disability is constructed in the medical discourse as a misfit to normalcy and signified socially in the institutionalisation or separation of the disabled in all spheres of life. The response to disability is simple: Either someone is intelligent and by implication has good life chances, or they are not intelligent and thus condemned to leading a

common life. In this view, poverty suddenly becomes an individual's fault and condemns him or her to the poorhouse. Disability was moreover regarded as something atypical that could be fixed or rehabilitated, or to be made normal. The obsession of the 20th century with normalcy was linked to its determination to efface disability.

However, in the last quarter of the 20th century, the voices of people with disabilities have profoundly changed the relationship between disability and society. Disability is now described and understood as an expression of social oppression and not as an individual tragedy. The explanation is that people are physically impaired but socially disabled and hence oppressed. Moreover, people with disabilities have the right to be independent and to be treated normally, and not with benevolence, charity, and institutionalisation.

The social model of disability has gained popularity in numerous disability movements across the world, but it has been subjected to criticisms as well. These criticisms are explored in the next chapter in an attempt to argue that the social model of disability is at an impasse, creating problems for students with disabilities who wish to access higher education in South Africa.

(IV) Conclusion

This chapter has tried to explain the relationship between disability and society from European antiquity to the 20th century and into the 21st century. It has done so by reviewing some of the limited Western literature on disability within the analytical framework of the Explanatory Legitimacy Theory. The Explanatory Legitimacy Theory argues that, in order to understand definitions and treatments of disability, one needs to understand the three interactive elements that are involved. These elements are description, explanation and legitimacy: disability is first defined by means of physical description, thereafter given meaning by an

explanation based on certain beliefs, and finally given the legitimacy of acceptance or rejection based on its explanation.

The treatment of disability in Judaism (Old Testament) and Islam oscillates between the religious and the ethical level, in which the former expresses God's will and the latter prescribes societal responses. At both levels, however, the relationship between disability and society is unresolved because of contradictory explanations and treatment of disability. On the one hand, disability is regarded as God's punishment for sin and therefore warrants the marginalisation of people with disabilities. On the other hand, disability is regarded as an expression of God's will and therefore warrants reverence for a disabled person.

Contrary to Judaism and Islam, Christianity (New Testament) provides a very different perspective on disability at both the religious and ethical levels. At the religious level, Christianity dissociates disability from sin. Sin, then, is the responsibility of all humankind. For Christ, the religious level was the fellowship of God and human beings, which requires a good heart on the part of human beings. At the ethical level, Christ includes people with disabilities in God's fellowship with human beings, invites people with disabilities to come to the temple, and cures others. This view of Christianity on disability influenced some of the responses to disability in the Middle Ages as noted in Zotikos, Saint Augustine and Saint Francis of Assisi. However, similar to Judaism and Islam, Christianity is still unable resolve the relationship between disability and society.

Ancient Greece does not have a definition of disability even though there are people with disabilities in Greek society. Instead, disability is perceived through a community model of disability, which is a cultural construct of the relationship between an individual's role and his or her physical ability. Scant evidence suggests that ancient Greeks practised infanticide to appease the gods if a disabled child was born. Whereas disability had no significance at the socio-

political level, it had significance at the magical level, in terms of which it was assigned contradictory functions in Greek mythology. In ancient Greece, therefore, the relationship between disability and society also remained unresolved and contradictory.

The Age of Enlightenment (18th Century) began to efface religious explanations of disability, as rationality replaced religiosity. Disability was now regarded as simply a physical condition that could be cured. Consequently, the idea of normalcy evolved, in terms of which disability was regarded as an aberration from the norm. Hence people with disabilities began to be institutionalised and separated from society, so that they could be either 'cured' or receive special 'education'. In this period, the relationship between disability and society was such that being disabled was an individual tragedy which needed to be solved, failing which an individual with a disability remained on the margins of society.

The beginning of the twentieth century witnessed aggressive measures to either 'cure' or get rid of people with disabilities. Institutionalisation and eugenics were rife before and after World War II. During the post-war period, however, struggles against the oppression of people with disabilities emerged. Significantly, this led to the creation of the social model of disability. This model finally resolved and stabilised the relationship between disability and society. It argued that people are impaired and not disabled; that it is society that disables people by denying them accessible environments; and that people with disabilities have the same rights as any other member of society.

The concept of benevolence is of particular interest in this chapter and in the disability movements. For a long time, the relationship between disability and society was not only characterised by oppression and marginalisation, but benevolence too. In terms of this view, people with disabilities had to be cared for by families, private charities and public institutions. It will be argued later that,

although benevolence is not by disability movements, it does partly remain a problem in supporting students with disabilities in South Africa.

Even though the social model of disability has gained popularity and acceptance, spreading from Britain to other parts of the world, it has not escaped criticism both within and outside the Disability Rights Movement. The next chapter discusses these criticisms to argue that the social model of disability has at the start the 21st century arrived at an impasse.

CHAPTER 4

EVALUATION OF THE SOCIAL MODEL OF DISABILITY

(I) Introduction

Chapter 3 has tried to articulate the changing relationship between disability and society from antiquity into the 21st century. It has illustrated the oscillating and unresolved relationship between disability and society until the social model of disability resolved and stabilised the relationship by squarely locating disability in an oppressive industrial society. This chapter argues that the social model of disability is now at an impasse and that approaches in disability studies must try to break the impasse by first understanding the basic idea of the social model of disability and then by operationalising this model. It aims to explain the misconception of both the social and medical models of disability and also to describe some broad post-modern criticisms of the social model. The idea of the impasse of the social model of disability will be elaborated on in Chapter 10, which focuses on the tensive intersection of benevolence, rights and the impasse of the social model of disability in supporting students with disabilities in higher education in South Africa. The idea of operationalising the social model will be elaborated in Chapter 11 with regard to the South African case.

(II) The Deadweight on the Social Model of Disability

On the basis of most of the literature on this topic, I argue that the social model of disability is at an impasse for four reasons. The first one is that this model has been largely misinterpreted. The second reason is that the medical model of disability has also been largely misunderstood. The third one concerns the weaknesses and criticisms of the social model of disability from some

perspectives. The final one is the functional overburdening of the social model of disability, which has arisen as a consequence to its misinterpretation.

(a) Misconceptualisations about and Weaknesses of the Social Model of Disability

The conceptual understanding of the social model in some of the current literature misses the point that the social model of disability is not a social theory, but a *model*, as clarified by Heywood: "Theories and models are both conceptual constructs used as tools of political analysis. However, strictly speaking, a theory is a proposition. It offers a systematic explanation of a body of empirical data. In contrast, a model is merely an explanatory device; it is more like a hypothesis that has yet to be tested. In that sense, in politics, while theories can be said to be more or less 'true', models can only be said to be more or less 'useful'" (Heywood, 1997: 19-20). In defence of the social model of disability, Oliver also states, "models are merely ways to help us to better understand the world, or those bits of it under scrutiny. If we expect models to explain, rather than aid understanding, they are bound to be found wanting" (Oliver, 1996: 40).

It is my contention that some authors need to take into account the distinction between a model and a theory, and in particular to understand that the social model of disability is not a social theory. For example, in criticising the social model of disability, Marks (1999) asserts, "Although the social model claims to be a general theory, which focuses on disabling environments, the emphasis is on certain kinds of barriers, particularly those which obstruct people with mobility impairments, at the expense of other kinds of barriers" (Marks, 1999: 88). Although her critique of the model in terms of its reference to disabling

environments is valid, her view that the model has the status of a theory is refuted.

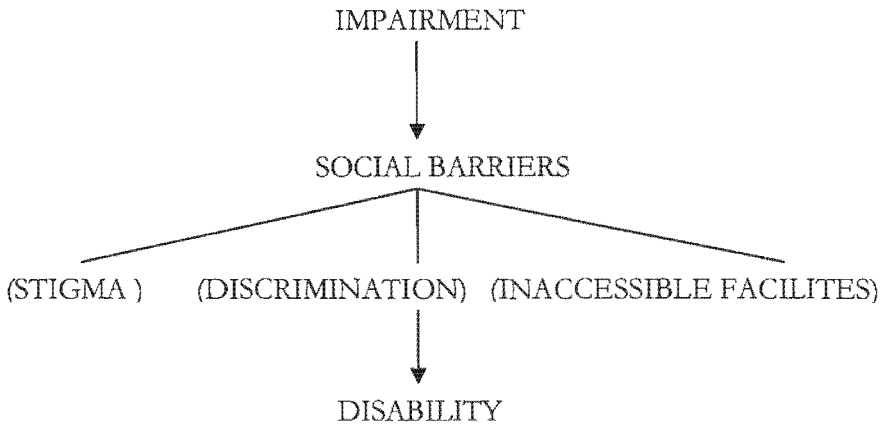
Terzi (2004) is aware of Oliver's contention that the social model of disability is not a theory. Despite this, she still treats the social model of disability as a materialist social theory. While her argument about the problems for a materialist perspective is understandable, it is misdirected. The social model is not an offshoot of a materialist perspective. Rather, Oliver (1990) has tried to move beyond the social model by proposing a materialist theory of disability within disability studies. Unlike Terzie (2004), Gleeson (1997) has aptly directed his historical materialist criticism towards disability studies and not towards the social model per se.

In fact, Oliver explicitly explains, "For me the social model of disability is about personal experience and professional practice but it is not a substitute for social theory, a materialist history of disability nor an explanation of the welfare state" (Oliver, 1996: 41). One good example of understanding of the social model of disability is Goodly (1997). He demonstrates that perspectives of self-advocacy with learning difficulties within the social model of disability could strengthen an alternative discourse and contribute towards a social disability theory.

What other authors should understand is that the basic idea of the social model of disability, as mooted by Hunt in 1966 (Hunt 2002), assembled by the Union of the Physically Impaired Against Segregation (1976), and formalised by Finkelstein (1980) and Oliver (1983), was to demonstrate that disability as a *social* category was not a physiological condition of an individual but the consequence of social barriers faced by people with impairments. Winter (2003) also demonstrates how the Disability Rights Movement conceptualised the problem of the oppression of

people with disabilities. The model social model of disability can be diagrammatically represented as follows:

Diagram 4.1: The social model of disability



The above model illustrates the fact that impairment is mediated (as shown by the first arrow) first and primarily by social barriers. Social barriers are in turn divided into three aspects (as shown by the three centrifugal lines from "Social Barriers") namely, stigma associated with disabilities, discrimination against people with disabilities, and inaccessible facilities or environments. This is precisely the purpose of the social model of disability: to expose the dominant oppressive relationship between disability and society. In other words, people with disabilities cannot function 'properly' because of the persistence of social barriers, and not because they were intrinsically inferior.

During the 1990's, in defence of the social model of disability, Shakespeare and Watson (1997) argued that the media distorted the meaning of the social model of disability during campaigns for anti-discrimination laws in the United Kingdom. They also stated that, because of the news coverage of such activism,

there was a misconception that the social model of disability was widely understood. They thus point out, "It is very common to read texts relevant to disability, which fail even to reference the work of Oliver, Barnes, Morris and others. This ignorance might be expected of various fields of the medical sciences, to whom the social constructionist approach is a fundamental challenge: however, it is more surprising to find disability studies neglected in other human sciences, and even in other areas of sociology" (Shakespeare and Watson, 1997: 294). Previously, Barnes and Oliver (1993) had shown how sociologists have not moved beyond Parson's functionalist sick role that has been applied in sociology, and particularly in medical sociology.

Although Shakespeare and Watson (1997) make a good point that there is widespread ignorance about the social model in some academic circles, they should also note the tendencies of rhetoric in social movements such as the Disability Right Movements. At the level of activism, the conceptual misconstruction of the social model of disability is also part of the problem. I equate this tendency to the euphoria of liberation when disability activists finally made a powerful observation about disability and society after centuries of being voiceless. The euphoria of liberation is underpinned by the wrong assumption that the struggle is over. Beatson observes, "In the early stages of a self-declared liberation struggle against oppression, its militants may be infused with a born-again religious zeal for the cause. Fighting for great abstractions like Justice, Equality, Freedom and Equality, they throw themselves into the struggle with fundamentalist zeal. They see and challenge 'oppression' everywhere, and denounce it with a raucous righteousness that borders on fanaticism. Having Truth on their side, no words are too extreme nor actions too abrasive for the advancement of their just cause. Their denunciatory fervour may also be turned upon disabled colleagues suspected of being less committed to the struggle or wholehearted in their attacks upon ableism" (Beastson, 1996: 173).

It is my contention that such so-called liberation euphoria vis-à-vis the social model of disability has resulted in several dead-ends for the articulation of the model. These dead ends can be attributed to the basic problem of negativity, in the sense that the social model of disability has its origins in negativity because it has been created in opposition to the medical model of disability. Simply put, the primary tenet of the social model of disability is the *protection* and *liberation* of the disabled individual *against* and *from* the medical model of disability. To a certain extent, of course, the social model had to be a negative model because it emanated from disability activism, which was critical of the negative conventions towards disability. The Disability Rights Movements throughout the world, did, after all, attack the dominant negative social perceptions of disability.

However, the consequence of such an attack has resulted in an automatic blanket approach towards what is regarded as a medical model of disability. Everything that the Disability Rights Movement disliked was lumped under the medical model of disability. As a result, problems were not analysed or contextualised. They were simply homogenised and tested on a binary scanner, which categorises them as belonging to either the social or the medical model. This dichotomy is equivalent to a discretionary decision by the proponents of the social model of disability to either accept or reject the tenets of their argument. Alternatives are not permitted. As one disability activist put it, "In truth we here encounter the first of our monoliths – often distilled in the slogan 'disability is a rights issue' – which inevitably means in my book that it will itself be disabled. For it is the central contention of this lecture, that monolithic or one-dimensional analyses and prescriptions are inherently unable to do justice to the complexities of the phenomenon that is disability. As for this one, flawed in its philosophical underpinning, it both proceeds from and reinforces a particular cast of mind – negative and adversarial. As it sweeps all before it, it throws whole orphanages out with the bath-water, and its excoriation of alternative perspectives leads to

error in its policy prescriptions. And all these features conspire to produce an intellectual and campaigning style which is repugnant", (Low, 2001: 1).

One the same note as Low, Llewellyn and Hogan (2000) too argue for an intellectual debate that does not seek to replace one model with the other but rather to put forward merits for different models in response to different research questions. They conclude, "The medical model should not continue to serve as the theoretical system for guiding disability research. As a self-contained frame of reference for the determination of legitimate questions, methods and theoretical accounts of disability, it can no longer account for the range of data produced in such research. Similarly, the social model extends the range of issues addressed by disability research, raising new problems and requiring different methods. It cannot, however, lay claim to be[ing] an complete theory of disability *per se*; genuine and psychological phenomena remain and demand different theoretical and methodological approaches for a better understanding of disability processes" (Llewellyn and Hogan, 2000: 164).

I think that this reductionist binary approach of medical model versus social model creates an analytical problem of tautology. The social model cannot define itself independently of the medical model. Similarly the medical model cannot be defined independently of the social model. Even when one eliminates the words "medical model" in a social model argument, the implications reverberate. For example, arguing for the self-determination of people with disabilities implies resistance to the history of paternalism and low expectations accorded to people with disabilities. Similarly, a description of the experience of people with disabilities under the medical model is usually a preface to and a justification for the rights of people with disabilities. The argument of the social model of disability is reduced to nothing more than a binary set of countervailing forces

(social and medical) around a single axis (disability), and that was not the intention of the Union of Physically Impaired Against Segregation. Certainly, Oliver (1983, 1990 and 1996) never explained the medical model of disability in this way either, as the next section on the misconceptions of the medical model explains.

(b) Misconception of the Medical Model of Disability

I think the problem of the binary set of countervailing forces of the social and medical models of disability is exacerbated by the diatribe against the medical model. This model has become a dumping ground for those who seem to misunderstand the social model. In other words, any perspective that rightly or wrongly criticises the social model is attributed to the medical model. This has created a problem of misunderstanding with regard to the distinction between what Harris (1993) calls the 'art' and 'science' of medicine. As a medical doctor, Harris is aware of the culture of medicine as rooted in natural science. However, he concedes that there are social aspects that also need to be considered, and that such aspects do not rule out the fact that people with disabilities might need medicine. Although he does not write in favour of the social model, he points out the good practices that do exist in rehabilitation medicine.

The denunciation of all that belongs to the medical model does not distinguish between medical practice and social conventions, though, and it also does not try to postulate how the two might influence each other. In contrast, Silburn (1993) tries to explain empirically how a social model of disability could be applied in a medical rehabilitation setting. She describes her team's strategy to apply the social model and how this was often resisted by the professional rehabilitation staff. She also states that, even in the face of such resistance (albeit diminishing over time), there were benefits of making people with disabilities part of the process.

Oliver (1996) disagrees with arguments that the social model of disability does not consider illness and impairments. He argues that doctors do indeed have a role to play in the lives of people with disabilities. He thinks that this role is one of "stabilising their initial condition, treating any illness which may arise and which may or may not be disability related. The problem arises when doctors try to use their knowledge and skills to treat disability rather than illness" (Oliver, 1996: 36). Oliver's contention is that the medical and rehabilitation profession is rooted in the ideology of normalcy and cure.

I have indicated in Chapter 3 that the nineteenth century's obsession with normalcy accorded unprecedented powers to the physician when the state permitted the physician to kill without penalty. Clearly, these powers have been stretched too far: from the doctor's simple prognoses and recommendations for effective treatment, to the doctor's arbitrary determination of who was fit to live or die. In the 20th century, it is not surprising, then, that medicine and its allied professions have had such an exclusive power over people with disabilities. People with disabilities were, after all, regarded as dependents, and allocated to different institutions that had to take 'care' of them. In fact, as Chapter 3 illustrates, long before what Foucault (2000) referred to as "*the birth of the clinic*", the disabled body was in existence, constructed and either taken 'care' of or controlled by someone else. The family played the role of guardianship; the State played the role of custodianship; the church played the role of philanthropy; and the judiciary codified disability.

By the time medicine was elevated to its present role of rehabilitation, society had placed value judgements on disability for a long time already. It expressed a spiralling entanglement of a system of paternalism towards people with disabilities. Hospitals were not simply clinical. Rather, the hospital as an institution developed its own systems of subjugating the subjective experiences of

people with disabilities in the same way that other institutions have done. It is analytically flawed and empirically incorrect to categorise and label the oppression of people with disabilities as a problem of the *medical* model. Rather, we should consider what Oliver calls the medicalisation of disability rather than the science of medicine.

One example of viewing disability within a medical model paradigm is a book titled *Coping+Plus Dimension of Disability* by Robinson et al (1995). It rightly addresses the emotional impact of disability on people with disabilities. However, it centres the problem on the disabled person whose disability is portrayed as a tragedy or loss that he or she must cope with. The book offers strategies for coping and functioning in society. At the centre of such strategies is a constant reminder that the people with disabilities are dependent on non-disabled people. This dependence is emphasised so strongly that the so-called Independent Living Movement is regarded as simply a way in which people with disabilities can depend on, rather than being a way of living independently. This is contrary to the foundation of the movement, which seeks to make people with disabilities independent and to acknowledge the relationship between their disabilities and society.

(c) Some Critiques of the Social Model of Disability

Since the formalisation of the social model of disability in the 1970's and since Oliver (1990) moved beyond it in *The Politics of Disablement*, disability has become a category of academic and political scrutiny in many parts of the world, such as the United Kingdom, Canada, the United States of America, Australia, South Africa, and in other countries. In fact, disability studies have now been established in some universities in Britain and North America. This development has invited different scholarly perspectives within disciplines such as sociology, law,

psychology, health sciences, anthropology, and history. Consequently, some of these perspectives have added new categories to disability studies.

Some authors argue that disability studies (or – incorrectly – the social model of disability) exclude impairment in its analysis. It is my contention, though, that impairment is not overtly excluded but rather that there is silence about it because it is regarded as an individual tragedy from the perspective of the medical model of disability. Crow (1996) observes, "Sometimes it feels as if this focus is so absolute that we are in danger of assuming that impairment has no part at all in determining our experiences head on, we have chosen in our campaigns to present impairment as irrelevant, neutral, positive, but never, ever as the quandary it really is" (Crow, 1996: 208). She continues, "This silence prevents us from effectively analysing the difficult aspects of impairment. Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realising our potential or railing fully against disability (our experience of exclusion and discrimination); many of us fear for our futures with progressive or additional impairments; we mourn past activities that are no longer possible for us; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairments. Yet our silence about impairment has made many of these things taboo and created a whole new series of constraints on our self-expression" (Crow, 1996: 210).

Similarly, Hughes and Paterson (1997) argue for a sociology of impairment in which there is a clear distinction between impairment and disability. They contend that people with disabilities experience both impairment and disability, and that the emancipatory politics of identity need to be considered. Even though

they direct this argument to the social model of disability, I think it is more appropriate for disability theory rather than for the social model of disability as I have already shown above, because it belongs to the post-structuralist perspectives of identity.

The issue of impairment is very important as part of this thesis. In Chapter 10, I argue that, even though the social model provides insight into the oppression of people with disabilities, developing countries are also concerned about the actual experience of impairments because assistive technology is a basic resource, whereas on the other side of the Atlantic the issue is citizenship.

Corker and French (1999) expressly advocate for discourse analysis by showing that the relations of power, meaning and identity have much to offer disability studies. They argue that disability operates within a discursive space as both a text and a discursive event. In their book, they have compiled articles on personal narratives, constructionist perspectives and cultural representation. Ingstad and Whyte (1995), too, have compiled articles on the cultural meanings of disability, difference and identity.

Furthermore, in her typology of disability identities, Darling (2003) argues that, although the literature on ideology is growing in the area of disability studies, there is still little understanding of the identities and roles of people with disabilities and of how such identities and roles are developed. To substantiate Darling's argument, I refer to a South African auto-biographer, Musa Zulu (2004), in which he describes his emotional journey and identity development after he was paralysed in a motor vehicle collision. When I asked him why his autobiography was expressed in narration, poetry and pencil drawings, he said that he wanted to show that he was not just disabled but also an artist with many talents. This turning point in his life is captioned "Thisability" (Zulu, 2004: 39) to signify that he embraced his identities.

Still on the question of identity, O'Tootle (2004) argues that the social model and disability studies are characterised by a sexist inheritance. She argues that part of the purpose of disability studies is to provide information about the disability. However, such purpose is not completely fulfilled because, when it comes to disabled women, "They are invisible because those of us with access to these academic gatherings have not formally acknowledged their work as vital to the survival and growth of our culture, as vital and as necessary as the efforts that we so passionately and proudly pushed forth in the beginning of the disability movement" (O'Tootle, 2004: 298).

Watson (2004) is critical of the exclusively macro-political agenda of the social model of disability. He argues that, even though structures should not be ignored, disablement should also be challenged at an interpersonal level. He maintains, "Social structures are contingent and invented... To discuss social structures without examining the language, the signs, the images through which structures emerge is to suggest that structures exist as some form of social reality... It is this interaction that should form the basis of any challenges of disablement" (Watson, 2004: 112).

What the above developments in disability studies show is that those who understand the meaning of the social model of disability have moved beyond it and are trying to create a social *theory* of disability. This is reflected in the ways in which disability permeates through enquiries such as policy studies. In his review essay, Prince (2004) states, "In disability policy, three paradigms are at play: the centuries' old view of people with disabilities as being 'worthy poor' deserving of local charity and eventually state assistance; the bio-medical model stressing the physical and mental limitations and incapacities of the person; and the more recent human rights and full citizenship perspective that seeks to enable persons with disabilities to participate in and contribute to society in accordance with their

aspirations and their status as members of a democratic political community. As the 21st century begins, all three paradigms are, in effect, reflected in the mass media and public discourse, creating complexities in program designs and challenges in mobilizing the disability community for innovations in policy" (Prince, 2004: 465).

Disability Studies have not only permeated traditional social services institutions but also into information technology and communication services. Guo, et al (2005) have not only used the social model of disability correctly but have moved beyond it by empirically showing how it could be used to assess access to the Internet for people with disabilities in China, where the model is not widely known. In their findings they also indicate how the Internet can either exclude or include people with disabilities and that there is a need for further research to untangle the dynamics they identified.

Priestly (1998) also indicates developments in disability studies by showing that these are no longer a matter of the difference between creationism and constructionism. He incorporates materialism and idealism, and constructs a four-fold typology to show how disability studies can be loosely classified into individual materialism, individual idealism, social materialism and social idealism.

With the emergence of disability studies, Oliver and Barton (2000) outline some of the tensions faced by disability studies. They specifically outline the tension between disability studies and medical sociology, which seems not to understand the purpose and inquiry of disability studies. They also discuss the tension and schism, between disability academics and the disability movement. They support the creation of disability studies that are academically stimulating yet relevant to the lives of people with disabilities and that give voice to people with disabilities. Pfeiffer (2003) echoes their sentiments.

In his review essay on disability studies, Meekosha (2004) – like Barnes (1999) before him – raises concerns about the insularity of the British materialist perspective and of the American literary and pragmatic focus, as well as the general lack of history in disability studies. Whereas Barnes laments America's reinvention of disability studies and the loss of socio-political and cultural bases of disability, Meekosha's concern is the need for disability perspectives in post-colonial countries and the separation of the disability movement from disability studies.

Disability studies also have to consider the concerns of social movements. Writing on the experience of the disability rights movement in New Zealand, Beatson (1996) observes that the movement has been held back by internal factors, which he categorises as inertia, schisms and contradictions. The source of the problems is that, whereas the disability rhetoric encompasses comradeship in the common struggle for people with disabilities, the reality is that there are other "people with disabilities who do not identify with 'the cause' (hence the inertia), while of those who are committed to political action there may be factional in-infighting and disagreement over both ends and means (hence the schisms and contradictions)" (Beatson, 1996: 169-170).

An illustrative example made by Beatson (1996) is that, though the four political actions (welfare, integration, consultation and identity) of the disability movement are not mutually exclusive, they cause schisms and contradictions with the movement. The demand for welfare provision requires the disability movement to emphasise the dependency of people with disabilities, and such emphasis seems to contradict the notion of independence and self-sufficiency also promoted by disability movements.

To summarise, then, I have shown some of the misconceptions and weaknesses and criticisms of the social model of disability, and I think the criticism on

impairment is relevant for this thesis and in general in this field. Indeed, the social model of disability does not satisfactorily consider impairments. Although it differentiates impairments from disability, it locates the latter at the centre of the argument and as momentum and justification for political struggles against the oppression of people with disabilities, while being oblivious to impairments.

Neglecting impairments is a major problem in the provision of support services for students with disabilities. Higher education institutions use impairments and disability interchangeably, as do most public and private institutions. However, when interacting with students with disabilities, they should actually regard these as impairments. In this regard, though, higher education institutions are not interested primarily in the distinction between impairments and disability. Rather they are primarily interested in ascertaining if the student's impairment warrants support services for a specific course or activity. As I will indicate in Chapters 6 and 7, the interpretation of United States' Section 504 of the Rehabilitations Act is primarily about impairments and how these relate to the course or activity relevant to the student's studies, rather than about the holistic approach of the social model of disability. This problem vis-à-vis impairments in higher education indicates that the social model of disability should also take into account how the actual experience of impairments impacts upon service provision at the level of agency in terms of both material resources and negotiation between a disabled person and the service provider.

(d) Overburden of the Social Model of Disability

Given such developments over the past thirty years, it is a futile exercise to be concerned only with the social model of disability in disability studies, as some authors still do. It might be the *sine qua non* of disability studies but it should not be the only focus. Such insular focus on the model overburdens it. I say it is

overburdened because I think the social model has limited functions and that it is erroneous to assign extra and external functions to it in the first place. The intrinsic function of the social model is to serve as a justification for the rights of people with disabilities. Instead, there is a need to move beyond, especially for post-colonial countries who have recently been introduced to the social model of disability, as is the case with South Africa, in which the model was introduced in the late 1980's and popularised in the 1990's.

Unfortunately, for those who seem to have ignored these developments, the internal validity of the function of the social model has been taken to burdensome heights. As I will demonstrate in Chapters 9 and 10, the disability model has been accorded a quasi-messianic status within and outside the disability movement. By this I mean that it is being regarded as the all purpose argument whose function is to obliterate all disability discontents. As I have demonstrated above, the social model arose from activism and was unprecedented at the time. As a result, the social model became the novel voice of people with disabilities and now forms the basis of many disability issues. Similar to other struggles in history, the social model was useful in that it allowed disabled voices to speak. The downside, however, is that it has crystallised into a salvific text for those who seem not to understand it.

For some, then, the social model of disability evolved into a promise of salvation, because it has been used to explain how the world of the disabled ought to be and how the movement should naturally proceed to realise such a world. As such, it is a moral text that attacks the oppression of the disabled and envisages a world free of oppression on the basis of disability. Naturally such a text cannot be challenged from within the movement, as such attack from within would be sacrilegious. This also means that it is no longer open to change. The social model has been cast in stone, so to speak. The only additions that are permitted

are simply examples that prove what the discourse of the social model articulates or some analysis within the discourse itself. So, the model remains static, as nothing more can be said about it and, similarly, nothing can be deleted from it, and yet more is expected to be practically gained from the model.

The social model of disability is regarded as self-evident truth that justifies redress. I agree that no one can deny the injustices that people with disabilities face. However, the problem is the implication of this truism. Consequently, the social model of disability seems to suffer from aversion to empirical rigour and debate. Invariably, arguments that are in favour of empirical tests are attributed to the medical model and tend to be rejected. Yet the social model of disability abounds with empirical evidence to demonstrate discrimination on the basis of disability and to use that evidence to make moral arguments and seek redress.

If the disability discourse were to be limited within the disability movement only or in the academy only, then it would neither be self-reflexive nor open to external scrutiny. So, once again, it remains a static, self-acclaimed and closed argument not amenable to scholarly scrutiny when, ironically, its foundations are in fact scholarly. On this issue of scholarship Cassuto concludes, "If boundaries become restrictions, the whole scheme undermines what the word 'university' describes: a community of scholars working across the range of knowledge for the good of the whole. In light of current attacks on academe as elitist, it is important to add that 'the whole' for which professors' work refers to all of society. Indeed, academe 'belongs' to society; here the idea of belonging is appropriate, since society pays the tab for the academic enterprise. When we restrict access to fields, we fuel a resentment that often seems motivated by a feeling of exclusion. That is a failure of accountability with vast implications" (Cassuto 1999).

By pointing out the serious problem of deadweight on the social model of disability, I am trying to indicate that, in this thesis, the social model of disability is not understood as a panacea to eliminate the oppression of people with disabilities. In particular, as I will argue in Chapter 10, part of the problem of supporting students with disabilities in South Africa is the impasse of the social model of disability, which means that the social model of disability is understood as the sole foundation of such support programmes in higher education. In this thesis, the social model of disability is recognised understood as having been a significant paradigmatic shift and yet its limitation are now recognised too. Consequently, the way forward lies in trying to operationalise it, as elaborated on in the next section.

(e) Resolving the Impasse of the Social Model of Disability

From the above discussion, I think part of the answer in resolving the impasse of the social model of disability lies in three arguments. The first one is to distinguish conceptually between the social model of disability and the endeavour towards achieving a social theory of disability, and to understand the contemporary concerns about constructing such a disability theory. For example, in the case of disability and genetic engineering, Reinders (2000) observes the ethical dilemma between normalisation and prevention. He uses normalisation to refer to the act of integrating the disabled into society and allowing them to participate fully like anyone else. By prevention he refers to recent genetic engineering, which makes it possible to identify an impaired foetus before it is born; this raises the possibilities of abortion. Reinders argues that normalisation and prevention are contradictory, because, while normalisation advocates for the integration of people with disabilities, prevention implies that such integration assumes that people with disabilities are inferior and that their presence is

unpleasant. Moreover, Oliver (2001) acknowledges the changing nature of globalisation or what he calls late capitalism. He mentions that such contradictory changes have implications for the disabled in terms of work, education, politics and the production of disability in late capitalism. Similarly, Barton (2001) recognises the exclusionary nature of contemporary society, which people with disabilities are likely to experience. He argues for the so-called 'politics of hope' in which the national and international disability movements continue to struggle against oppression. In the same book, Barton compiles edited articles that investigate a range of contemporary issues, such as feminism, justice, inclusive education and empowerment.

The second argument is that the social model needs to be operationalised so that we can move beyond it. As I will argue with regard to the South African case in Chapter 11, such operationalisation requires research, policy, strategy and implementation. However, this is not a novel idea. The early proponents of the social model of disability already investigated practical approaches to disability, the disabled individual and society. The origin of such ideas lies in the foundations of the Independent Living Movement (ILM), and not necessarily the Disability Rights Movements. The ILM used the social model pragmatically, and did not only rely on the rhetoric of activism. The ILM thus balances activism for the rights of people with disabilities and the practical needs of such people.

Moreover, there should be practical steps that can be taken to translate the social model into reality by means of theory and research. Arguments about some shortcomings in disability research have been raised, though. Morris (1992), for instance, argues for an inclusion of feminist methodology in disability research. Zarb (1992) proposes a participatory research that would be accountable to people with disabilities. Barton (1998) recommends a demystification of disability research processes in which the non-disabled researcher actually heeds the voices

of disabled participants. Barnes (2003) reviews emancipatory disability research and argues that its sustainability depends on resource support. On the question of general disability research, Oliver too had already mentioned, "Disabled people, whose intellectual labours have produced the social model, have done this without access to the kinds of resources available to international academic superstars, professionals and policy makers, as well as the usual coterie of hangers-on and free loaders. Imagine how much farther down the road we might be if disabled people had been given these resources to develop our own social theory, our own quality measures for human services and our own classification schemes" (Oliver, 1999: 169).

The final argument concerns the provision of support for people with disabilities. This thesis specifically investigates support for students with disabilities in South Africa. The capacity building approach for people with disabilities, as suggested by Balcazar and Keys (2001), is an admirable development of the elementary vision of the ILM. Their approach includes both disabled and non-disabled people, while emphasising that the former must be in control of the process. It also involves research to test the context and assess the needs of people with disabilities, instead of assuming a blanket intervention, as is commonly expressed in the rhetoric of the social model of disability. The approach is participatory and self-evaluative instead of assuming a tandem of popular struggles; winning the rights; supply of resources and more resources.

There are three implications of this section for this thesis. The first one is that supporting students with disabilities in South Africa needs to be research based. The CHE survey that is part of this thesis is a first step in the right direction and I hope it will encourage more research on the subject. The second implication is that national and institutional policies are needed to guide the provision of such support. As Chapter 9 will indicate, South Africa has no national higher education

disability policy, and this absence of a policy is delaying the systematic provision of support for students with disabilities in the country. Moreover, policies need to be translated into strategies that can be implemented in reality. As I will argue in Chapter 10, articulating the social model of disability in a post-colonial setting is not enough. We need to move beyond this, and to be practical at the same time. The third and final implication is that, although context is important, there are also global pressures and networks, which make it difficult for national policies to be applied in a purely universalistic or particularistic manner. The difficulty will be explained in Chapter 5, which focuses on disability and the right to education.

(III) Conclusion

This chapter has identified and discussed critiques of the social model of disability. These critiques are based on the misconceptions of both the social model of disability and the medical model of disability, and on the undue burden that was placed on the social model of disability. As argued above, the social model has been wrongly interpreted as a theory (rather than merely a model) that explains all disability problems. Moreover, the social model of disability has often been wrongly assigned the duty of solving all disability problems. This has resulted in an impasse. Similarly, the medical model of disability has been misunderstood as being limited to a clinical setting rather than being recognised as a set of disabling practices.

Such misconceptions have caused the present impasse of the social model of disability. This impasse is illustrated by the constant negation of the medical model, which has resulted in the binary approach of the medical versus the social model. The dichotomy is so stark that there are no grey areas and no alternative explanations. Such alternative explanations cannot be allowed because the

discourse of the social model tends to be closed and intolerant towards empirical rigour and critical interrogation. It does not allow anything to be added or removed from its tenets. This has caused unnecessary animosity between medical sociology and disability studies. These debates are monotonous, however, and cannot solve practical problems except to articulate the rights of people with disabilities by showing the oppressive nature of society towards disability – an idea that is now recognised but does not take us any further.

This chapter has tried to clear up these misconceptions by explaining what Oliver (1983) and Finkelstein (1980) meant by the medical and social models of disability. It has also shown some of the developments and tensions within disability studies. Of particular importance is the fact that disability studies are moving away from merely describing the social model of development towards putting it into practice through research, and even moving beyond that by developing a multidisciplinary disability theory.

Critical for this thesis is the suggestion how to break the impasse of the social model of disability. One way to realise that the social model of disability is not a theory but merely a model, which sketches a relationship between disability and society. For the model to work, it needs to be operationalised in the same way that the Independent Living Movement initially approached disability problems, i.e. with pragmatism instead of rhetoric. Moreover, we need participatory research, policy, strategy and implementation, which are issues that I will elaborate on when investigating the South African situation in Chapter 9.

Chapter 3 has shown the relationship between disability and society with the purpose of highlighting the legacy of benevolence and showing how the social model of disability was originally a powerful attempt to resolve the changing relationship between disability and society. Chapter 4 has discussed the social

model of disability because this currently seems to be the bedrock of disability studies. It also indicated that this model had arrived at an impasse and that it is necessary to move beyond the rhetoric. The chapter has emphasised that it is imperative to operationalise disability studies in a post-colonial setting and in the context of the provision of support for students with disabilities in higher education in South Africa. This chapter has also indicated that global changes and technological changes have an important impact on disability issues. An important derivative of these changes is the question of the right to education for people with disabilities, which is the subject matter of the following chapter.

CHAPTER 5

DISABILITY AND THE RIGHT TO EDUCATION

(I) Introduction

The purpose of this chapter is two-fold. Firstly, it tries to show the paradigmatic frameworks within which education for people with disability has been provided. These frameworks focus on the general provision of education, but could be applied at any level of education as section IV tries to do so. Secondly, the chapter highlights that, even though the disability rights movements have unequivocally asserted the rights of people with disabilities, the problematic nature of rights should also be considered because they are seldom discussed unless such discussion arose from problems with public and private support services. Rights are problematic anywhere in the world. However, in the context of post-colonial countries, they pose a particular problem of universality versus particularity and formal rights versus real rights in the context of scant resources or competing priorities in general, and in the provision of disability support in higher education in particular. This chapter is not intended to provide answers, but rather to indicate that the question of rights has tensions of its own that only become evident at the level of practice. This problem of rights, as I will show in Chapter 10, intersects in a tensive manner with benevolence and the impasse of the social model of disability. I further contend that it is at this tensive intersection that supporting students with disabilities finds itself in the South African higher education system.

There are six sections in this chapter. The first one describes Peters' (1993) frameworks within which education for people with disabilities has been provided thus far. The second section outlines the influence of the medical model

of disability, which has dominated the education of people with disabilities in South Africa. The third section constructs a comparative three-fold typology of the framework of disability support in higher education. The fourth section highlights the problematic nature of rights and the implications thereof for the provision of support for students with disabilities in South Africa. The fifth section is a commentary on the four preceding sections, and the final one concludes this chapter.

(II) Disability Paradigms and Education

The changing provision of education for people with disabilities has been influenced by a changing social understanding of disability, which is underpinned by cultural values and ideological assumptions in different temporal and social settings. The changing understanding of disability is reflected in the paradigmatic shifts and practices in the education of people with disabilities.

Peters (1993) provides a cultural-ideological framework for analyzing the education of people with disabilities so that we can understand the policies and practices in the provision of education for people with disabilities in diverse cultural and ideological settings. She explains the shifting paradigms in the understanding of disability and consequently in the provision of education for people with disabilities. Although these are frameworks on general education, I do find them useful in trying to understand the contemporary position of students with disabilities, as section IV will indicate. She explains four ideal typologies of paradigms by looking at their underlying assumptions, educational goals, consequences, and associated problems.

Peters does not explicitly explain how she uses the concept of paradigm in her cultural-ideological framework of the construction and understanding of disability and education. She seems to use the concept of paradigm both as a model that

explains phenomena, and again in the sense used by Thomas Kuhn (1962), where the word refers to an intellectual tradition in the pursuit of knowledge. However, judging from the way in which Peters explains her framework, she is definitely and primarily using Kuhn's definition of a paradigm. This thesis follows her approach. Kuhn defined a paradigm as an unprecedented mode of scientific activity and research that encompassed a particular intellectual uniqueness that successfully pre-empts other modes and opens up new ways of finding knowledge. In his explanation of the progression of science and scientific method, he explains, "Aristotle's *Physica*, Ptolemy's *Almagest*, Newton's *Principia* and *Optiks*, Franklins *Electricity*, Lavoisier's *Chemistry* and Lyell's *Geology* – these and many other works served for a time implicitly to define the legitimate problems and methods of a research field for succeeding generations of practitioners. They were able to do so because they shared two essential characteristics. Their achievement was sufficiently unprecedented to attract an enduring group of adherents away from competing modes of scientific activity. Simultaneously, it was sufficiently open-ended to leave all sorts of problems for the redefined group of practitioners to resolve. Achievements that share these two characteristics I shall henceforth refer to as paradigms" (Kuhn, 1962: 10).

The medical paradigm is the first typology of Peters' (1993) framework. The assumptions underlying the medical paradigm are characteristic of functionalism in sociological theory as pioneered by Talcott Parsons in the 1950's. In functionalist theory, education is based on meritocracy, and it prepares and determines one's social role and status later in life. In the learning process, individuals are tracked and labelled according to their abilities to perform according to curriculum requirements and social expectations. Individuals are separated and graded during the learning process and, as adults they are expected to occupy social roles according to their abilities.

The medical paradigm has the same characteristics of labelling and separating according to normalcy or ability and abnormality or disability. Normalcy and ability are thus regarded as the direct opposites of abnormality and disability. In the learning process, normal students are distinguished from abnormal ones. Consequently, students with disabilities are separated from mainstream learning classrooms and their education is provided by means of specific education programmes, so that they can occupy specific roles as 'handicapped' adults. This is so because "Parsons who subscribes to this paradigm assume that pathological symptoms may be objectively assessed. Application of a label to abnormality reduces ambiguity. We can ascribe physical/mental characteristics to a particular person and thereby foreclose knowledge about the person's history, self-image, character and social status. The disability becomes the paramount characteristic of such a person" (Peters, 1993: 28).

As disability becomes the primary identity of such individuals, prescription, cure and treatment become educational goals imposed on the person with a disability. Education, disability and health become intertwined in a hierarchical relationship as follows: firstly, education is regarded as a social virtue that must ideally be undergone by everyone. The medical paradigm consequently defines the individual as disabled, abnormal and unhealthy and hence not fit to receive the ideal education. Education and health are superimposed on the disabled person such that the person with a disability receives education on condition that she or he is separated from the normal process of education and that s(he) receives education and treatment concurrently.

Essentially, the consequence and problem of the imposition of health and education on disabled individuals is disempowerment of the individual by professionals. The person with a disability is denied the role of being a student and later denied the possibility of choosing an occupational role. It is from this

understanding of disability that access to higher education for people with disabilities has been regarded as exceptional rather than normal. Moreover, it is within this paradigm that people with disabilities have been absent in higher education institutions for a long time, at least until the post-war period. Section III will particularly show this mode of thinking in the education of children with disabilities in South Africa. The aim is not to describe their education *per se*, but rather to demonstrate why it was unthinkable to have a visible number of students with disabilities in higher education in South Africa even after World War II, a period during which developed countries started enrolling students with disabilities.

The second ideal typology of perception is the social paradigm. This differs from the medical paradigm only to the extent that an individual with a disability is understood as lacking ability – as socially defined or perceived – to function normally in society, and not as diseased and innately different. However, the social paradigm still shares many of the characteristics of the medical model. People with disabilities are still viewed as different from those without disabilities. Pupils with disabilities are still separated from mainstream learning process and their education becomes specialised by professionals. Pupils are not just separated within mainstream schools but they also receive their education in special schools, their learning process is called special education, and their condition is termed leaning disabilities. By means of this process, education and remediation are once again superimposed on the person with a disability.

Consequently, persons with a disability are sheltered in special schools and denied socialization in mainstream society. They become inferior recipients of private or public welfare. The problem with this paradigm is that pupils are denied self-determination and mainstream socialization, as happens in the learning process of mainstream schools.

The third ideal typology of perception is the political paradigm. This is underpinned by the conflict theory, as characterized by Marx and Weber. Conflict theory generally shows that social groups enter into conflictual relations because of different interests, competition for resources or the oppression of one group by another. Similarly, the political paradigm's understanding of disability is that it is a historically constructed condition that oppresses people with disabilities. The underlying assumption is that people with disabilities are an oppressed minority whose condition is socially constructed. Disability is not an innate or biological condition but, instead, an experience, because society is disabling people with impairments.

Consequently, because the political paradigm sees society and not the person with a disability as the problem, the educational goals focus on ability and not disability. In terms of this view, students with disability should be integrated into mainstream schooling. There should be equal access and opportunity in education. The principle is that education is a universal constitutional right and that no one should be denied education on the basis of disability. Thus, there should be no special schools but desegregation and integration in the learning process.

This paradigm can be partly applied to the contemporary assumptions underlying much of the provision of support for students with disabilities around the world. In most countries that provide such support, it is a rights issue. Students with disabilities are protected by laws and policies that outlaw discrimination on the basis of disability. These laws and policies recognise the political oppression of and struggles by people with disabilities in fighting for equal rights, treatment and access to higher education and other services.

The problem with the political paradigm is that political rights are influenced by legislation and political power, which makes it difficult to implement and monitor

them. Moreover, legislation and political power do not guarantee change in society's perceptions about disability and ability of people with disabilities to receive an education. "Attitudes of classroom teachers, employers and society in general undermine efforts towards full integration. As a result, many school children with disabilities may be physically integrated in classrooms but remain socially isolated and academically under-achieving due to lack of access to alternative modes of learning within these classrooms. Schools often become sites of failure rather than equal opportunity" (Peters, 1993: 31-32).

The final ideal typology is the pluralistic paradigm. This paradigm is based on social interactionism, which argues that meanings, values and symbols are socially constructed within a particular cultural and temporal context. This implies that normalcy and abnormality are culturally relative and laden with ideology.

The goal of education in the pluralistic paradigm is to acknowledge and support diversity. Ability and disability should thus not be seen as the defining basis for discrimination. People with disabilities should be integrated into mainstream education, with the intention not of accommodating them, but of supporting their different educational needs and educating society that diversity is a positive influence in the pool of different talents and contributions to society. The pluralistic paradigm advocates equality, integration, resocialisation to appreciate diversity, and the support of different educational needs of people with disabilities. "Overall, the educational objectives of the Pluralistic Paradigm are these: 1) to embrace the nature of diversity as a positive force, 2) to foster sensitivities and respect for diverse learners, 3) to recognise the role of cultural factors that mediate the perceptions and treatment of diversity" (Peters, 1993: 33).

The pluralistic paradigm is unfortunately not yet accomplished in education in general, nor in other public and private services, nor in higher education. As

section IV will indicate, the present paradigm underlying the contemporary provision of support is the political one. Unfortunately, as Oliver (2004) noted and as I will elaborate on in Chapter 11, the political paradigm or what Oliver calls the entitlement approach in disability services has failed the implementation of disability policies. Oliver thus argues for a citizenship approach, which I think has some similarities with Peters' pluralistic paradigm. The following table summarises Peter's (1993) paradigms of disability and their theoretical underpinnings:

Table 4.1: Paradigms of Disability, their supporting Ideological/Cultural Theory and Outcomes

PARADIGM	SUPPORTING THEORY	OUTCOMES
Medical	Functional (Dis)ability	Labelling
		Segregation
Social	Social Exchange	Educational Tracking
	Welfare Provision	Professional Gatekeepers
Political	Class Conflict	Unequal Class Relations
		Struggle for Political Power
Pluralistic	Symbolic Interactionism	Social Knowledge
		Individual Differences as Positive Contribution

(Source: Peters, 1993: 34)

In conclusion, this section has explained the four paradigms that underlie educational provision in general, and it has applied some of these to higher education. The next section highlights the role of the medical model in the education of children in South Africa. The following section is not a history of the education of children with disabilities. It is rather an indication of the assumptions of the medical model. It suggests that part of the reason why people with disabilities have been absent in the South African higher education system was because they have been condemned to seclusion and confined to low levels of education.

(III) The Medical Model and Education of People with Disabilities in South Africa

In most documented cases, the education of people with disabilities in South Africa, as in most parts of the world, was based on the medical model and established by the benevolence of Christian missionaries or a benevolent individual through public charity. These schools were later partly paid for by the state. For example in South Africa, the Dominican Sisters established the Grimly Institute for the Deaf-and-Dumb in Worcester in 1863 (South African Interdepartmental Committee on Deviate Children, 1945: 2). Similarly, in 1817 in the United States of America, the American Asylum for the Education of the Deaf and Dumb was established at Hartford in Connecticut with the assistance of the Congregational Clergymen of Connecticut. These establishments were invariably not initiatives of the state but of private individuals who committed themselves to helping people with disabilities to access some education (Disability Museum, 2004)

Of course, there are several educational projects in South Africa and elsewhere, including higher education projects, that were established through benevolence and public charity. However, what sets the education of people with disabilities

apart is that such an education was meant to mould people with disabilities to 'fit' into their places in society. It was not special education as such, but rather an exclusive and yet isolated education for people who were already outcast, as I have explained in Chapter 3. It was benevolence propelled by pity and paternalism and encasing people with disabilities in a glass ceiling, which created more need for benevolence, pity and paternalism. People with disabilities were educated to acquire basic literacy and manual skills. From the onset, their education was actively designed to keep them in low skill crafts. Higher education for people with disabilities was unimaginable in the 19th century and early 20th century, not just in South Africa but internationally.

With the advent of special education in South African in, Leipoldt and Cleaver (1918) reckoned, "it may be accepted as an axiom that where a child is defective to such a degree that his retention in class demands extra care and attention on the part of the teacher, that child has no business to be in class. It is the acceptance of this truth that has led in recent years to the development of special classes and schools for the benefit of such 'high degree defectives' to whom the general term 'cripple children' is applied", (Leipoldt and Cleaver, 1918: 28). In 1918, the Administrators Notice No. 322 (under section 11(b) of the Education Act Further Amendment Ordinance No. 16 of 1916 effectively authorised the school medical inspector to exclude "verminous children, mentally defective children, and children suffering from any communicable disease" (Leipoldt and Cleaver, 1918: 7). The education of people with disabilities in South Africa, as in other parts of the world, was thus exclusionary and restrictive and yet vividly tainted with benevolence. The philosophy of special education was to educate sub-humans to acquire the most elementary human decency with the paternalistic assistance of benevolent individuals.

Not only was the education of people with disabilities exclusionary and restrictive, but it was made for the convenience of the teachers and the remaining generally 'normal' school children. It was not about improving the learning of disabled pupils, but rather to prevent the performance of the disabled pupil from delaying classroom progress. In his argument for special education and special classes, Moll (1918) observed,

- Regarding the child: "They are permanently incapable of receiving proper benefit from the instruction given in ordinary schools. Even if they do get a little knowledge, and that with great difficulty to themselves and their teachers, still, even so, they are unfitted to make practical use of that knowledge. They require an entirely different kind of education." (Moll, 1918: 26).
- Regarding other children: "In most favourable circumstances the defective children sit in the class as mere ciphers, but it happens all too frequently that they are a serious and marked cause of delay in the progress of the whole class" (Moll, 1918: 26).
- Regarding the teacher: "every teacher who has such children in his class can bear witness to the terrible trial which they are. If such a mentally deficient is absent for one day the difference is at once most marked. The teacher feels as if he had almost nothing to do. Certainly it is not every teacher who is able to teach these deficient children. Many do not even begin to do so. The more conscientious, after a time of fruitless effort, generally give it up as a hopeless task" (Moll, 1918: 26).
- "Recommend special classes to gain lost ground and special school for permanent 'morons'" (Moll, 1918: 26).

Moll's arguments are typical of the dominant discourse of normality as I have explained in Chapter 3. In his view, disabled children needed special education

because they were not normal. Special education did not mean teaching the same curriculum but rather teaching in a different manner and at low standards of quality and abstraction. Effectively, this meant a lower standard of education for 'abnormal' pupils. Moll reiterates this argument when he states that disabled children are either unable to understand or make use of the normal classroom knowledge, hence justifying the need for special education.

Moll also states that disabled children delay the general progress in the classroom. Such an argument does not only express an obsession with normality but also with meritocracy in education. Pupils' school performance is based solely on their aptitude and merit. The obsession was particularly emphasized in the use of the IQ test. Hence mentally ill pupils were the primary interest of special education. The main indicator was their school work progress. If they performed below the average of the time, then they were not fit to receive 'normal' education, regardless of the type of disability. So was the fate of disabled children.

However, in 1928, the South African government reported different causes of performing below average as follows:

- "Psychological: those with an inborn inferiority in general intelligence. It is this group, which is usually referred to as "mentally defective".
- "Those with special disabilities such as poor auditory or visual imagery, word blindness, incapacity for verbal or abstract symbols, inability to spell, etc. These children need special psychological and pedagogical methods,
- "Those with temperamental defects, who need to be taught how to adjust themselves to their surroundings and to learn to control their emotional reactions. They require individual study and guidance, with some system of mental inspection and child guidance clinics...

- "Social causes: children who are late coming to school because of living in remote areas or those whose parents are constantly on the move, so that they attend many schools irregularly, or those who play truant. This class also includes children handicapped by unsatisfactory homes or great poverty.
- "Pedagogical causes: large classes, lack of suitable classification, faulty teaching methods, badly drawn up curricula, instruction through a medium other than the home language, and similar errors in the school may delay children in their progress through the school course.
- "Physical causes: physical causes may lead to backwardness, as for example deafness, defective eyesight, fatigue and malnutrition, hormone disturbance, debilitating diseases such as chronic malaria, bilharziasis and hookworm disease", (South African Inter-Departmental Committee on Mental Deficiency, 1928: 99-100).

Such differences, though, were not discerned in order to improve the education of disabled pupils but rather to make it easier for the education system to determine which disabled pupils were to be selected for special education and which were to be institutionalised. Reading from the last bullet in the previous list, Moll stated that permanent 'morons' were fit for special education. Elsewhere he states, "Higher grades of imbecility are sometimes found in the schools. They cannot be suffered to remain in the classes, and it seems waste of time to give them a trial in the auxiliary classes, as no success is to be expected. It would be better to put them in an institute at once (unless the parents can look after them). To do this certificates from two doctors are necessary (Act No. 38 of 1916)" (Moll: 1918: 7).

The pattern that emerges in the education of people with disabilities has three characteristics. The first one is the separation of disabled pupils from mainstream

education and other pupils. The second one is the degradation of their curriculum to suit their 'sub normality'. The final one is to produce low-skilled individuals by virtue of their disability – any disability. These developments effectively meant that a disabled body had no place in mainstream education, which is underpinned by the philosophies of elitism, meritocracy and competition. It implies that disabled body cannot be part of the elite because it is poor and excluded. It also implies that the disabled body has no positive merit because it is abnormal and cannot compete because it is unfit.

Special education, elitism, meritocracy and competition make it understandable why higher education was undoubtedly a closed space for people with disabilities. From its foundations, higher education was designed for middle class young men from respected backgrounds. It was a place for the refinement of young men who would soon assume prominent and respectable roles in society. It could not have been made for disabled pupils. Hence students with disabilities who managed to reach higher education were not a priority for universities, technikons and colleges, as I will shown both in the American case (Chapter 7) and in the South African case (Chapter 9).

The medical, political and pluralistic paradigms as explained in this chapter so far are relevant to this topic because Chapters 3 and 4 have argued the oppressive nature of the relationship between disability and society and the need for a political struggle to gain such rights. However, as the pluralistic paradigm argues, rights do not guarantee attitudinal change and acceptance of diversity. This is one of the problems with rights that this chapter will also discuss. However, before a discussion on rights, I will look at the framework of the provision of higher education for students with disabilities. This comparative typology is by no means exhaustive or conclusive. It is limited to the observations I made when looking into policies and legislation that specifically covers this issue. The aim is to

indicate the position and current status of supporting students with disabilities in South Africa, the United States of America and other developed countries in general. This positioning will be further used in Chapter 10, when arguing that such support in South African higher education finds itself at a tensive intersection of benevolence, rights and the impasse of the social model of disability.

What this section indicates is an entrenched manner of thinking about the education of people with disabilities based on the medical model of disability. Such thinking is partly responsible for the under-representation of students with disabilities in higher education. Although the medical model has been dominant for many years, the trend has shifted towards more inclusive education in different countries (Armstrong and Barton, 1999). Hence higher education institutions have been making provisions to support students with disabilities across the globe. Different countries have different frameworks within which they provide such support. The following section investigates and develops these frameworks.

(IV) Frameworks of Providing Disability Support in Higher Education

The education of students with disabilities in higher education around the world is underpinned by the social model which, in reading Peters' table above (Table 4.1), is a combination of the both the political and pluralistic paradigms.[18] Countries, and in particular the institutions that provide support for students with disabilities in higher education, believe in equal opportunity, equal access, human rights and diversity. As will be seen below, some countries have special policies,

[18] Note that Peters (1988) does not use the term 'social paradigm' to mean the same as the social model of disability. The social paradigm deals with roles in society, while the social model deals with oppression in society.

legislations and regulations that provide for the support of students with disabilities.

In trying to understand how the national context in which higher education institutions in other countries provide support for students with disabilities, I have discerned and developed three frameworks in which this is undertaken. They are: (1) the legal mandate framework; (2) the enforceable rights framework; and (3) the human diversity framework. I have used three criteria to make the distinctions in the frameworks, namely: the agent of provision and sanction for the provision of support; the normative standards of disability support; and the enforceability of providing such support.

(a) Legal Mandate Framework for Disability Support in Higher Education

The legal mandate framework exclusively entitles students with disabilities to receiving support in higher education institutions. The agents of provision and sanction are a general anti-discrimination legislation; a law that provides specifically for students with disabilities in higher education; policies that provide for the support of students with disabilities in higher education; and regulations that specify the implementation of this provision. The normative standards underlying this framework are equal opportunity, civil rights and fair advantage for people who qualify for higher education courses and programmes. Supporting students with disabilities is enforceable by a statutory agent or civil court and grievance procedures within the institutions of higher education. The only example in the world of this framework seems to be that of the United States of America, and it is described at length in Chapters 6 and 7.

(b) Enforceable Rights Framework for Disability Support in Higher Education

The enforceable rights framework provides for disability support within legislation that deals with people with disabilities in general. The agents of provision and sanction are a general anti-discrimination disability law and policies that provide specifically for students with disabilities in higher education. Parts of that law and policies are extrapolated and interpreted to support higher education students with disabilities. The normative standards underlying this framework are human rights, equal opportunity and fair advantage for people who qualify for higher education courses and programmes. The supporting of students with disabilities is enforceable through a statutory agent or civil court. The United Kingdom and Australia, both discussed below, Sweden[19] and Italy[20], are examples of this framework.

The first example of the enforceable rights model is the United Kingdom. The Disability Discrimination Act of 1995 provides for anti-discrimination against people with disabilities. The Disability Commissions Act of 1999 provides for the establishment of the Disability Right Commission whose function is:

(a) "to work towards the elimination of discrimination against disabled persons;

(b) "to promote the equalisation of opportunities for disabled persons;

(c) "to take such steps as it considers appropriate with a view to encouraging good practice in the treatment of disabled persons; and

(d) "to keep under review the working of the Disability Discrimination Act 1995" (Department of Works and Pension: Disability Unit).

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[19] Sweden functions on the basis of the Disability Ombudsman Act of 1994, and the Equal Treatment of Students at Universities Act of 2001 (Handikappombudsmannen website at http://www.ho.se/start.asp?lang=en&sida=999, accessed 12 June 2004).

[20] In Italy, the Law 17/99 appoints Delegates of Rectors for Disability "with function of monitoring, coordinating and supporting all the activities related to the integration (of people with disability) within the University" (European Agency for Development in Special Needs Education website at http://www.european-agency.org/heag/homepages/italy/index_en.html, accessed, 11 June 2004).

The Disability Act of 1995 has been amended to form the Special Education Needs and Disability Act of 2001, whose Chapter 10 prohibits disability discrimination in further and higher education in public institutions of education. It also extends the duties of the Disability Rights Commission. As part of its three parts time scales, from 1st September 2005 public institutions will be required to make physical adjustments to premises for accessibility. Since 1st September 2002 and 1st September 2003 institutions are already required to make reasonable adjustments and provide assistive technology respectively.

The Disability Rights Commission has now established a Disability Rights Conciliation, which mediates in disputes that involve disability discrimination. Individuals (or students with disabilities in this case) may use the Disability Discrimination Act of 1995 and the Special Needs and Disability Act of 2001 to take the dispute to a civil court if they are dissatisfied with the conciliation outcome. However, the Commission's codes are not legal obligations. Rather they are used as part of evidence in civil courts. In the case of Australia, the court case would be decided under the Commonwealth of Australia Disability Act of 1992 and Section 72 of the Equal Opportunity Act of 1984. The Human Rights and Equal Opportunity Commission monitors the standards of the Act.

At the level of higher education, section three of the *Code of Practice for the Assurance of Academic Quality and Standards in Higher Education*[21] in the United Kingdom contains the principles to guide institutions in providing support for students with disabilities in higher education. The general principle of the section is, "Institutions should ensure that in all their policies, procedures and activities, including strategic planning and resource allocation, consideration is given to the means of enabling disabled students' participation in all aspects of the academic and social life of the institution" (Quality Assurance Agency for Higher Education).

The Quality Assurance Agency for Higher Education lists the following principles to guide the provision of support for students with disabilities:

- "implementing procedures which ensure that the needs of students with disabilities are addressed at all stages and levels of academic and resource planning;
- embedding the fair and equal treatment of disabled students in all operational practices;
- identifying clearly the locus of senior management responsibilities in relation to arrangements for students with disabilities;
- ensuring that senior managers and other key staff have an adequate understanding of the legal framework concerning people with disabilities;
- ensuring that management systems include the gathering of information to enable well-informed decisions to be made regarding participation and progression of students with disabilities;
- including the needs of disabled students within the remits of all resource allocation, academic management, estates and services committees;

[21] Australia's code is the 1988 "Student with Disabilities: Code of Practice for Australia's Tertiary Institutions" and the 1996 "Guidelines Relating to Students with Disabilities" by the Australian Vice-Chancellor's Committee.

- incorporating the views of disabled students in the development and review of the physical environment, academic programmes and services;
- identifying designated contact(s) for disabled students with specialist expertise and effective channels of communication with senior managers;
- providing staff development in disability awareness and equality for all staff;
- monitoring and reviewing the impact of all institutional policies, procedures and practices on students with disabilities with a view to continuous improvement;
- the implications for disabled students of collaborative provision and articulation of arrangements involving study in more than one institution and/or other partner organisation" (Quality Assurance Agency for Higher Education)

(c) Diversity-Rights Framework for Disability Support in Higher Education

The diversity-rights framework provides for disability support within a general national anti-discrimination legislation and policy. The legislation and policy are used to formulate specific policy for student with disabilities and form a legal basis to determine disability discrimination disputes in higher education. The normative standards underlying this framework are human rights, respect for diversity, equal opportunity and fair advantage for people who qualify for higher education courses and programmes. Such support is not enforceable by a specific disability law. Rather, institutions of higher education are expected to implement the policy of supporting students with disabilities and, if disputes arise, they would be resolved within the framework of human rights rather than entitlement.

South Africa, Canada and Denmark[22] are examples of the diversity-rights framework. The South African case is described in Chapter 8, but Canada is briefly discussed below.

The Canadian context for the provision of support for students with disabilities is guided by the Human Rights Act of 1976, whose purpose is "to extend the laws in Canada to give effect, within the purview of matters coming within the legislative authority of Parliament, to the principle that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted" (Canadian Department of Justice). Section 3 of the Act prohibits discrimination on the basis of disability too. The Canadian Charter of Rights and Freedoms provides a general code of anti-discrimination. The Canadian Human Rights Tribunal may mediate or conciliate in disputes within its jurisdiction, and civil courts can also be employed to determine disability discrimination disputes.

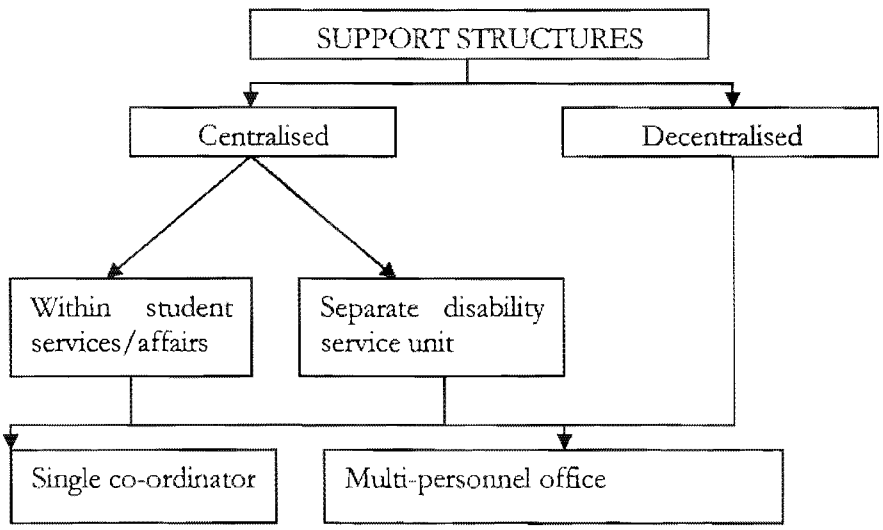
The framework that I have constructed is based on countries that make a national effort to ensure anti-discrimination for student with disabilities. This effort is made in a form of policy or legislation. There are countries that make no such effort. However, the absence of such policies does not mean that disability anti-discrimination campaigns are absent. China and Russia are example of countries that have a recent history in the struggle against discrimination on the basis of

[22] The Denmark Disability Council is guided by the Folketing (Danish Parliament) order B43 of 1993 on the equalisation of opportunities and treatment of disabled people, (European Agency for Development in Special Needs Education website at, http://www.dh.dk/bsf43.htm, accessed 11 June 2004). The Constitution prohibits discrimination on the basis of, inter alia, disability.

disability. They too have just begun to make efforts towards anti-discrimination. For example, China has formulated the *Outline of the Tenth Five Year Plan for the Disabled in China (2001-2005)* (People's Daily Online 2004).

Within these three frameworks with regard to supporting students with disabilities in higher education there seem to be two kinds of structures. One is centralised and the other is decentralised. Within the centralised structure, there are two types: one is a separate unit, whereas the other is situated within student services. However, there is no standard way of structuring in a support structure. The following diagram is an ordered way of trying to show how support services are typically structured across the world.

Diagram 5.1: Types of disability support structures



Support services are either centralised or decentralised. Centralised disability services administer to all students across faculties in the institutions, and are situated either within student services/student affairs or established as separate units. In terms of the former, they tend to form part of other support services, such as career counselling, writing skills and employment placement. Such

examples are the Rand Afrikaans University (now the University of Johannesburg), the Cape Technikon (now the Cape Peninsula University of Technology), the University of the Western Cape, Oxford University and Boston University (which I describe in Chapter 7).

Centralised services can also be established as separate units. Such units do not form part of student services or student affairs. However, their separation does not mean they cannot or do not collaborate with other student services on campus. Centralised services can either be administered by a single person or an office with more than one person. Examples of such centralised disability service units are the University of Cape Town and the University of the Witwatersrand, which I describe in Chapter 7.

Decentralised support services form separate disability service offices that administer exclusively to a particular school, department or faculty. Similar to centralised disability services, decentralised service systems can have either a single person responsible for an academic unit or an office with more than one personnel servicing a single school or faculty. An example of a decentralised disability support system is Harvard University, which I also describe in Chapter 7.

(V) Disability Rights

Cogently referring to the rhetoric of rights, Benatar (1992) observes, "Rights are in vogue. Everybody wants them and everybody wants to say that they respect them. To say otherwise is to be morally and politically impolite, even boorish. Governments and individuals do not wish to have it said of them that they violate rights. It is regarded as a slur of the worst order to be accused of rights violation" (Benatar, 1992: 1). He observes that the preoccupation with the rhetoric of rights is manifested by the substitution of moral arguments for claims to rights and also

by the proliferation of rights. He also argues that the consequence of the abuse of rights trivialises and confuses the use of the concept of rights.

Benatar's observation has serious implications for the right to education for people with disabilities in the light of Drewett's (1999) argument that the meaning of rights in disability discourse is underdeveloped. The least that the disability rights movements can say about disability rights is that people with disabilities have been oppressed and that they morally deserve redress. This argument is echoed by Hyland (1987), when she argues that disability rights have a moral justification and should be understood within the social justice moral framework. She equates the rights of people with disabilities with the rights of minorities, women, gays and lesbians, all of which are protected by law.

Judging from the declarations and demands of disability rights declarations from other parts of the world, as listed in Appendix B, it seems that they are also arguing for a moral justification of rights and demanding protection from their respective governments and recognition from other citizens. For example, in the Disability Rights Charter of South Africa, people with disabilities in the country recognise themselves as the worst victims of apartheid because of negative social attitudes and further discrimination on the basis of gender and class. They therefore demand – among other things – that, "Disabled people shall have the right to mainstream education with personal assistance where necessary, appropriate assistive technology and specialised teaching" (Howell and Masuta, 1995: 25).

Another way of seeing how disability rights are understood is by the common contrasts between rights and needs in disability studies. "A 'human rights' position is fundamentally different from a 'needs' position because it challenges power relations, structures and practices in society which are held together by the

State. A needs position, on the other hand, looks to the state as possible mediator and problem solver in situations in which a particular group – or people ascribed to a particular group – are constructed as vulnerable and dependent" (Armstrong and Barton, 1999: 215). Cole (2002) also subscribes to the human rights framework when examining disability discrimination and other struggles for human dignity. Watson (2004: 111) adds that disability rights should not simply be an individual issue. Rather, he argues that disability movements should characterise their activism with ethical rights, expectations and interpersonal relations to positively transform the social relations of people with disabilities.

The social relations of people with disabilities within disability rights are captured by Engel and Munger (2003: 241) in their proposal of a recursive theory of rights and identity. Focusing particularly on employment, they argue that the relationship between society and the law is mutually constitutive because, while rights shape identity, identity itself constructs rights to protect that identity. By researching the life stories of Americans with disabilities under the ADA, they conclude that: disability rights can change the way people with disabilities look at themselves; the everyday discourse of disability rights can transform or effect change in the treatment of people with disabilities; proactive institutional transformation through cultural shifts and litigation avoidance can effect change too at the level of agency.

While the concept of rights within a human rights and moral framework is convincing at face value, there are practical problems that raise the need to justify or question rights. The elusive question is what are rights? Freeden (1991) indicates that there is a difference between rights and human rights, and that some see rights as a subset of human rights whereas others see it the other way round. He argues, however, that human rights are the most basic and encompassing rights and thus defines a human right as a "conceptual device,

expressed in linguistic form, that assigns priority to certain human or social attributes regarded as essential to the adequate functioning of a human being; that is intended to serve as a protective capsule for those attributes; and that appeals for deliberate action to ensure such protection" (Freeden, 1991: 7).

I would suggest that the disability rights movements have four problems to solve regarding rights. The first problem is the argument about whether human rights are universal or particular. Gloppen and Rakner (1993) refer to the United Nation's Universal Declaration of Human Rights (1948) and indicate that this is underpinned by European traditions of rights and is often at odds with regional declarations of rights, such as the African Banjul Charter and the Arab Charter of Human Rights, which are context specific. The problem for the disability rights movement, then, is to ascertain whether and to what extent disability struggles are common around the globe, given that disability cuts across national boundaries and cultures, and yet taking into account such specificities. By this I mean that the international disability movement should realise that there are tensions in trying to secure rights for an international movement, such as Disabled People International. Moreover, access to education is determined by more factors than just disability. Meritocracy, class, gender, religion and geographical position are some of the additional factors that affect access to education in different countries. Thus, in a country where racism is deeply entrenched, for example, disability rights are bound to collide with civil rights.

This brings us to the second problem of competing rights or a hierarchy of rights. Gloppen and Rakner (1993) list six types of human rights: personal rights; civil rights; political rights; social and economic rights; cultural rights; solidarity rights. McQuoid-Mason, et al (1991) categorise civil and political rights as first generation rights and include values such as freedom from government interference and participation in political life. Social, cultural and economic rights

are second generation rights and include the right to decent standards of living and work. Cultural rights are advocated by communitarians who "emphasise the importance of belonging to a distinctive community as an essential component of, as well as a means to, individual well-being, or 'flourishing', as it often termed (with gestural connotations). Communitarians have defended (usually with qualifications) the importance of patriotism and nationalism, which tend to be disparaged from the cosmopolitan viewpoint connoted by the idea of universal human rights, as well as from the individualistic perspective sometimes said to be fostered by the 'culture' of rights" (Edmundson, 2004: 177). There are also third-generation rights, which are neither communitarian rights nor individual rights. These are future generations rights and belong to humankind (Edmundson, 2004).

The problem with these types of rights is that some argue that first generation rights are more important than other types of rights, because they create environments that are conducive for democracy. Others, however, argue for the primacy of second generation rights. For example, Kollapen (2003) argues that human rights are insignificant when people live in squalor and lack the basic material resources to live. Albert adds, "In fact, access to a wheelchair or a hearing aid is a basic human right for someone who would otherwise be unable to take part in any social activity" (Albert, 2004: 4). Thus in an environment that prioritises rights, people with disabilities need to articulate the position in which they locate every right that they demand. If all the rights they demand are equally weighted, then they would still need to articulate how they would respond and mobilise against trade-offs, competing demands of other citizens and justifying their rights against their criticisms, such as those laid down by Low (2001) who warns the disability rights movements against inflationary rhetoric.

The third problem that disability rights movements have to take into account is that rights are laden with ideology. Gloppen and Rakner (1993) outline three ideological traditions in respect of rights. The first is the liberal tradition, which espouses personal and civil rights. The second is the democratic tradition, which espouses political rights. The third is the socialist tradition, which advocates social and economic rights based on distributive justice. These traditions are historical in context and reflect the political climate of each context. However, disability is not a context specific category. It is universal and cuts across other social categories as well. Moreover, disability rights movements might be an international feature but there are inter and intra ideological outlooks that underpin their demand for disability rights. How these outlooks affect different social positions of people with disabilities is a question that also needs to be investigated.

Still on the problem of different ideological traditions, Allen (2002) points out that the contemporary discourse on Human Rights is a synthetic product of the Cold War struggle among Liberal Internationalists, Realists and Marxists. He argues that contemporary Human Rights discourse is more useful for global capitalism and predictability of the markets than morally justified legal claims to basic standards of living. He concludes that it is forces outside the Human Rights discourse that will continue to produce real outcomes for social justice.

The fourth problem is that rights are not only claims but that they must be recognised by other citizens (Machan, 1989). This process becomes problematic in what Lee (2002: 149) calls "simplistic politics" in his critique of the social model of disability. He asks, "Producing evidence of this inaccessible, segregated and exclusionary world is relatively straightforward. Yet how far is the 'able-bodied' majority prepared to go in reconstructing 'its' social order so that 'it can accommodate a far wider spectrum of disability?" (Lee, 2002: 149). This

observation not only indicates some weaknesses of the social model of disability, but it also indicates the limitations to claims and justification of rights. For rights to be effective, part of it lies in them being recognised by someone other than the right-bearer.

In terms of the provision of support to students with disabilities, the above problems with rights are applicable. The right to education is not as straightforward as it sounds. It is restricted by the regulations of higher education institutions across the globe, as Chapters 6, 7 and 8 will show. The typical restriction on the right to education at tertiary level is generally three-fold. Firstly, the person with a disability must be qualified to enter an institution of higher education. Secondly, he or she will receive assistance in as far as his or her impairment restricts the academic requirements of a particular academic course of activity. Thirdly, the student's claim for assistance should be made within reasonable limits.

These conditions might apply relatively well in developed countries because schooling for children with disabilities has gradually been mainstreamed to prepare pupils for higher education. In contrast, in developing countries like South Africa, most pupils with disabilities are educated to a limited extent in order to qualify for vocational training rather than higher education. The second restriction of assistance is problematic everywhere. As Appendix C indicates with regard to the lawsuit against Boston University, the issue of what warrants supports touches at the very core of the right to education. If the right-bearer (a student with a disability) claims assistance from the right-addressee (higher education institution) and there is disparity of claims and duties, then there is bound to be a conflict as exemplified by the lawsuit case. Such tensions have not yet been felt in South Africa, partly because of what I call the path of misconception in Chapter 10. This path presupposes that by simply articulating

disability rights and the right to education and deriving such rights from the social model of disability, one has successfully justified comprehensive support for students with disabilities. Instead, I argue that the very noting of rights has its own tension, as I have begun to indicate in this section.

The question of reasonableness is also problematic in most cases. Part three of this thesis (i.e. Chapters 3 to 5) will indicate that institutions of higher education are partly mindful of resource constraints. The issue of resources is usually translated into what constitutes a reasonable claim. It is a fact that developing countries like South Africa cannot afford assistive technology as do developed countries like the United States of America. Moreover, even in developed countries there are limits to what is reasonable. The Boston University case in Appendix C is an example of this tension between 'minimalist' views and 'extremist' views of what is reasonable with regard to providing support for students with disabilities. Once again such tensions have not been felt in South Africa thus far, partly because of what I call the path of hope in Chapter 10. This path wrongly assumes that disability support can be sustained from the legacy of benevolence, and be rescued and obtain additional resources through the transformation process. I argue that such a path is contradictory because Constitutional rights cannot co-exist with the legacy of benevolence and that transformation within the context of benevolence cannot produce real support for students with disabilities in South Africa. Rather, support structures should be viewed as being positioned at a tensive intersection of benevolence, rights and the impasse of the social model of disability. This idea will be developed further in Chapter 10.

(VI) Commentary

The above section has identified the different paradigms of education for people with disabilities and outlined the education of people with disabilities in South Africa as based on the medical model of disability. It has also tried to develop a rights-based typology of higher education for students with disabilities. The chapter has further pointed out that disability rights are based on the human rights approach and on the rejection of needs approach. However, it also indicated that rights are contested moral precepts and that their conflictual manifestation is evident at agency level, as with the case of supporting students with disabilities. The tensions are real in developed countries, and they are looming in South African, as Chapters 9 and 10 will demonstrate.

It is difficult and often futile to suggest ideas strictly for developing or developed countries, as Albert (2004) indicates with regard to human rights and development. Instead, where there are commonalities, one should emphasise mutual learning and, where there are differences, one should suggest alternatives. On the issue of rights and their seemingly underdeveloped status in disability studies, my threefold suggestion is as follows:

Firstly, the social model of disability remains a basic structure for the struggle of people with disabilities. Regardless of its weaknesses, it has resolved the centuries old oscillating relationship between disability and society, as I have been argued in Chapter 3. This has indicated the oppressive tendency of society under the veil of religion, ethics, culture and economic productivity. From the social model of disability, it can be seen that there are claims to rights as manifested in anti-discrimination legislations and policies. Secondly, however, the concept of rights has been used as a straightjacket approach of demands rather than debates. I

contend that, from the typologies of Peters (1993) and Priestly (1998), we can begin to understand the possible conceptualisation of rights from different perspectives within and outside disability studies and in the interaction between disability studies and outside disability studies. For example, if disability rights are understood within the creationist perspective, then it is likely that second generation rights would be the bedrock of disability rights. However, if a constructivist approach is applied, then first generation rights would likely be the bedrock of disability rights. Finally, advocacy and the demand for access should run across the conceptualisation of disability rights. Access and advocacy have been central issues in disability struggles. It is of no use to have these rights without accessible resources, assistive technology or accessible environments to materialise those rights. Moreover, it is another struggle to have rights that are not recognised by other citizens. Advocacy and conscientisation are important too.

(VII) Conclusion

To summarise, then, the provision of education for people with disabilities has been undertaken within different paradigmatic frameworks underpinned by cultural and ideological settings. These frameworks are: the medical; the social; the political and the pluralistic. Each paradigm determines how and where people with disabilities are educated: The medical paradigm emphasises separate and special education. The social paradigm emphasises remediation and tracking. The political paradigm emphasise integration, and the pluralistic one stresses diversity and equity.

The pluralistic paradigm is the contemporary framework within which support is provided for students with disabilities. I have discerned three such frameworks, namely: the legal mandate framework, the enforceable rights framework, and the diversity rights framework. Within the legal mandate framework, institutions are

required by law to provide support for students with disabilities in higher education. With the enforceable rights framework, national policy and disability law protects students with disabilities. And lastly, the diversity-rights framework protects students with disabilities through principles of human rights and equality.

Although these frameworks sound straightforward, they are laden with struggles over the nature of rights. Right are contested moral and philosophical precepts. There are different types of rights and different kinds of rights, and rights are also proliferating in contemporary society. Unfortunately, in the context of this proliferation and these contemporary debates, the disability rights movements and disability studies have said little about the conceptualisation of disability rights. This thesis has suggested that the conceptualisation of disability should take into account contemporary debates and locate disability struggles within the debates with the social model as the base.

In conclusion, Part I of this thesis (comprising Chapters 1 to 2) has given the background to this thesis. It indicated that the thesis was a comparative study of access to higher education for students with disabilities with the aim of showing the tensive intersection of benevolence, rights and the social model of disability. Part II (comprising Chapters 3 to 5) has conducted a conceptual analysis of benevolence, rights and the social model of disability by discussing the relationship between disability and society and the social model of disability. The current chapter in particular has highlighted the problematic nature of rights and suggested how disability rights could begin to be conceptualised. Part III (comprising Chapters 6 to 9) describes the provision of support in both the United States of America and South Africa. The following chapters (10 to 11) describe the actual legislations and policies that support students with disabilities. These chapters will be used in Chapter 10 of Part IV to compare the two

countries and then argue for the tensive intersection of benevolence, rights and the impasse of the social model of disability.

PART III

Disability Support Provision in the USA & SA

CHAPTER 6

LEGAL FRAMEWORK FOR PROVISION OF SUPPORT FOR STUDENTS WITH DISABILITIES IN AMERICA

(I) Introduction

The purpose of this chapter is to describe in detail the legal mandate framework of the American system with regard to supporting students with disabilities, as already outlined in Section IV of Chapter 5. This will explicate the formal rights that entitle support services to students with disabilities in the United States of America. It will also indicate that such rights are not straightforward, but subject to certain conditions and interpretations as Section V of Chapter 5 has indicated with regard to the problem of rights.

This chapter has two sections. The first describes the rules and regulations issued to implement subpart E of Section 504 of the amended Rehabilitation Act of 1973. These regulations were issued by the Department of Health, Education and Welfare (HEW)[23]. The second section describes the provision of the Americans with Disabilities Act of 1990 (ADA).

(II) Section 504 of the Rehabilitation Act of 1973[24]

The Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. Section 504 of the Rehabilitation Act of 1973 is an

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[23] HEW was renamed the Department of Health and Human Services in 1980 after the Department of Education Organisation Act of 1979 provided for a separate Department of Education.

[24] This section is drawn from the US Federal Register (1977 May 4), "Nondiscrimination on Basis of Handicap" by the Department of Health, Education and Welfare.

amendment to this Act, enacted to guarantee civil rights for disabled Americans. This law is applicable to any program or activity receiving Federal financial assistance and to recipients that operate or receive or benefit from federal financial assistance for the operation of such programs or activities. "All such recipients of federal funding are prohibited from discriminating against disabled persons and are required to remove any communication, architectural, policy/practises or any other barriers that prevent disabled people from participating in, benefiting from, or being employed by such programs" (Bruno, 1980: IA-1). Section 504 covers program accessibility, employment practices, pre-school education, school education, post-secondary education (higher education), health services, and welfare and social services. The particular focus of this thesis is on subpart E of Section 504, which provides for civil rights of students with disabilities in higher education.

Subpart E states that institutions of higher learning, including vocational education programs, must ensure that their programs and activities are accessible to students with disabilities. It has five sections of provision. The first section covers admissions and recruitment, and the following provisions apply:

- A disabled person[25] who qualifies for admission may not be denied admission or subjected to discrimination in admission and recruitment.
- Programs may not set limits or quotas in their admission policies for students with disabilities.
- Tests and criteria for admission may not have disproportionate and adverse effects on the disabled person. The tests must be validated for their purpose on condition that no alternative test proves less

[25] The Act uses the word "handicapped". I however use "disabled" for consistency in this thesis and conformity to contemporary terminology.

disproportionate and less adverse than the one being used. The test should also undergo constant evaluation to validate it.

- Admission tests should measure aptitude and not the extent of a disability. This means, "The tests must be selected and administered so as to ensure that when a test is administered to an applicant who has a visual, hearing, manual, or speaking impairment, the test will reflect the applicant's aptitude or achievement level (or whatever other factor the test purports to measure) rather than merely showing that the applicant does indeed have a visual, hearing, manual, or speaking impairment (except where the vision, etc, is what the test is supposed to measure)" (Bruno, 1980: IA-23).
- The tests should be administered as often and timely as are other admissions tests, and the facilities in which and with which the tests are administered must be accessible to people with disabilities.
- Generally, there should be no preadmission inquiry but rather a confidential inquiry or follow up after admission. Preadmission inquiry is only accepted for programs that redress past discrimination on the basis of disability.

The second section regulates the general treatment of students. The rules and regulations require that:

- Once admitted, students with disabilities should not, on the basis of disability, "be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any academic, research, occupational training, housing, insurance, counselling, financial aid, physical education, athletics, recreation, transportation, other extra-curricular, or other postsecondary education program" (Department of Health, Education and Welfare, 1977: 2268). This regulation also applies

to concessions such as transport and bookstores within the universities and colleges.

- No qualifying students with disabilities may be excluded from any course or part of a course.
- The programs should be operated in the most integrative and appropriate environments.

A time line was created in order for colleges and universities to comply with the regulations and to make the necessary changes. Universities and colleges were given sixty days to make their programs accessible to students with disabilities. A period of three years after the passing of the regulations was stipulated for colleges and universities to make the necessary structural changes to their facilities so that they would become accessible to students with disabilities. Where such changes were made, institutions were required to produce a transitional plan in which they list and describe the changes that were to be made and to name the person responsible for implementation of the plan. A disabled person or a representative of an organisation for disabled people was required to be part of the decision making process for structural changes (McCartney, 1980).

The above section has thus indicated three points of relevance for this thesis. The first point is that there is no place for benevolence in the provision of support for students with disabilities in the United States of America. The second one is that such support in state funded higher education institutions is a legal entitlement, which constitutes a positive right to receiving such support. The final point is, however, that such a right is not administered in *laissez faire* manner but restricted by the Act and by institutional curriculum rules, which, as I have already mentioned in the previous chapter, often results in conflict as indicated by the Boston University case in Appendix C. Thus, while benevolence has been replaced by rights, such rights are often in conflict with institutional rules and require further debates and resolutions, or in the case of lawsuits, judgements.

(III) Americans with Disabilities Act of 1990

The Americans with Disabilities Act of 1990 also applies to students with disabilities. It is, however, not an entitlement law like the Rehabilitation Act of 1973. Instead, it is a civil rights legislation, which provides for all Americans with disabilities. This section outlines the ADA and explains the extent to which is applicable or not applicable to higher education students with disabilities. The government of the United States of America promulgated the following four point purpose of the Americans with Disabilities (ADA) of 1990:

(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;

(2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;

(3) to ensure that the Federal Government plays a central role in enforcing the standards established in this Act on behalf of individuals with disabilities; and

(4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day day by people with disabilities.

With some exceptions, the ADA provides accessibility and anti-discrimination on the basis of disability for the following range of activities: employment; public accommodation; state and local government services; public transport; and national telephone relay services. The relevant Secretaries under which these activities fall were required to issue the regulations relevant to the particular section of the ADA. For example, the Secretary of Transport was

responsible for issuing regulations to govern Title II of the ADA, which provides for public transportation.

Under the ADA, a disabled person is one who:

1. has a physical or mental impairment that substantially limits one or more major life activities;
2. has a record of such an impairment; or
3. is regarded as having such an impairment.

(a) Principles of ADA for Higher Education

Gordon and Keiser (1998) have put forward precautionary notes on the application of ADA to education. I will only focus on the parts that are relevant for supporting students with disabilities in American colleges and universities. They observed that there is usually confusion in understanding the underpinnings of ADA in relation to students with disabilities in higher education. They explain the following six principles in contextualizing such support with regard to the ADA:

- *Principle one: The ADA is a civil rights act, not an entitlement program*: This principle means that the concepts that formed the ADA are different from those that formed regulations on special education and support students with disabilities. The ADA evolved from the workplace anti-discrimination laws, court rulings and consequently the Civil Rights Act of 1964. In contrast, the amendment of the Rehabilitation Act of 1973 with Section 504 is an entitlement program, and funding was mandated for remedial services. The ADA guarantees that a qualified disabled student has equal access to higher education programs and that he or she does not have an unfair advantage over non-disabled students. It does

not, however, guarantee services for students with disabilities. On the other hand, the Rehabilitation Act regulations provide the actual equal opportunity for students with disabilities in higher education.

- *Principle two: To be protected by the ADA, an individual must be disabled relative to the general population.* Determination of disability with regard to performing the essential tasks of an academic program is not discretionary. For the student to be regarded as disabled to perform an essential academic task, he or she must be disabled relative to the average American population. The argument for this principle is that anti-discrimination has to take into consideration performance standards and essential academic program functions. This implies that a student who had some support in secondary school might not be provided with such support, if according to the essential tasks and performance standards at college or university the student is not regarded as being disabled.
- *Principle three: Successful compensation belies substantial impairment.* Successful compensation means that impairment has been accommodated so that the individual can no longer be regarded as disabled in that regard and would not qualify for support. Compensation is required only to minimize the negative impact of a disability to ensure that an individual is able to perform an essential task. "What characterizes true disability is that efforts at compensation go far beyond what most of us endure in daily life. Furthermore, compensatory efforts are often unsuccessful in allowing for normal functioning" (Gordon and Keiser, 1998: 13). For example if a student suffers from severe vision impairment and thus blurred vision, but could see satisfactorily with spectacles, then such a student cannot be regarded by the ADA as disabled and is disqualified from disability support or compensation.

Frierson (1998) adds that, even though the ADA provides for disability accommodations, there are limits to what can be provided. "Accommodations and auxiliary aids that create an undue burden on the organization or service provider are not required. For example, a student disabled by a respiratory condition may not demand that expensive air filtration devices be placed in all university buildings" (Frierson, 1998: 73).

- *Principle four: The process of qualifying an individual as disabled under the ADA requires current, detailed, and professional documentation.* Student cases are all different and are considered in detail by colleges, universities and courts. That is why it is important that proof of disability should be current, performed by a certified professional and relevant to the required support. It also means that support requests cannot be documented on a prescription pad. Instead, requests should be justified to allow judicious review by colleges and universities.
- *Principle five: Institutions are required to provide accommodations only to those individuals who meet the essential functions of a job or educational program.* The ADA protects the rights of students with disabilities who are otherwise qualified to perform essential functions of an academic program. It aims to prevent discrimination on the basis of disability. The corollary is that if a student's disability is not relevant to the essential functions of an academic program, then the student would not qualify as disabled and eligible for support. The ADA does not provide for a blanket approach to disability. Rather, the criteria for eligibility for support are academic qualification, and limitations in performing essential functions of a program.
- *Principle six: Accommodations should only address the Interactions between functional impairments and task demands.* This principle of the ADA does not equate

> diagnostic criteria with support for students with disabilities. It means that, even though a student might be regarded as disabled, he or she will not automatically qualify for such support. The otherwise qualified student has to present proof that his/her disability limits his/her ability to perform the essential tasks of his/her academic program and that, with support, the student would have an equal opportunity to perform the task.

Looking at both the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, I think they have a complementary relationship but can be contradictory, depending on interpretation. They are complementary because the ADA is a general and encompassing legislation that guarantees disability rights in the United States of America, whereas the Rehabilitation Act of 1973 is specific to higher education (post-secondary education) by providing entitlement to students with disabilities. Without the ADA, students with disabilities could face discrimination as long as it does not relate to their studies. However, the ADA guarantees the protection of students with disabilities in matters that might not be related to their studies.

These two legislations can also be contradictory at the level of interpretation. As has already been explained, the two legislations provide for conflict resolution avenues. However, in the case of a conflict, a student has to decide whether she or he is suing a university or college in relation to either the Rehabilitation Act of 1973 or the ADA. Depending on the nature of the complaint either legislation might be irrelevant and contradictory or relevant and complementary. The example of the Boston case in Appendix C indicates some contradictions in interpretation within the Rehabilitation Act of 1973 and between the ADA and the Rehabilitation Act of 1973. The case indicated different interpretation of the Rehabilitation Act, which led to the lawsuit.

Moreover, there was a question of the relevance and conflicting relationship with the ADA, because it was understood that the case had been lodged under the Rehabilitation Act and yet the ADA does not allow an 'extremist' interpretation of support as interpreted by the Rehabilitation Act.

(V) The Impact of the Separation of the Church and State for Disability Support in the American Higher Education

The American support system for students with disabilities has its limitations. One of these limitations is the separation of the Church and State. In the American case, Anderson reckons, "the separation of church and state poses a unique challenge for achieving in the religious sector what the government has tried for decades [to do] in the public: the social advancement of rights for people with disabilities" (Anderson, 2003a: 2). This challenge is illustrated in the religious higher education sector, which is not governed by federal law. This means the Rehabilitation Act of 1973 does not provide for access to religious higher education institutions that receive no state funding. Anderson's argument is that religious higher education lags far behind public higher education institutions in terms of providing support for students with disabilities.

In a pilot survey of 244 institutions of higher education accredited by the Association of Theological Schools in America and Canada, Anderson (2003b) indicates how theological institutions lag behind public institutions in access to higher education for students with disabilities. Eighty-six percent (86%) of the 244 institutions said that their curriculum did not promote access for students with disabilities. When asked if faculty members were aware of difficulties faced by students, only 20% said yes, 46% were neutral and 34% said no.

I have two comments about Anderson's research. Firstly, the problem that Anderson identifies suggests that, while the American pragmatism is commendable for operationalising the social model of disability, it has lost sight of the overall role of social advocacy for people with disabilities. Support for students with disabilities in America is done primarily to avoid lawsuits against institutions. It is thus not part of a diversity approach, which, I contend, countries should try to pursue. Part of the answer lies with Oliver's (2004) argument about a citizenship approach, which I explain in Chapter 11.

Secondly, the separation of the Church and the State also indicates the limited institutions that disability activists target. Activism for disability rights in developed countries like the United States of America and the United Kingdom has been directed mainly at government institutions. It was not really directed at other institutions, such as the family and the Church. Disability rights movements seem to have forgotten that the relationship between disability and society was not only about the government, but about the entire society. Hence disability struggles have made mainly legalistic issues without social significance, responding only to a fear of litigation.

(VI) Conclusion

In conclusion, supporting students with disabilities in the American higher education is thus undertaken within the legal mandate framework. Institutions of higher education that receive significant federal financial assistance are subject to the Rehabilitation Act of 1973. This Act prohibits discrimination on the basis of disability in the recruitment, admission and treatment of student during their studies. The Act also provides some criteria to restrict the legal entitlements. However, the Rehabilitation Act of 1973 excludes religious institutions as outlined above. This is a concern for the protection of rights of students with disabilities in religiously based higher education institutions.

Apart from the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990 also protects the civil rights of American with disabilities. It prohibits discrimination on the basis of disability in different activities, such as employment, health and transportation. It also gives the government a central role to play in protecting the rights of people with disabilities in the United States.

The above-mentioned two legislations can be both complementary and contradictory, depending on the specific interpretation of the provisions and the nature of the conflict or lawsuit. Moreover, the legalistic nature of supporting students with disabilities seems to have lost sight of social advocacy, in terms of which the pluralistic paradigm argues that disability awareness should not be a matter of confronting only government institutions but social attitudes too.

This chapter has provided an outline and identified some of the limitations of the legal framework within which the United States of America provides support for students with disabilities in higher education. The following chapter (Chapter 7) elaborates further on this issue. It furthermore indicates that such systematic support has not always been there, by outlining key selected illustrations of the establishment, problems with and development of disability support in America. It also illustrates the practical application of the Rehabilitation Act of 1973 by considering two cases, namely, Harvard University and Boston University, both in Massachusetts, America.

CHAPTER 7

SUPPORT FOR STUDENTS WITH DISABILITIES IN AMERICA

(I) Introduction

Chapter 6 described the legal framework within which support is provided for students with disabilities in the United States of America. In trying to understand the practical application of the legal framework, this chapter describes selected key historical developments and the contemporary provision of support for students with disabilities in the United States of America since World War II. This chapter consists of five parts. The first part outlines the foundations of higher education disability support by describing the case of Delta Sigma Omicron at the University of Illinois in the late 1940's. The second part describes the case of Ed Roberts to illustrate the developments during the Disability Rights Movement in the 1970's and early 1980's. The third part describes the challenges facing disability support services in higher education in the early 1980's. The fourth one illustrates the progress made in the late 1980's and 1990's. The final part reports the case studies of Harvard University and Boston University, which were researched in 2004.

The American higher education disability support system is relevant for my thesis for two reasons. Firstly, the University of Illinois in the United States claims that it is probably the first university in the world to provide formal support for students with disabilities. The previous chapter has also shown that, in 2003, the United States celebrated its 30th anniversary of the enactment of Section 504 of the Rehabilitation Act. Given such a comparatively long history

of disability support, the American experience definitely has lessons from which the South African higher education support system can learn. Secondly, as will be seen in Chapter 9, the South African support system for students with disabilities is based on the American model in certain important areas, such as the service structures and areas of concern. This similarity is helpful when a comparison between South Africa and developed countries (particularly the United States of America) is made in Chapter 10 to show the tensive intersection of benevolence, rights and the impasse of the social model of disability.

(II) Foundations: Fellowship and Comradeship

(a) The Fraternity: Delta Sigma Omicron

This section describes one of the illustrative earliest cases of support for students with disabilities in the United States of America. The purpose of this case is to illustrate a part of the history of disability support in America and also to illustrate the argument of benevolence in the establishment of such support.

The case that will be described is that of the University of Illinois. I am quite aware that the earliest recorded case is that of Gallaudet University, which was founded in 1864 for deaf students. In my view, however, this case is not illustrative because, unlike other mainstream institutions of higher education, Gallaudet University is exclusively for deaf students and that implies the automatic provision of support for such students.

A more illustrative earliest example of support for students with disabilities in the United States of America is at the University of Illinois. In 1948, the Veterans Administration Hospital in Galesburg, Illinois was converted into a satellite campus for the University of Illinois for World War II veterans who

wanted to purse higher education. Dr. Timothy J Nugent initiated a temporary rehabilitation programme for eight male students with disabilities. The programme moved to the main campus after the satellite campus was closed despite the students' protest against the university's decision to close the satellite campus. The programme was to be a fraternity called the Delta Sigma Omicron (DSO). The purpose of the DSO iwas:

- To promote the social and recreational welfare of the members of DSO and all people with disabilities everywhere;
- To explore, encourage and promote, in particular, educational possibilities on a higher level for persons with disabilities, and to promote all phases of their school life;
- To make known the opportunities and possibilities that exist for persons with disabilities everywhere, by using the media and advocacy in higher education;
- To stimulate research and actively contribute to research to the benefit of all persons with disabilities;
- To act as an educational body both for persons with disabilities and the public alike as to what can and should be done for persons with disabilities in procuring for them opportunities for normal pursuits. (Disability Resource and Educational Services, 2004).

The fraternity still exists today as a national body, although it has been developed to be part of the Division of Rehabilitation - Education Services of the University of Illinois whose objectives are:

- Coordinating the provision of academic modifications and adjustments, auxiliary aids and services and environmental adaptations for qualified individuals with disabilities.

- Providing advocacy support and technical assistance and outreach on disability-related issues to University departments and the community at large.
- Participating in the design, performance and application of the most recent disability and rehabilitation research.

(Disability Resource and Educational Services, 2004).

The DSO is a key foundation for the formal support system for students with disabilities in the United States of America. Its development and growth are evident from its participation in the Division of Rehabilitation – Education Services at the University of Illinois. Other key developments in disability support are the Rolling Quads and the Independent Living Movement.

(III) Independent Living: Rolling Quads

This section describes the early struggle by students with disabilities in America to receive support. It is not a comprehensive history of this struggle, though; rather, it is the case of a particular individual that illustrates the context within which such a struggle was fought. The purpose of this case also builds on the argument of benevolence and the rights of people with disabilities to receive higher education in the United States of America.

Such access to higher education for students with disabilities has not always been protected by law in the United States. Higher education for students with disabilities was loosely structured and the framework governing it was *ad hoc*[26]: It furthermore was based on benevolence. "Before World War II, postsecondary educational opportunities for severely disabled adults were so rare that only the

[26] See Appendix A for an example of a 1966 pamphlet on advising disabled people who were planning to pursue higher education.

most highly motivated blind, deaf, or mobility-impaired individuals obtained a college education, and then only with extensive, long-term assistance from a few dedicated missionary individuals – physicians, teachers, parents and lay volunteers" (Tickton et al, 1981: i).

The case of Ed Roberts who studied at the University of California at Berkeley illustrates the general state of students with disabilities in higher education. Ed had suffered from polio in 1953. He pursued his education until he reached secondary level and wanted to pursue higher education. He "planned on applying to the University of California at Los Angeles, one of four U.S. universities at the time that had special programmes and accessible campuses for students in wheelchairs" (Shapiro, 1993: 44).

The struggle for Ed's college education began with securing funding from the California Department of Rehabilitation. The department refused to pay for Ed's four year degree education. On the one hand, Ed's counsellor reckoned that it was a waste of money to sponsor Ed. because he would not be employed upon completion of his studies. On the other hand, Ed's high school president, the dean of students and his academic adviser all appealed in his favour. Nonetheless, the California Department of Rehabilitation refused their appeal. It was only when the school officials took the issue to local newspapers that the state agency finally relented and agreed to pay for Ed's higher education fees.

When Ed was admitted to the University of California at Berkeley, he was confronted with the problem of finding a place to live. The university facilities were inaccessible and there was no dormitory whose floors could support the weight of Ed Roberts' eight-hundred-pound[27] iron lung. "He knew he had to keep searching until he found a sympathetic person who was open to bending

[27] Eight hundred pounds are approximately three hundred and sixty-three kilograms (362.874 kg).

the rules. Roberts found one in Dr. Henry Bruyn, the director of student health services" (Shapiro, 1993: 45). Dr. Bruyn suggested that Ed move onto the third floor of the university's Cowell Hospital, where Ed would live in a one- person student infirmary dormitory.

So Ed lived alone in the empty wing of the Cowell Hospital with no undergraduate experience of dormitory life. He hired attendants, who were paid for by the government, to help him with his wheelchair, eating and dressing. Ed could, however, detach himself from the iron lung for several hours during which he would attend classes and socialise. Sometime he would be helped by willing students. This was the first financial programme of its kind in America.

By the time Ed completed his undergraduate degrees, there was a handful of students with disabilities on his campus. Twelve students with disabilities were living in Cowell Hospital in 1967 and Ed had been awarded his master's degree in political science. In 1968, the dormitory had become a formalised state run programme. Naturally, the proximity, isolation and commonality of the Cowell (disabled) students turned into a fellowship, which became organised and took on the name the "Rolling Quads". "In their late-night bull sessions on the hospital floor, Roberts and his friends, in their wheelchairs and iron lungs, would strategize constantly about breaking down the common barriers they faced – from classrooms they could not get into to their lack of transportation around town – and dissect the protests for self-determination of minority students" (Shapiro, 1993: 47-48).

The Rolling Quads began to realise that living in Cowell made them students by day and patients by night, and that living in a hospital carried its own stigma. The idea was thus to secure private and accessible residential accommodation. Eventually, they decided to establish students with disabilities' anti-dropout programme that would be run by students with disabilities. Earlier, a counsellor

had wanted to evict a Cowell student on the grounds of poor academic performance. The Rolling Quads drew up a petition and appealed to the student body for support. The counsellor was reassigned. The supportive programme was to become a fortress for the students with disabilities.

In 1970, the Rolling Quads established the Physically Disabled Students' Program (PDSP) with an $81,000 grant from the Department of Health, Education and Welfare and $2000 from the university. The PDSP was established on the premise of ensuring the independence of students with disabilities. This meant that students with disabilities had to take control of their lives. "Independence [was] measured not by the tasks one could perform without assistance but by the quality of one's life with help" (Shapiro, 1993: 51). Like the social model of disability, explained above Chapters 3 and 4, the PDSP, too, rejected the custodial health system in favour of independent living, based on the premise that the disabled person is more conscious of his or her interests than the medical profession professes to know. The PDPS performed the following tasks:

- Accessibility and accommodation: Disabled counsellors searched and secured accessible private residential accommodation for students in wheelchairs.
- Assistantship: They secured attendants to help in identifying and meeting the basic needs of students with disabilities.
- Mechanical workshop: They also ran a twenty-four-hour wheelchair workshop to fix malfunctioning wheelchairs, which, if left unfixed would have meant that the student could not attend classes. The workshops also modified some cars and vans to allow students with disabilities to manoeuvre pedals with their hands.

- Advocacy: The program was designed to help students find their way through the bureaucratic structures of the university student services.

Unintentionally, over time, the PDSP became a service house for people with disabilities in general and not just specific to students on campus. Consequently, it unfortunately functioned beyond capacity. The PDSP finally contemplated creating a new organisation parallel to the PDSP that would cater for non-students. In 1972, the Centre for Independent Living (CIL) was created as that organisation. Ed Roberts headed the CIL in 1974, and in the following year became the director of the state Department of Rehabilitation, which "a decade earlier [had] deemed it 'infeasible' that he would ever hold a job" (Shapiro, 1993: 55).

About thirty years later, the Independent Living Movement would pride itself in asserting, "In the independent living movement we reject these definitions that limit us, because they do not describe our aspirations in society. In fact the medical definitions or model has to a great extent contributed to placing us out of society in special institutions and ghettos. We describe a place *in society*, participating as equal members with something to say and a life to lead; we are demanding the right to take the same risks and seek the same rewards" (Brisenden, 1998: 26).

The case of Ed Roberts and the Independent Living Movement is an instructive illustration of the struggles and victories of students with disabilities in the United States of America in their search for support. It is also an illustration of the early application of both the idea of disability rights and disability support services in higher education, which was a challenge in the early 1980's.

(IV) Elementary Support: The Challenges of the '80s

This section looks at the early challenges faced by students with disabilities seeking support in the American higher education system. It is not a history of the challenges that confronted higher education institutions in general, but focuses rather on some key problems that confronted those institutions who tried to support students with disabilities. This section will also be used to develop the argument of shifting from benevolence to real rights, which, as will be shown in Chapter 10, is not the case in South Africa.

The gradually increasing presence of students with disabilities in American higher education after the enactment of Section 504 of the Rehabilitation Act of 1973 and its regulations required that. by 1979, universities and colleges had to have designed support services for students with disabilities. Technically, these regulations meant that all state funded institutions of higher learning provided support for students with disabilities. The fact of the matter was, however, that the institutions were poorly prepared for such services. Moreover, there was no official blueprint for designing such services at the time. Institutions relied on piecemeal pamphlet material such as the one contained in Appendix A.

Consequently, American colleges and universities developed different strategies through learning by experience, experimentation, collaboration and emulation. This process has, however, been preceded and guided by challenges that institutions have faced in providing services to students with disabilities. Each institution faced different sets of challenges and these services thus developed in the context of scepticism, trial and error. As Moss and Fox recall, "Too often, CPST[28] programme personnel and other professionals, parents, and LD[29]

[28] CPST (Colleges and Postsecondary Training).

[29] LD (Learning Disabilities).

students themselves accepted the unexamined assumption that CPST programs would not be feasible... In many cases, CPST programs personnel have simply not been aware that the learning students with disabilities existed. Some have not understood or appreciated the special problems of these students. Indeed, certain programs and services have inadvertently been so designed as to discriminate against students with auditory or visual learning disabilities. These students may be affected in ways similar to deaf or blind students, although to a lesser degree" (Moss and Fox, 1980: 25-26).

(a) Challenges and Strategies

Judging from the literature reviewed in Chapter 3, it appears that, from its foundations, the American disability support system has been based on four areas, namely; advocacy, curriculum flexibility, staff development and students life (Tickton et al, (1981)). Advocacy involves the education and sensitisation of the college and university communities about disability, and thereby defends the rights of students with disabilities. Curriculum flexibility facilitates the modification of the methods and media of education to enable students with disabilities to receive such education at its intended standard or quality. Staff development refers to capacity building for academic and administrative staff to acquire skills in teaching and interacting with students with disabilities. Student life is the comprehensive social and academic orientation and support provided for students with disabilities on campus. I will outline the challenges and strategies faced by institutions according to these four areas in the section below. It should be noted at the outset, however, that such challenges are not exclusive to America. Leicester (1999), for example, writes about the difficulties faced by students with disabilities in the United Kingdom, whereas Hutchinson et al (1988) write about the difficulties faced by students with visual impairments, also in the United Kingdom.

(i) Advocacy

Chapter 3 of this thesis has analysed the understanding of the relationship between disability and society from antiquity to the twenty-first century, thereby illustrating the treatment of disability through the centuries, from liminal objectification to socio-political subjectification, which advocates for the rights of people with disabilities. As in any other social movement, advocacy has been the touchstone of the Disability Rights Movement in the Americas, Africa, Asia, Canada, Europe, Australia and New Zealand. The advocacy on college and university campuses is actually an extension of the Disability Rights Movement's advocacy on the global political terrain.

There has been an engagement in disability rights and advocacy across the world since the 1960's, and reaching it is zenith in the 1980's. The United Nations declared 1981 as the Year of the Disabled and 1990-2000 as the Decade of the Disabled[30]. North America has engaged in disability struggles and activism through organisations such as the Centre for Independent Living and Disability Action. For developing countries, too, Labadidi (2003), for example, describes several disability organisations in Egypt that have helped and advocated (albeit not through activism) the visibility of people with disabilities in public life. The Action Group to Defend the Rights of the Disabled in the USSR had been engaged in advocating for disability rights through activism, which was, however, suppressed by the Communist Party because it regarded it as subversive (Raymond, 1989). Abu-Habib (1997) describes and explains cases of active struggles and advocacy of the rights of people with disabilities and in particular of disabled women in the Middle East. In Israel, the Bizchut was established in 1992 and initiated the Equal Rights for People with Disabilities

[30] Refer to Appendix B for the chronology of key events in disability rights, and to Appendices C and D for the United Nation's declarations with regard to disability rights.

Law (Gills, 2003). The struggle for disability rights has thus been a global phenomenon.

I have elected to use the word advocacy generally instead of distinguishing between the terms advocacy, self-advocacy and collective self-advocacy, because we need to take into account those individuals who are not disabled and who nonetheless advocate for the rights of people with disabilities and who do not belong to the Disability Rights Movement. Such people may be parents of people with disabilities, policy makers, academics and other social movements. Moreover, the scope of my thesis makes the distinction irrelevant. "In reality however, advocacy and self-advocacy can be difficult to distinguish and may coexist" (Swain et all, 2003).

Activism and advocacy in disability struggles provided some answers to the early challenges that American universities and colleges faced in providing information and increasing sensitivity about the needs of students with disabilities. Several strategies for overcoming these challenges are documented in the *1981 Idea Handbook for Colleges and Universities: Educational Opportunities for Handicapped Students*, incorporating research on how some American colleges and universities have thus far approached challenges of providing support for students with disabilities. Tickton et al (1981) identified some strategies of advocacy, which I group into nine categories. The first one comprises exhibitions on disabilities or specific disabilities. This not only involved images but also the presence of people with disabilities to demonstrate their careers and skills. The second one is film festivals in which there are different themes on disability awareness. The third one is documentary material, both visual and written, in which students with disabilities express their experiences and needs. The fourth category is panel discussion. The fifth one is workshops on disability. The sixth one is seminars on disability awareness. The seventh

category comprises simulation exercises by non-disabled college community members. In these exercises non-disabled people are given a 'feel' of what is like to be, for example, blind or in a wheelchair. The eighth category is symposiums or conferences in which institutions discuss challenges and learn from each other. The final category is social events in which both disabled and non-disabled students are invited to participate.

1. Exhibitions on disabilities or specific disabilities; this not only involves images but also the presence of people with disabilities who demonstrate their careers and skills;

2. Film festivals in which there are different themes on disability awareness;

3. Documentary material, both visual and written, in which students with disabilities express their experiences and needs;

4. Panel discussion;

5. Workshops on disability;

6. Seminars on disability awareness;

7. Simulation exercises by non-disabled college community members; in these exercises, non-disabled people are given a 'feel' of what is like to be, for example, blind or in a wheelchair.

8. Symposiums or conferences in which institutions discuss challenges and learn from each other;

9. Social events in which both disabled and non-disabled students are invited to participate.

(ii) Curriculum Flexibility

The steadily increasing enrolment of students with disabilities in the early 1980's was accompanied by three challenges faced by instructors, lecturers or tutors in the classroom. The first one was to alter traditional modes of teaching. The second one was to find and use technology that was designed or adaptable to meet the needs of students with disabilities The final challenge was to use more than one medium to ensure accessibility; to the classroom, in the classroom and about the classroom work.

In 1981, the American Chemical Society Committee on Chemists with Disabilities produced its first edition of *Teaching Chemistry to Students with Disabilities*[31]. I will use this document in this section to point out some components of curriculum flexibility in the early years of supporting students with disabilities in America. Four principles underpin curriculum flexibility:

(a) The first principle is that students with disabilities have different needs and each support provision should be designed to meet the needs of a particular student and not for all students with disabilities. This can only happen when curriculum flexibility becomes part of the process of negotiating and deciding how best to produce the least restrictive environment in learning settings. "Students with disabilities may need to preregister and initiate a pre-semester discussion with the teacher on things that can be done before the semester begins. Once the term begins, the teacher can be alert to the potential needs of students and initiate a discussion when it seems appropriate... It is imperative that the student be personally involved in discussions of special arrangements. Unfortunately, teachers uncertain of what to do might bypass the student and consult only other teachers or advisors. The result of such a procedure is

[31] Available on the Internet: http://www.rit.edu/~easi/easisem/chem.html, accessed 20 April 2004.

explained by a person with a disability who earned a doctorate and is now a practicing research chemist: 'I was constantly frustrated in my attempts to arrange presemester conferences by teachers who said that they had 'already spoken to so-and-so and everything was arranged'. This left me completely in the dark about what had been arranged and unable to express my views on what needed to be arranged'" (American Chemical Society Committee on Chemists with Disabilities, 1993: 6).

This principle dispels the first misconception about people with disabilities, which is that all people with disabilities are the same. The language of commonality has moved from an understanding that people with disabilities experience discrimination and stereotypes to a practical understanding that therefore they must all be the same. It is important to distinguish between the common problems faced by people with disabilities and the differences in disabilities, levels of disability, and personalities of people with disabilities. This means that individual students with disabilities have different needs, in the same manner as non-disabled students do.

(b) The second principle is to recognise that the disabled student's needs are part of the common needs of all students. The ACS explains, "From the teacher's point of view, students with disabilities have three kinds of classroom needs: those common among students in general; those that call for care in lecturing and leading discussions; and those that require special arrangements" (American Chemical Society Committee on Chemists with Disabilities, 1993: 6). With regard to such special arrangements, the ACS points to the need for the lecturer, instructor or tutor to be as flexible as possible. Flexibility is means using alternative forms of teaching, learning and evaluation that would allow the disabled student to receive the same or close to the same educational benefit as any other students in the programme, course or classroom experience. The

following examples are extracts from the ACS on flexibility in the chemistry curriculum:

Example 1: Classroom teaching: "Without an interpreter, neither deaf nor hard-of-hearing students can follow what other students are saying if remarks come from the back of the classroom. The teacher can help in several ways: by passing out printed material before class; by inserting appropriate pauses during demonstrations; by repeating questions asked by other students; and by summarizing classroom discussion on the blackboard at logical points. These practices can be useful to all students. Because many scientific terms do not have signs in sign language[32], students with hearing impairments can benefit from seeing new terminology on the blackboard or on overhead transparencies. In discussion sessions, the teacher can help to keep the deaf student abreast by controlling the pace of the discussion. Allowing only one student to speak at a time, again, can benefit the entire group" (American Chemical Society Committee on Chemists with Disabilities, 1993: 8).

This example illustrates a crucial instance of curriculum flexibility in the classroom. It points to verbal ways of teaching and interaction in the classroom that we (non-disabled students) are accustomed to and take for granted, i.e. that everyone can hear and understand the content of the subject. It also illustrates that, even though one may not be able to provide interpreters for deaf or hard-of-hearing students, there are other ways in which such students could be helped to participate in the classroom. In other words, flexibility does not only mean using alternative methods of teaching, but that one can still use existing resources, albeit for a different purpose.

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[32] During this period, ACS noted that the Technical Sign Project Staff at the National Technical Institute for the Deaf was collecting, evaluating, and recording signs for scientific terms, including chemistry.

Example 2: Classroom learning: "Students with impaired vision have their own ways of learning from graphics; the use of raised-line drawings is one such method... Still, the student can learn from graphics presented in class if the material is described carefully. Such material is best described in a consistent fashion - for example, clockwise or left to right. Students who are blind find it useful to have access to molecular models of structures discussed in lectures" (American Chemical Society Committee on Chemists with Disabilities, 1993: 7).

This example shows that curriculum flexibility is not just about alternative ways of teaching but also alternative ways of learning. In this example, an instructor has to recognise that, although it is taken for granted that diagrams can only be learned through vision, they can also be learned from abstraction. Such flexibility implies that the instructor needs to include the disabled student in the process of teaching by finding out, for example, if the particular blind student could easily learn from abstraction or not.

Example 3: Evaluation: "Special conditions may make it necessary to test students with disabilities orally or with the assistance of a reader/writer. However, disabled and able-bodied students often can take tests at the same time and place by using measures that include:

- Putting tests and/or answers on tape or in Braille
- Using talking calculators with an earplug
- Using a typewriter or writing guide" (American Chemical Society Committee on Chemists with Disabilities , 1993: 12)

This example is a reminder that, even though students with disabilities need support services, they need not be isolated in the learning process. Instead, their learning can and should take place in the same environment as that of non-

students with disabilities. This not only requires flexibility in terms of using assistive technology, but also flexible thinking by the instructor.

The three examples above indicate that flexibility comes in the form of: alternative methods of teaching and learning; assistive technology; alternative use of existing resources; flexible thinking; and involvement of students with disabilities. Moreover, the most important element of curriculum flexibility is to ensure that students with disabilities are taught in the same environment as non-disabled students.

(c) The third principle in curriculum flexibility is for the lecturer, instructor or tutor to try to dispel some negative assumptions about the presence of a disabled student in the learning process. In the case of chemistry, the ACS dispels the myth that students with disabilities present potential dangers to themselves and to other students in the laboratory. The ACS presents two counter arguments. The first one is that any chemistry laboratory is a potential hazard for laboratory users. Students with disabilities or chemists do not make it any worse or better than it already is. Secondly, every laboratory is supposed to have safety measures that all students are supposed to learn, including students with disabilities. Citing an example of visually impaired students in chemistry programs, ACS reckons, "Blind students negotiate best in familiar surroundings. Even though they may never need to visit remote parts of the laboratory, they should familiarize themselves with the entire setting. A short time with the lab instructor locating sinks, reagent shelves, hoods, safety showers, and the like will orient the student and help to determine the best place to work. The student will find the exits, learn the bench configurations, memorize the positions of the utilities, and so forth. The laboratory becomes familiar and comfortable. This orientation session can also be used to explain the safety rules and outline fire drill and other procedures. It is also the time to explain what locations in the laboratory pose the

greatest potential hazards" (American Chemical Society Committee on Chemists with Disabilities, 1993: 22).

This principle counteracts a typical problem of regarding the education of a disabled person as a burden. Chapter 3 has shown how disability has been viewed in either negative or supernatural ways. The education of people with disabilities is no exception. As section III of Chapter 5 has shown in the case of South Africa, special education has isolated disabled learners not only from non-disabled learners, but also from mainstream society. It is thus not surprising that, in institutions of higher learning, the first reaction is to see disability as a burden not because it is hard but because traditional ways of learning and teaching are unable to cater for students with disabilities. So this principle of inclusion and participation allows the learning process to take into account the needs of students with disabilities too.

(d) The final principle is the use of technology that is designed or adaptable to alternatives modes of teaching and learning. The ACS (p.23) listed the following adaptive equipments:

- Voltmeters and multimeters with audible readout
- Talking thermometers
- Light probes (used as part of readout devices; they emit a tone that increases in pitch proportionally to changes in light intensity)
- Liquid-level indicators
- pH meters
- Talking balances
- Spectroscopes
- Electronic calculators with Braille printout
- Braille labellers

- Braille rulers and meters
- Braille thermometers
- Laboratory glassware with raised numbers
- Sandpaper labelling for hazardous chemicals
- Spoons with sliding covers
- Electronic calculators with both voice and Braille output
- Microcomputers equipped with interfacing cards to control a variety of instruments

Assistive technology varies for different disabilities and academic courses. This also implies variations in the cost and affordability of such technology. The fact that assistive technology is available does not necessary mean that an institution of higher learning will be able to afford it. As this chapter and Chapter 9 will indicate, funding is a major challenge for disability support services for students with disabilities in South Africa.

The curriculum flexibility examples as noted above from the ASC document have thus highlighted important considerations and some myths that needed to be dispelled about students with disabilities. The document has nonetheless recommended the consideration of inclusive and participatory education for students with disabilities. It has also highlighted some of the different ways in which curriculum flexibility can be approached. Most importantly, it emphasises a positive and non-discriminatory perspective on the education of students with disabilities.

(iii) Staff Development

Another early challenge that American colleges faced was how to change the attitudes of staff towards students with disabilities. The fact of the matter is that

academic staff members were not trained to handle disability and, because there have been little or no people with disabilities on campuses, there had been little interaction between students with disabilities and staff. Consequently, by the time people with disabilities were protected under the law and began to flock into higher education, problems of interaction emerged. Nathanson (1980) vignettes twelve actual syndromes to illustrate the feelings and thoughts of college staff that might have had good intentions, but lacked an understanding of putting a person first before his or her disability. These syndromes are:

- **Syndrome One: All That Matters Is Your Label**: In this situation, a student with cerebral palsy met with the Director of Residence Life to discuss accommodation after touring the campus. The director was pleased to inform the student that the dormitories were accessible and that the university would be able to provide her with an attendant. The student replied that she did not need an attendant. However the director insisted, "iIt is really no problem for us – we have done it for all the other cerebral palsied students and the arrangement worked out just fine" (Nathanson, 1980: 19). The problem here is that the student is not being 'ungrateful', but rather that the director has a blanket perception of disability. The condition of a specific disability (cerebral palsy) thus homogenises the students, instead of the needs of a particular disabled student being met.

  This syndrome recollects Principle One on curriculum flexibility as mentioned by the American Chemical Society Committee on Chemists with Disabilities. One of the challenges faced in supporting students with disabilities is the constant need for creativity, because each disabled student has different needs, even though he or she might be experiencing a similar disability as other students. As the Harvard

University and Boston University case studies will show in the final section of this chapter, the best approach for students with disabilities is one that is tailor-made. The point is, while the principles and aspects of support for students with disabilities are common across institutions of higher learning, the actual support for an individual student needs to be custom-made even for students who experience the same disability.

- **Syndrome Two: I Feel Sorry For You**: A sophomore student in a wheelchair visited his old friend who is the school's activities advisor and tells him that he got a part in a school's play. The advisor was pleased, but spoke to the student in a soft slow voice when asking him how he was doing. When the student had left the premises, the advisor met a faculty staff member in the corridor and reminisced, "How active that boy used to be – he really used to be something; it is such a pity" (Nathanson, 1980: 20).

  This syndrome is reminiscent of Sizamile's newspaper story mentioned in Chapter 3. Pity is commonly the first reaction of non-disabled people towards people with disabilities. The problem of pity on campus is that it undermines the ability of a disabled student and makes the rest of the university community feel compelled to compensate for the 'tragedy'. Consequently, pity undermines the academic merit and extracurricular achievements of a disabled student.

- **Syndrome Three**: **Don't Worry, I will Save You**: A blind student complained to her academic counsellor about "too much work" in a literature course and her inability to work on a due assignment. The advisor promised to do something about it. Indeed, the counsellor spoke to the professor, explaining how much the student had to deal with. The professor agreed to exempt the student from submitting the

essay, and promised that the student would receive a good grade because she was working hard and would soon graduate.

Nathanson's contention is that the student's failure to complete the essay was simply condoned because she was blind. Had she not been disabled, the counsellor would not have deferred the matter to the professor, and the professor would not have conceded. The problem once again is that the student was never motivated to rise above her course work. Instead, her complaint was attributed to her disability and not, for example, to her study skills.

- **Syndrome Four: You Present Too Many Problems For Us To Handle**: The chairman of the chemistry department called the Dean of Students to say that something should be done about a student in a wheelchair in an introductory chemistry course. He explained that the student would not be able to perform all the required work in the laboratory and that he was a danger to himself and other students. The Dean asked if the chairman had discussed the matter with the student upon which the chairman asked, "What would be the point?"

  This syndrome recollects Principle Three of the American Chemical Society Committee on Chemists with Disabilities on curriculum flexibility, which dispels the myth that students with disabilities present potential danger for themselves and other students. Nathanson explains that the problem in this situation is the typical staff perception of students with disabilities as a burden on campus. Academic staff members do not take the time to discuss with a disabled student alternative ways of learning without altering the curriculum and its requirements. They automatically assume that admitting a disabled student implies lowering the standards.

- **Syndrome Five: I Know What's Best For You:** An upper sophomore who was deaf visited a career advisor to discuss her plans to become a teacher. She mentioned that her hearing impaired cousin was also a teacher. The advisor interjected, stating that she was not aware of any deaf teachers at least in the state and told the student that her hearing impairment would pose difficulties for her and the students. The advisor advised the student to rather pursue a career in computer science because she did well in mathematics and because that career did not require much verbal communication.

  In this example, the advisor delimits options for the students based on her best 'knowledge' of what is suitable for the student, without discussing it with the student and perhaps doing some research on deaf teachers. This syndrome hits at the core of the arguments of the Independent Living Movement and the social model of disability, as Chapter 3 has tried to explain. The core argument is that people with disabilities know what they want and also know how to lead their lives with appropriate support that is void of paternalism and ableism.

- **Syndrome Six: If I'm Lucky, We Won't See Each Other Today:** A junior with congenital deformities of the face and head made an appointment with the counselling centre psychologist to cope with the death of a younger brother. They had three sessions and the student observed that, even thought the psychologist was outwardly friendly; he appeared uncomfortable when talking face to face during sessions. During the course of the therapy, the psychologist started missing appointments with excuses, and talking in impersonal and professional words when meeting the student. When the psychologist finally honoured the subsequent appointment, he was uncomfortable and

tended to fidget with a pencil and avoided eye contact. After the session, he informed the student that he reckoned everything was under control and that there was no need to meet again.

Nathanson (1980) explains that this example illustrates the feeling of revulsion or the unconscious rejection that some people feel towards body deformities. "These feelings are transmitted by impatience and avoidance. The student may be kept waiting, transactions may be cut short or the usual warm greeting or extended handshake may be absent" (Nathanson, 1980: 25). Consequently the student may be viewed with contempt and intolerance, and be deprived assistance or blamed for using his disability to secure unfair advantage.

Avoiding students with disabilities is not an isolated event, as the outline of the historical understanding of disability in Chapter 3 shows. The relationship between disability and society has been contradictory and unstable. Regardless of the different perceptions about people with disabilities, the social position of people with disabilities has always been an avoided and isolated space. The above is only one of the many anecdotes of exclusion told by people with disabilities.

- **Syndrome Seven: I'm Amazed At Your Courage**: Just before the summer vacation, two freshmen stopped in to inform their advisor that they had passed their entire courses. One of the students was blind. The advisor showered the blind student with praise and, almost as an afterthought, the advisor told the other student to "keep up the good work".

  The problem with the advisor's reaction is the underlying assumption that the blind student is supposed to be academically inferior. Passing all

the courses is thus a source of astonishment to the advisor. For the blind student to have passed all the courses means that he must either be extraordinary or have worked extraordinarily hard. The other student, in contrast, was expected to pass the entire set of courses. His ability as a non-disabled student is perceived as self-evident. "Common examples of this syndrome in the college community are the non-disabled student who remark to a disabled classmate in a somewhat condescending, infantilizing manner, 'You're really super, you're just like the rest of us' and the faculty member who gives the disabled student an inflated grade because he is 'so motivated and determined, and works so hard'" (Hourihan, 1980: 26).

This syndrome is connected to Syndrome One, which makes the disability take precedence over the student. In this case, the disability of a student automatically lowers expectations. Interestingly, if a disabled student performs above expectations, then he or she is considered hard working and outstanding. This means that the instructor cannot change his or her attitude towards the intellectual capabilities of a disabled student. Instead he or she would try to rationalise why a disabled student performed well, instead of recognising that, for example, even if a student is in a wheelchair, blind or deaf, his or her intellectual capacity remains intact. In fact, it is an interesting observation that most of our learning time takes place while we are actually sitting in a chair in a classroom, seminar room, conference room, boardroom, library, study room or relaxing outdoors, yet it is hard to imagine that a person who is confined to a wheelchair can also learn while sitting.

- **Syndrome Eight: Who's More Anxious, You or I?** A cerebral palsied freshman who had severely impaired speech raised his hand to respond

to the professor's questions, but was constantly ignored. After several classes, he questioned the professor about not being given a chance to speak. In subsequent classes, the professor allowed the student to speak. However, the processor interjected inappropriately by cutting the student short and trying to anticipate what the student would say by 'completing' his sentences. The professor was neither willing to accept that he did not understand the student's speech, nor to ask the student for clarification.

In this situation, the professor is displaying his anxiety about the student's disability, but cannot accept that fact. This anxiety is often displayed by the tendency to speak unusually loudly, softly, slow, quickly or simplistically to students who are disabled. "Common examples of this syndrome on the college campus are fellow-student hesitation at bringing up the subjects of sports, dating, sexuality and physical appearance around disabled students, and members of the college community who are quick to refer disabled students to the 'handicapped students advisor' to handle the smallest of matters rather than directly working things out with the student" (Nathanson, 1980: 27).

Interacting directly with students with disabilities poses some challenges for any member of a higher education institution, because of little engagement of personalities and a general lack of interaction between disabled and non-disabled student. As this thesis will argue in Chapters 9 and 10, support services for students with disabilities should not be treated as clearing houses for disability matters on campus. Rather the institutional culture should be changed to embody disability issues as one of the more general disadvantages faced by students, similar to race

and gender, so that they become part of executive, academic and service functions of a university, technikon or college.

- **Syndrome Nine: You Want To Be Just Like Everyone Else, but I Won't Let You:** When a crowded elevator opened, an elevator operator instructed other students to move back because there was a disabled student who wanted to exit in a wheelchair. Leaving the elevator unattended, the operator wheeled the student down in the corridor asking where she was going. The student told him that she was okay, she could wheel herself, but the always pleasant and ever-helpful operator insisted on taking the student to her destination.

  This example is typical of the college community tending to see students with disabilities as helpless and dependent and always making unnecessary demands. "Common examples of this syndrome are the speech professor who encourages the disabled student to present a discussion related to his disability – 'it would make a marvellous topic'; the overly-helpful dormitory neighbour who continually knocks on the disabled student's door asking if assistance is needed; and the faculty member who, during the first session, asks disabled students to identify themselves and good-naturedly tells them they will be permitted extra time on examinations" (Nathanson, 1980: 28).

Sensitising college and university communities about disability does not end with teaching people how to interact with students with disabilities in the classroom, but should be applied more generally within the campus. Jonhs (1980) relates her experiences with some people with disabilities and her experiences as a secretary working with disabled professionals and students with disabilities. She tentatively suggests the following:

- When you accompany someone, lead the way because it is easier to be led than to be pushed.
- If a blind friend has something despoiling her clothing, do not hesitate to tell her or reassure her of her appearance.
- It is not advisable to pet a guide dog because that distracts it from its primary purpose.
- Be conscious of the needs of a disabled person and work out a buddy system in case of emergencies.

Staff development as an aspect of providing support to students with disabilities highlights some of the common mistakes and challenges that face academic staff in interacting with students with disabilities. Staff development also implies that staff members have to undergo a constant learning process overcoming their assumptions about students with disabilities and to reflect on their actions. It also requires staff members to engage with students with disabilities in devising alternative ways of teaching.

It should, however, be borne in mind that the challenges facing staff members in interacting with students with disabilities are not a new challenge in the academy. The admission of non-traditional students in some institutions of higher learning has produced similar challenges. The admission of younger students in institutions of higher learning has, for instance, produced a different institutional culture and response to that of a traditionally older student population. The admission of more women, students from poor educational backgrounds and different cultural backgrounds in historically privileged white and male dominated institutions, too, has produced challenges, such as institutional racism, high drop-out rates and gender stereotyping. Such challenges are being addressed in programs, such as academic support programs, diversity programs, and gender equity programs. As I conclude in

Chapter 11, I point out that the challenge of disability should also be understood within the challenge of grappling more broadly with **diversity** in which there are different levels of preparedness, different cultural meanings and different ways of learning.

(iv) Student Life

The area of student life for students with disabilities in America was very underdeveloped in the beginning stages of providing support as mandated by Section 504 of the Rehabilitation Act of 1973. The emphasis was on forming student organisations for students with disabilities exclusively, of which Delta Sigma Omicron described above is an example in point. Student life at the time focused primarily on advocacy on campus. From the students' side, advocacy was necessary because "they often find that they are not fully informed about their rights as disabled persons and that they need to advocate and represent their interests on campus" (Tickton et al, 1981: 41).

The challenge for universities and colleges was to assist students with disabilities in setting up self-help and advocacy organisations and to educate students with disabilities about their rights. By 1981, several institutions had such organisations. Examples were: Independents at the State University of New York, Buffalo; Students Organized For Every Disability United For Progress (SO FED UP) at the Brooklyn College of the City University of New York; Students for Mobility at Kent State University; and Society to Educate and Assist Ramapo College Handicapped (SEARCH) at Ramapo College of New Jersey.

(V) Progress Since Section 504[33]

This section describes some of the documented progress since the effective date of Section 504 of the Rehabilitation Act of 1973. The purpose of this section is to see what lessons South Africa can learn from the American approach to supporting students with disabilities. It will also be used in Chapter 9 to differentiate the United States of America from South Africa in terms of the practicalities of shifting from benevolence to real rights.

Ten years after the effective date of Section 504 of the Rehabilitation Act 1973, the National Centre for Education Statistics[34] produced national statistics on higher education and disability in America. Relevant to this thesis to demonstrate progress since the challenge of the 1980's, the national statistics included, "(1) enrolments of postsecondary students with disabilities, (2) institutions enrolling students with disabilities, (3) support services and accommodations designed for students with disabilities, (4) education materials and activities designed to assist faculty and staff in working with students with disabilities, and (5) institutional records and reporting about students with disabilities" (Lewis and Farris, 1999: 3).

The first logical step that institutions had to take with regard to students with disabilities was to recruit people with disabilities to enrol into their programmes. The following bar graph in Figure 7.1 indicates the national percentage of

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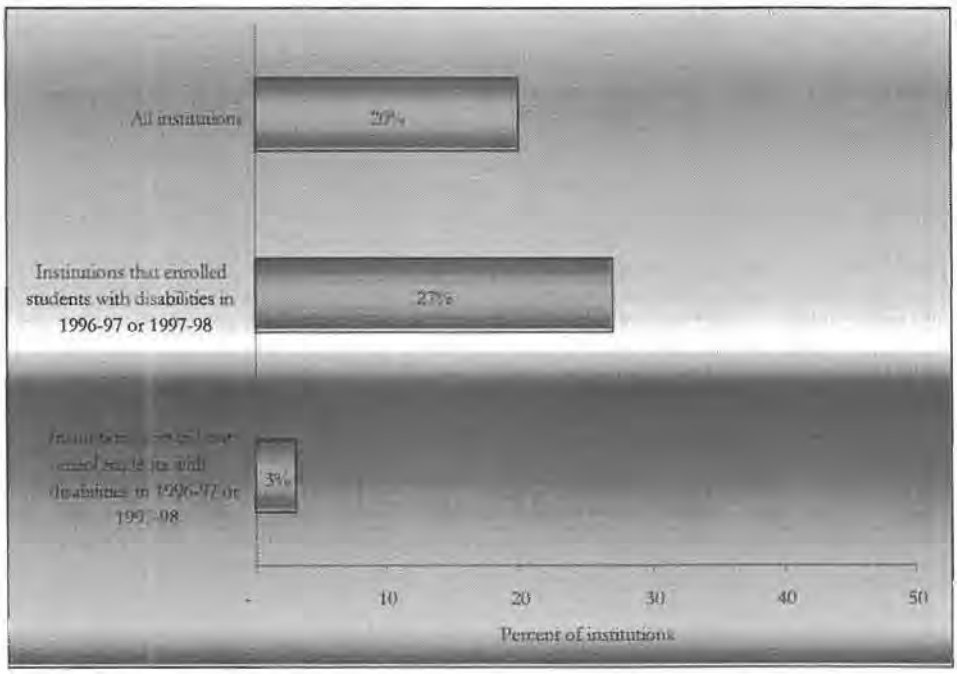
[33] Section 504 of the Rehabilitation Act of 1973 was regulated, and part of the regulations was that the effective date was July 1979, by which time all government funded institutions of higher learning should begin to comply with the Act. The earliest date that I deal with in this section, is 1989, which is ten years after the effective date of Section 504.

[34] All the American statistics in this section are from the National Centre for Education Statistics (NCES) website (www.nces.ed.gov), although they are referenced with different authors. Note that not all data in the NCES website was collected by the NCES.

institutions in 1996-7 and 1997-8 that designed specific outreach programmes to recruit people with disabilities to apply to their institutions.

Figure 7.1: Percentage of 2-year and 4-year postsecondary education institutions that have developed special outreach or recruitment materials or activities designed specifically to recruit students with disabilities, by whether the institution enrolled students with disabilities in 1996-97 or 1997-98



(Source: Lewis and Farris, 1999: 21)

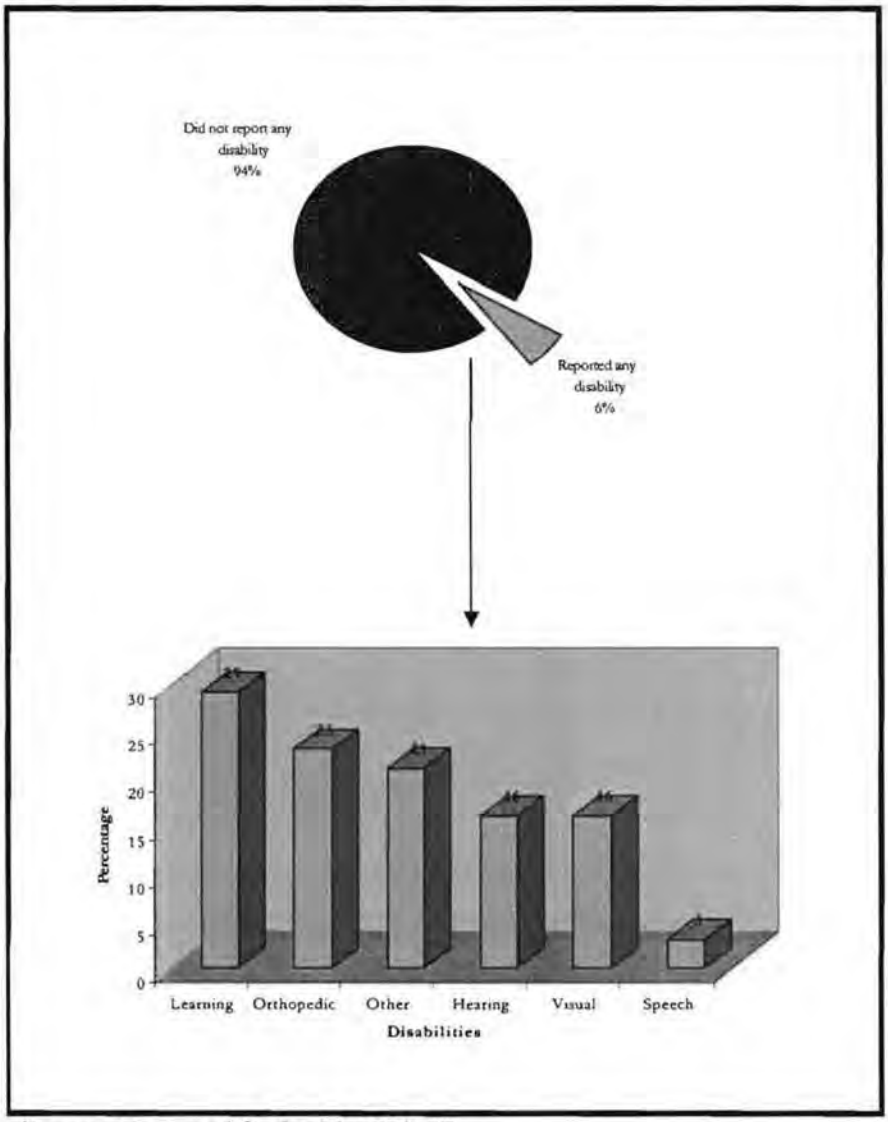
Note: Information about students with disabilities represents only those students who identified themselves to their institution as having a disability, since these are the only students about whom the institutions could report (Laurie Lewis and Elizabeth Farris, 1999: 31).

Both those institutions that enrolled students with disabilities and those that did not in 1996-1997 or 1997-1998 were asked if they had developed specific recruitment programmes for students with disabilities. Twenty percent (20%) of all institutions that were surveyed had created some recruitment or outreach

programmes to encourage people with disabilities to apply to enrol in their institutions. Institutions that enrolled students with disabilities in 1996-1997 or 1997-1998 were also more likely to have established recruitment programmes than institutions that did not enrol students with disabilities in those years. This is reflected in the bar graph above in which twenty-seven percent (27%) of institutions that enrolled students with disabilities had recruitment programmes for students with disabilities and only three percent (3%) of institutions that did not enrol students with disabilities in 1996-97 or 1997-98 had recruitment or outreach programmes. Moreover, according to Lewis and Farris (1999), "Among institutions that enrolled students with disabilities, public 2-year and 4-year institutions were more likely than private 2-year and 4-year institutions to have developed special outreach or recruitment materials or activities. In addition, large institutions were more likely than medium institutions, which were more likely than small institutions, to have developed such materials or activities" (Lewis and Farris, 1999: 31). The materials and outreach or recruitment activities that targeted organisations included high school counsellors, other postsecondary institutions, business or employers, community and civic organisations and vocational and rehabilitation agencies.

Furthermore, researching for the National Centre for Education Statistics, Horn and Berktold (1999) provide statistics on the representation of students with disabilities that are enrolled in postsecondary education in 1995-1996. The following pie chart and bar graph in Figure 7.2 indicate the percentage of undergraduate students who reported having a disability and the percentage of a disability type that was reported by the students enrolled in 1995-1996.

Figure 7.2: Percentage of 1995-96 undergraduates who reported a disability, and among those with disabilities, the percentage of those reporting each disability type



(Source: Horn and Berktold, 1999: iii)

NOTE: In this survey conducted by the National Postsecondary Student Aid Study (NPSAS), twenty one thousand (21,000) undergraduate students enrolled in 1995-1996 were asked if they had a disability and if so what type of disability they had.

NOTE: Percentages do not add up to 100, because some students reported muluple disabilities (Horn and Berktold, 1999: 3).

As can be observed in Figure 7.2, six percent (6%) of the students reported themselves to be disabled and ninety six percent (94%) said that they were not disabled. Further, the largest category of students who reported to be disabled said that they had learning disabilities (29%). Twenty three percent (23%) said that they had orthopaedic disabilities. Sixteen percent (16%) reported visual impairments and another sixteen percent (16%) reported hearing impairments. Thus these four categories were clearly the most dominant, since speech disabilities made up only three percent (3%). The "other" category, which comprises twenty one percent (21%) of reported disabilities, refers to any other health related disability.

With respect to the study, according to Horn and Berktold (1999), undergraduate students that reported a disability were likely to be older, white and non-Hispanic. In terms of fields of study, there were no marked differences between disabled and non-disabled students. "For example, roughly one-fifth of students with and without disabilities (17 and 20 percent, respectively) were in business-related fields; 18 and 15 percent, respectively, were in humanities; and 11 and 13 percent, respectively, were in health fields" (Horn and Berktold, 1999: 4). Moreover, students with disabilities were less likely to be enrolled in state 4-year institutions than non-disabled students, but equally likely to be enrolled in private non-profit 4-year institutions. They were also more likely to be enrolled in sub-baccalaureate institutions such as public 2-year institutions. The comparison of enrolment of students with disabilities and non-disabled students is represented and elaborated in Rable 6A as follows:

Table 7.1: Among 1988 eighth graders who completed high school, percentage who enrolled in postsecondary education in 1994, and percentage distribution according to type of institution, by disability type and status[35]

		Four Year Institutions			Other Institutions		
	Total enrolled	Total	Public	Private, not for profit	Total	Public 2 Year	Other[36]
Total	70.4	59.4	39.8	19.6	40.6	34.4	6.2
Does not have a disability	71.7	61.5	41.3	20.2	38.6	33.6	5.3
Has a disability	62.8	42	28.1	14	58	44.9	13.1
Visual impairment	70.4	48.8	30.9	17.6	51.6	44.2	7.4
Hearing impairment or deaf	60.2	39.8	33.5	6.3	60.2	47	13.2
Speech impairment	58.5	49	34.5	14.5	51	47.6	3.5
Orthopaedic impairment	73.9	71.4	53.6	17.8	28.7	23.6	5.1
Learning disability	57.5	28.2	17.6	10.5	71.8	53.9	17.9
Other disability or impairment[37]	65.9	44.3	28.4	15.9	55.7	42.8	13

(Source: Horn and Berktold, 1999: v.)

Table 7.1 indicates the percentage of 1988 graders who completed high school and enrolled in postsecondary education as of 1994, which is two years after most of them had finished high school. It also indicates the percentage of student enrolment according to whether a student has a disability or not and also according to the type of institution. The total percentage of all students that enrolled in postsecondary education as of 1994 was approximately seventy

[35] This section will not focus on the types of disability but rather on the comparison between disabled and non-disabled students. The purpose is to deal with disability in general rather than looking at specific disabilities.

[36] Students enrolled in private, for-profit institutions; public less-than-2-year institutions; or private, not-for-profit less-than-4- year institutions.

[37] Parent reported student had any other disability, including health problems, emotional problems, mental retardation, or other physical disabilities, and had received services for it.

percent (70.4%), as shown by the first uppermost left statistic in the table. A relatively high percentage of students with disabilities were enrolled during this period: approximately sixty-three percent (62.8%) of students with disabilities were enrolled in postsecondary education compared to approximately seventy-two percent (71.7%) of non-disabled students.

Of the total students who enrolled in postsecondary education fifty-nine percent (59.4%) were enrolled in four year institutions and approximately forty-one percent (40.6%) were enrolled in other institutions, amongst which were two-year institutions. Within the four year institutions, students with disabilities were less likely to be enrolled in them (42% in 4 year vs. 58% in 'other) compared to non-disabled students (61% in 4 year vs. 38% in 'other').

Horn and Berktold (1999) conclude that students with disabilities were less prepared than non-disabled students to enter 4-year public and private for-profit higher education institutions. They conclude, "Overall, with respect to gaining access to higher education, the data indicate that students with disabilities fall behind their counterparts without disabilities in their high school academic preparation for college. As a consequence, students with disabilities are less likely to be academically qualified for admission to a 4-year college and among those who enrol in postsecondary education, students with disabilities may be less prepared to undertake college-level courses" (Horn and Berktold, 1999: 5).

When students with disabilities are already in the different types of institutions, they are given support, as regulated by Section 504 of the Rehabilitation Act of 1973, which became effective in 1979. These support services vary according to disability and what students with disabilities actually request. Table 7.2 below lists some of the frequently stated support services for students with disabilities by type and size of institutions. These are results of the Postsecondary Education

Quick Information System (PEQIS) survey, which was conducted in the spring of 1998, to investigate the enrolment of students with disabilities in 1996–97 and 1997–98.

Table 7.2: Percentage of 2-year and 4-year postsecondary education institutions that enrolled students with disabilities in 1996-97, or 1997-98 by type of accommodations offered to students with disabilities, by institutional characteristics

Among institutions enrolling students with disabilities, percentage providing various services or accommodations[38]									
Institutional characteristics	Institutions enrolling students with disabilities	Alternative exam formats or additional time	Tutors to assist with ongoing coursework	Readers, classroom note taker, or scribes	Registration assistance or priority class registration	Adaptive equipment and technology	Textbooks on tape	Sign language interpreters/ translators	Course substitution or waivers
All Institutions	72	88	77	69	62	58	55	45	42
Institutional Type									
Public 2-year	98	94	87	82	77	81	66	66	48
Private 2-year	47	55	51	18	26	30	11	10	15
Public 4-year	98	100	82	93	83	80	85	68	69
Private 4-year	63	90	75	66	53	39	49	29	35
Size of Institution									
Less than 3,000	63	82	71	55	48	43	40	28	29
3,000 to 9,999	99	99	90	93	88	86	82	71	61
10,000 or more	100	100	84	100[39]	95	97	93	96	81

(Source: National Centre for Education Statistics, 2000: 2)

Table 7.2 above shows some of the most commonly used forms of curriculum flexibility. Of all the institutions that were surveyed, 88% had alternative exam formats, 77% had tutors to assist students with disabilities and 69% used scribes, note takers or readers (a reading device connected to a computer) in the

[38] These are not complete services but rather those that are more frequently stated.

[39] Statistics are estimated at 99.6 percent, which is rounded up to 100 for presentation in this table.

classrooms. Nearly half (45%) had sign language interpreters. The least favoured method was course waivers.

Public institution (both 4-year and 2-year) show a generally higher percentage of alternative methods of teaching and curriculum accessibility for students with disabilities than private institutions (both 4-year and 2-year). Public 4-year institutions also have a relatively higher percentage of curriculum flexibility methods than private 4-year institutions. Moreover, there is a greater difference between the public 2-year and private 2-year institutions. For example, while 82% of public 2-year institutions use scribes, only 18% of private 2-year institutions use them. Moreover, medium (99%) and large institutions (100%) were more likely to provide more services than small institutions (63%).

The National Education Centre for Statistics does not explain the differences in providing support for students with disabilities in terms of both type and size of institutions. However, I think it is plausible to suggest that public institutions are more likely to provide support services because they are obliged by federal law to provide support for students with disabilities, because they receive substantial state funding, which is the main reason for falling under the provisions of Section 504 of the Rehabilitation Act of 1973. Moreover, bigger institutions are more likely to provide more support services than smaller ones because they generally have more students with disabilities and more resources than smaller ones.

Support for students with disabilities consists of more than different types of services. Staff members are also given materials and activities to assist them in working with students with disabilities. Lewis and Farris (1999) indicate that, in both 2-year and 4-year public institutions, the most used method of educating staff are one-to-one discussions with staff members who request information. The second most used methods in both cases are workshops and information

resources. The least used methods in both cases were annual mailings to staff members.

Figures 7.1 and 7.2 and Tables 7.1 and 7.2 above have respectively displayed percentages of: institutions recruiting students with disabilities; undergraduates students reporting disability; enrolment of students with disabilities by type of institution; support services by institutions; and staff development materials by institution. Another issue is to determine the percentage of students with disabilities that manage to stay and complete a qualification in college compared to non-disabled students. Table 7.3 below provides statistics in this regard from a survey of undergraduate students who enrolled for the first time in 1989-1990 and who were surveyed in 1992 and 1994.

Table 7.3: Percentage distribution of 1989-1990 beginning post secondary students according to highest undergraduate degree attained by 1994, by disability status and first institution attended

	None[40]	Certificates[41]	Associate's[42]	Bachelor's[43]

[40] None refers to students who were still enrolled and had not yet earned a postsecondary qualification within the 5 years covered by the survey.

Table 7.3: Percentage distribution of 1989-1990 beginning post secondary students according to highest undergraduate degree attained by 1994, by disability status and first institution attended

	None[40]	Certificates[41]	Associate's[42]	Bachelor's[43]
TOTAL	50	13	11	26
Does not have a disability	49	12	12	27
Has a disability	59	19	6	16
Public 4-year				
Does not have a disability	44	3	5	48
Has a disability	55	8	3	33
Private, not-for profit 4-year				
Does not have a disability	28	2	3	67
Has a disability	35	6	2	57
Public 2-year				
Does not have a disability	63	12	18	6
Has a disability	66	21	7	6
Other institutions[44]				
Does not have a disability	40	45	13	2
Has a disability	59	33	6	2

(Source: National Centre for Education Statistics, 2000: 3)

The first row shows the total percentage of students according to qualification attained. Fifty percent (50%) of the surveyed undergraduate students had not attained any qualifications and were still enrolled. Thirteen percent (13%) had been awarded vocational certificates, 11% had been granted associate's degrees and 26% percent had received a bachelor's degree. Rows two and three

[41] Vocational certificates.

[42] Associate's degree refers to a 2-year college qualification.

[43] Bachelor's degree refers to a 4-year college or university course qualification.

[44] Students enrolled in private, for-profit institutions; public less-than 2-year institutions; or private, not-for-profit less-than-4-year institutions.

disaggregate the percentages according to the categories of disabled and non-students with disabilities. Fifty nine percent (59%) of students with disabilities, as compared to 49% of non-disabled students, had not attained a postsecondary qualification by 1994. Students with disabilities were more likely to attain vocational certificates (19%) than non-disabled students (12%). However, non-students with disabilities were more likely to attain associate's degrees (12%) and bachelor's degrees (27%) than students with disabilities (6% and 16% respectively).

Focusing on public 4-year institutions, non-disabled students were more likely than students with disabilities to obtain bachelor's degrees[45]. Forty-eight percent (48%) of non-disabled students were granted bachelor's degrees compared to thirty-three percent (33%) of students with disabilities. Moreover, fifty-five percent (55%) of students with disabilities had not obtained postsecondary education qualifications compared to forty-four percent (44%) of non-disabled students.

With regard to public 2-year colleges, the difference between disabled and non-disabled students' attainment of 2-year college qualifications is relatively small for non-attainment of qualifications and for attainment of bachelor's degrees. Sixty-six percent (66%) of students with disabilities in public 2-year institutions had not yet received a postsecondary education qualification compared to a close sixty-three percent (63%) of non-disabled students. Moreover, six percent (6%) of both disabled and non-disabled students who started in public 2-year institutions obtained bachelor's degrees. With regard to vocational certificates 21% percent of students with disabilities obtained vocational certificates compared to non-

[45] This trend is the same as in private, not-for profit 4-year institutions, as in rows 6 and 7.

disabled students who show 12% versus the 7% and 18% for associate's qualifications respectively.

The overall statistics presented in Table 7.3 essentially show that students with disabilities who first enrolled in postsecondary education in 1989–90 were more likely to have lower levels of degree attainment. However, Horn and Berktold (1999) explain that, compared to non-disabled students, there are factors that might be attributed to disabled students' low rates of persistence and low attainment of degrees. They reckon, "students with disabilities were more likely to have delayed their postsecondary enrolment a year or more after finishing high school (43 versus 32 percent). They were also more likely to have completed high school through earning a GED (i.e., they passed the General Education Development exam) or alternative high school credential (12 versus 6 percent). Corresponding to being older, students with disabilities were also more likely to have dependents other than a spouse (25 versus 13 percent)" (Horn and Berktold, 1999: iv).

In summarising this section, there are four aspects of the progress after the effective date (1979) of Section 504 of the Rehabilitation Act of 1973 that are important for this thesis, and which also have lessons for South Africa, as I will argue in Chapter 10. The first aspect is the actual enactment of Section 504, which amended the Rehabilitation Act of 1973 and regulated the provision of support for students with disabilities in America. Section 504 has created a mandatory legal framework within which such support is provided for students with disabilities in the United States of America. The second aspect is the actual existence of support services for students with disabilities and staff development in terms of assisting students with disabilities. The legal right to support services has been transformed into a real right because of the resources that are needed to realise support services for American students with disabilities. This will be

illustrated in the next section on Harvard University and Boston. The third aspect is research into the support services for American students with disabilities. This is a crucial aspect because of the following: it explores trends in disability support in postsecondary institutions; it evaluates the quality of such support; it analyses the profile of students with disabilities, which is lacking in South Africa, as Chapters 8 and 9 will show. The final aspect of the progress is that these research studies do not claim that there are meticulously executed disability support projects at various institutions of higher education. Rather they rightly and importantly point out the problems facing both an institution and students with disabilities in terms of cumbersome access to postsecondary education, lower participation rates and lower graduation rates.

To recap in anticipation of the next section, Sections II-V have summarised the key historical developments in the provision of support for students with disabilities in the United States of America. These developments are: (a) certain key foundations after World War II, with some cases as examples; (b) the struggle of the Independent Living Movement in the 1970's; (c) the challenge of the 1980's in trying to establish the mandatory provision of support for students with disabilities; and the progress ten years after Section 504 of the Rehabilitation Act of 1973 was effected in July 1979. The following section (Section VI) is a contemporary case study of support for students with disabilities at Harvard University and Boston University in the United States of America. The cases will indicate the institutions' policies, support structures, support services, funding and networking.

(VI) Two Cases of American Institutions

(a) Methodological Narrative

In the beginning of 2004, I had the opportunity to travel to the United States of America; I was based at Harvard University for five months as part of the requirements of my PhD scholarship. Before I went to the USA, I had already decided that I would explore what some American universities were doing in terms of providing support for their students with disabilities, so that I could find first-hand comparative contemporary data to contrast with South Africa. I thus decided to include Harvard University in my research because I would be based there and because Harvard had an elaborate and interestingly decentralised disability support system. While at Harvard I had to choose another university or college in Massachusetts at which I would also conduct my investigation into disability support systems. I thus chose Boston University as my second case study because it was a centralised system of support and because, like Harvard University, it also had substantial resources to support its students with disabilities. There are other well-resourced institutions near Harvard University, such as the Massachusetts Institute of Technology and Boston College. However, given the relatively wide scope of support at Boston University, I thought it would be particularly beneficial to investigate it. Besides, as Chapter 6 has already described, all higher education institutions that receive some money from the federal or state government are legally obliged to provide support for students with disabilities. The difference lies in how institutions provide disability support provisions and how many resources institutions generate to pay for such programs or projects.

At Harvard University I conducted interviews in five units[46] and one at the Admissions Office. Initially, I intended to interview all schools. However, as I interviewed more schools, the marginal utility of information was decreasing because I was beginning to get the same information, and so I decided to stop at five. In addition to these five units, however, I also interviewed the disability co-ordinator at the Admissions Office because I thought this needed further investigation: here was an interestingly vigorous system of selection, which incorporated a disability co-ordinator at the level of the Admission's Office to ensure that students with disabilities were not inadvertently left out. In total, then, I interviewed six units.

At Boston University, I had a group interview session with the director plus the clinical director of disability services and one co-ordinator. I interviewed the three of them in one session. I decided on this approach because, as I had already mentioned with regard to Harvard, the information that I was receiving from each co-ordinator was the same because they were working within a stipulated legal framework.

The following section reports on the two cases of the provision of support for American students with disabilities at Harvard University and Boston University. As noted above, Harvard University is an example of a decentralised system of service provision, whereas Boston University is an example of a centralised system of service provision. These two examples serve three purposes. The first one is to describe the actual process of disability support to substantiate the legal framework that is described in Chapter 6. The second one is to highlight some of the challenges that face disability support services even at elite private institutions.

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[46] The units are. Graduate School of Business, Graduate School of Education, Law School, School of Public Health, and The Disability Resource Centre, which services Harvard College and the Faculty of Arts and Sciences.

The final purpose is to use the data to make an argument about the United States' position relative to South Africa in the tensive intersection of benevolence, rights, and the social model of disability. This argument will be developed in Chapter 10, following the South African discussion in Chapters 8 and 9.

(b) Disability Support at Harvard University

(i) Disability Policy

In terms of the Federal law of the United States of America, Harvard University is obliged to provide support for students with disabilities and not to discriminate against those students. Students are specifically protected under Section 504 of the Rehabilitation Act of 1973 as described and explained in Chapter 5. There is also another supporting legislation, which is the Americans with Disabilities Act of 1990 (ADA), which is also described in Chapter 6. The principles underlying this support are equal access, non-discrimination and civil rights for qualified people with disabilities. There is no formal written policy at Harvard University, but rather accepted practices that comply with the Federal law, in particular, Section 504 of the Rehabilitation Act of 1973.

In the case of complaints about contravening the policy, students have four channels through which they can resolve the problem. These channels depend on the level at which the problem occurs and the institutional and legal procedures. The first channel is a resolution between a student and an instructor, tutor or lecturer. The second channel is the intervention of the disability unit. The third channel is the Disability Compliance Officer in the Office of the Assistant President, which I will describe later. The final one is litigation using an applicable

law such the Rehabilitation Act of 1973 or the American with Disabilities Act of 1990.

(ii) Structure of support provision

Support systems for students with disabilities are decentralised. Besides the main Disability Resource Centre, each school runs its own disability support programme. In practice, this means that the Harvard University Disability Resource Centre services both the undergraduates' Harvard College and the Graduate School of Arts and Sciences, which both fall under the Faculty of Arts and Sciences, and each of the other ten schools have their own independent disability services office. The schools are: Law School; School of Public Health; Medical School; Graduate School of Education; Divinity School; Graduate School of Design; Continuing Education; Graduate School of Business Administration; School of Dental Medicine; Kennedy School of Government. When I enquired why the support provision was decentralised to the other schools, the answer was that Harvard University was a large institution and could not centralise its support services if it wanted to fully serve each disabled student. Moreover, each school had different core curriculum requirements, which would be a burden and impossible for a centralised system to know and apply effectively. This highlights the issue of applying disability provision in context, an issue on which I will elaborate further in Chapters 8 and 9 with respect to South Africa.

Typically, each school has a director and disability co-ordinators. Directors oversee the running of the office and also evaluate the disability documentation that is submitted by students. Co-ordinators typically have direct contact with the students and assist them in the actual implementation of support. Task designation is not, however, as clear cut as I have put it. Depending on the

numbers of serviced students with disabilities and disability office staff numbers, the tasks may overlap. For example, the duties of disability co-ordinators are not simply to oversee the provision of support, but to participate in the process as much as they can. As one co-ordinator explains, "It can range from the most menial task like answering the phone and filing, to more sophisticated office tasks like setting up a database, which I did last year and maintaining the database, to actually meeting with the students, reviewing documentation and determining what kind of accommodations are appropriate for them. I think because we are a small office I end up doing a range of things."

Each disability service office has its own structure depending on the number of students it services. If there are higher numbers of students that need support, then more staffing is required. However, what is common is that each disability service office has a director who works with disability co-ordinators. Where there are few students who need services, one person may work both as a co-ordinator and *de facto* director. For example, the Director of the disability office at the School of Public Health has direct contact with students with disabilities because of the small number of students he services. When asked if he was the only person in charge of support serves for students with disabilities, he replied, "I mean, it is four, including me there's four Student Affairs staff... But I'm the one that's doing all of this [work to support students with disabilities]. Now, but it depends on the population, because I know the school of Education, from my understanding, has a huge population of students with disabilities... I probably have of a thousand students, these [students with disabilities] are the ones that have identified and asked for accommodation, I probably have less than twenty in that group [of students with disabilities] and of that twenty, ten or so are actively asking for accommodation in any given semester, because some of my students are doctoral students and if their only accommodation is time and a half on

exams, after their first two years of their five-year programme, they go off and do research."

Even though the disability services are independent from each other, they are accountable to the Disability Compliance Officer for the whole university. The Disability Compliance Office is situated within the Office of the Assistant to the President. The compliance officer's duty is resolving conflict about disability support, deciding on documentation of student disabilities and ensuring that the university has reasonable accessibility and non-discriminatory practices towards disabled members of the university. That includes both students and staff at Harvard University.

(iii) Non-disclosure

The admission process at Harvard University, like at other universities and colleges in the United States of America, does not require students to disclose their disabilities. Students may disclose their disabilities once they are admitted and perhaps seek support. Some students disclose their disabilities in their application forms even though there is no obligation for them to do so. The Admissions Office that I mentioned earlier has a disability co-ordinator who goes through each application of admitted students, to see if there are any indications of a disability in the students' application entries, or if the student has expressly stated that he or she has a disability. If there are such indications, then the co-ordinator sends the names to the relevant school to notify the other co-ordinators of the possibility of the student asking for accommodation. This system was established in 1997 to "ensure that no disabled student falls through the crack", said the Admissions Office disability co-ordinator during the interview.

When students (disabled and non-disabled) are admitted to the university, they are all sent letters explaining Harvard University's disability services and they are encouraged to apply for support services if they are disabled. An example of such an invitation is an excerpt of a letter from the School of Public Health, which reads, "In addition, I would like to make you aware of support services for students with disabilities. With appropriate documentation, accommodations are available to all Harvard students who have learning, physical or other disabilities. There is a form located in your admitted student packets and on-line at www.hsph.harvard.edu/admins/offstuds/disability.htm".

Harvard University policy is not to keep separate records or statistics of students with disabilities. The disability offices, however, might keep a record of the students that they service. These records are simply for student contacts that are used by the disability office to communicate with the students with disabilities whom they service. Federal law does not require postsecondary institutions to keep separate statistics of students with disabilities. In fact, disability sensibilities discourage universities and colleges to put quotas on the number of students with disabilities they admit. The objective, as noted in Chapter 6 on the legal frameworks, is equal access, equity and non-discrimination.

The baseline in the admission policy is that any disabled person is entitled to pursue a programme of study at Harvard, provided they meet the academic entrance and course requirements. This policy requirement is clearly stated in Section 504 of the Rehabilitation Act of 1973. A reason that underlies this requirement is that all public secondary schools are also required to provide support for disabled pupils and so, by the time their disabled pupils graduate, they should be ready for higher education like any other pupil. Moreover, the values of equal access, non-discrimination and fair advantage underlie such an admission policy.

(iv) Support services

The first requirement for service provision is that students have to submit reasonably recent documentation to prove his or her disability. The documentation needs also to justify the support that the student seeks. If the disability does not justify the support, then the student will not be given the support. One co-ordinator relates, "Often the students come to us with all sorts of problems that are not disabilities. We have gay students coming to us asking for accommodation and because homosexuality is not a disability, we have to turn them down. And there are students who have disabilities but want accommodations that are not necessarily related to that disability and we have to turn down those requests as well."

If students do qualify for support, then they receive any type of service which they have requested. None of the co-ordinators I interviewed recalled any situation in which a qualifying student could not get support because of financial constraints. If a service is not available on campus, then it is sourced from private companies. "Sometimes when it comes to psychiatric issues we outsource some, but mainly everything that's learning disability or ADD [Attention Deficit Disorder] gets outsourced to a professional", said a co-ordinator during the interview. This is vital information, because the situation of funding in South Africa is bleak, as elaborated on in Chapter 9, in which the different implications for our country will be discussed.

Importantly, too, at Harvard University, service provision tends to be highly stratified by disability types. In each school, a co-ordinator may be responsible for administering services for a particular disability, such as learning disabilities and deafness. In cases where co-ordinators do not have enough knowledge about a

specific disability, they consult a private professional. During the interview, one co-ordinator said, "Students with allergies have made a very wide range of requests and for some of them it is been difficult for us to understand how those requests would actually help the students with an allergy. So we are going to outsource that as well."

Stratifying disabilities by types is justified as an administrative advantage and not a labelling process. "Using broad terms is easier than being specific. It is one thing to categorise a student under a field in a student database – oh, the student is mobility impaired, or the student has a repetitive strain disorder. Even though we end up doing that on one level, it is completely the opposite of the way we actually treat students. I think that is important as we look at every student as an individual", said a co-ordinator during the interview. This approach will be further discussed in Chapter 9.

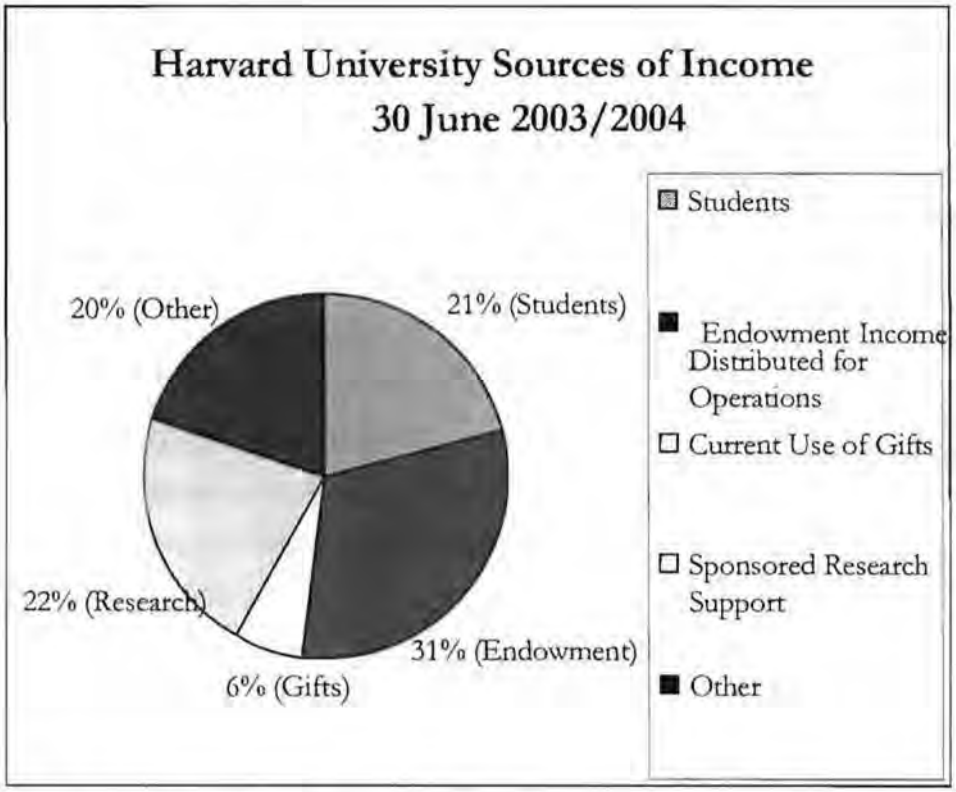
It should also be noted that the disability service office often employs student volunteers, mainly as personal assistants to students with disabilities. Often students with disabilities choose their own assistants. Volunteers perform tasks such as note taking, photocopying and fetching library material. The volunteers are paid an hourly rate by the disability service offices. The payments come from the budget of the employing disability office. Again this highlights the ability of Harvard University to afford the financial provision needed to provide support for specific and individual students with disabilities.

(v) Funding

The issue of the availability of funding is fundamental for the provision of support to students with disabilities. Harvard University is a private, not-for-profit institution of higher learning with 6,650 undergraduates and 12,900

graduate students.[47] Disability service offices are fully paid for by the schools. The schools themselves are partly paid for by the university and partly receive funds from – among others – student fees, endowments, gifts and research support. The following circle graph in Figure 7.3 shows the proportions of Harvard University's sources of income, which according to the annual report totaled net assets of $23,096,256 on 30 June 2004, showing real growth of income of 4.6% since 1993:

Figure 7.3 Harvard University sources of income as of 2003 June 30 financial statement.



(Source: Adapted from the Harvard University Annual Report 2003.)

[47] Harvard University Annual Report (June 30th: for the financial year 2002/2003).

Twenty-two percent (22%) of the income is from sponsored research; twenty-one percent (21%) from student fees; twenty percent (20%) from endowments and six percent (6%) from current use of gifts. Other sources of income such as government funding and interest on investments amount to thirty-one percent (31%).

Compared to higher education institutions in South Africa, as I will mention in Chapter 9, Harvard is a very wealthy institution that can afford most of what some institutions in the United States of America and institutions in developing countries cannot afford. However, being a wealthy university does not mean that support services come at no cost. One co-ordinator explained, "For assistive technology, well for the most part, because we are such a technology-driven academic environment, there's no student who can function here without a computer, so they're expected to have computers. They typically do their exams on computers. So let's say a student who wants to run a Voice Activated Software, so instead of typing, they can speak it, we expect them to purchase that. We do not support their technology. If there's something that we need to do, for an example we have a student who's hearing impaired; the way she hears is that she has something implanted in her hearing aid, which will work if the faculty member teaching wears a particular kind of microphone, which projects his voice right into her ear, so of course, we purchase the piece of equipment for the faculty member to use."

It was thus understandable why all the co-ordinators that I interviewed at Harvard said that they had never turned back a single student because of unavailability of funding. Moreover, in contrast to the South African case discussed in Chapter 9, none of the disability co-ordinators said that they had to raise funds from external sources to pay the disability office. However, they did

indicate that they were not prohibited from sourcing funding outside the university if they deemed it necessary to do so. And as noted above, the schools do raise funds for themselves, and part of each school's budget is allocated to the disability office under that school.

(vi) Networking

Harvard University through the Disability Compliance Officer, disability directors and disability co-ordinators is part of the Association for Higher Education and Disability (AHEAD). AHEAD is the national body that advances and promotes equal access to higher education for students in America. It runs conferences, workshops and meetings to discuss problems and progress regarding disability advocacy, curriculum flexibility, assistive technology and staff development. It is in these forums that the system of support provision for students with disabilities in America is strengthened and developed further. This is its main form of networking and collaboration with other disability co-ordinators in the United States of America.

(c) Disability Support Provision at Boston University[48]

(i) Disability Policy

Similar to Harvard University, Boston University does not have a formal policy on support services for students with disabilities. In its pamphlet, the Boston University Disability Services writes, "Boston University recognizes that students with disabilities can succeed when provided with appropriate support services and accommodations. The Office of Disability Services professional staff is

[48] At Boston University, I had a session interview in which I interviewed the Director, the Clinical Director and the coordinator [why not capital 'C'?] together as a group.

experienced in providing services and accommodations to assist Boston University students in meeting academic and programme requirements and ensure that full access to campus life. College, Schools or program requirements are not waived, and substitutions for required courses are not provided."

In its evaluator sheets and information pamphlets for evaluators of students with disabilities, it further states that "The Office of Disability Services ('Disability Service') provides academic accommodations and services to students with disabilities[49]. Students seeking accommodations must provide appropriate medical documentation of their disability so that Disability Services can: 1) determine the student's eligibility for accommodations: and 2) if the student is eligible, determine appropriate academic accommodations."

(ii) Structure of support services

Boston University's Disability Services are situated within the Office of the Vice President and Dean of Students. The unit is headed by a Director who is also the ADA[50] Compliance Officer. There are also the Clinical Director, the Assistant Director and disability co-ordinators who are primarily in contact with the students and who concentrate on specific disabilities, such as deaf and hard-of-hearing, blindness and learning disabilities, all of which are serviced by a professional.

In terms of job descriptions, the Director explained, "I'm the Director of Disabilities. I have two tasks; the one is to manage the provision of disability accommodation services for students and also [the second] the university's

[49] Different evaluator sheets specify the types of disabilities, such as physical (green sheet), learning and attentional disabilities (yellow sheet) and physical disabilities (green sheet).

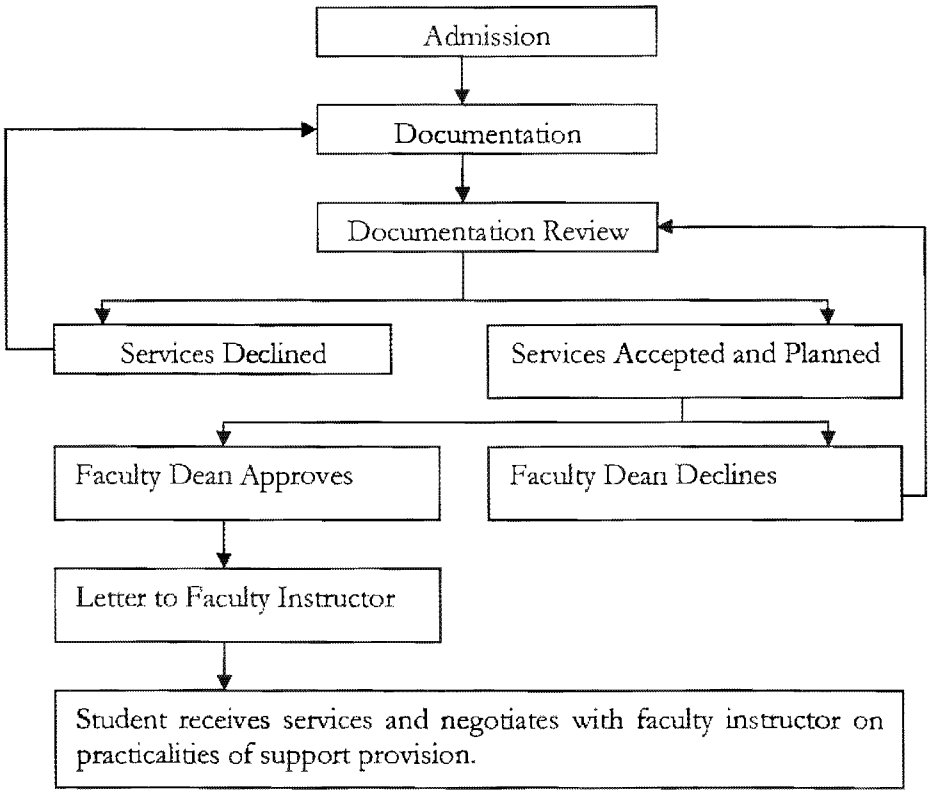
[50] ADA is an acronym for the American with Disabilities Act.

compliance." The Clinical Director similarly explained, "My duties are chiefly with students with learning disabilities, attention disorders and psychiatric disorders. I review the documentation to see if students are eligible for accommodation, what accommodation they can receive and I also run a tutoring service and the summer transition programme for incoming freshmen and that's it." One co-ordinator added, "And I work with the deaf and hard of hearing students and basically, primarily I'm responsible for making sure that they have accommodation in classrooms or any other activities they participate in on campus, which can mean depending on the student, if there's sign language users, then providing Sign Language Interpreters. If they are not sign language users, we have a service called, "Computer Aided Real-time Transcriptions" which is basically wide captioning of lectures.

(iii) Procedures for Services

From the interview and the documents of Boston University, I constructed the following diagram to present the procedures that Boston University uses to provide academic support for student with disabilities. The text below the diagram explains it.

Diagram 7.1: Admission procedures for disability services



Once a student is accepted into a program of study, the faculty notifies him or her of the disability services, and invites him/her to apply for the services needed. For the student to qualify for disability services, he or she needs to submit documentation from a qualified professional. This documentation describes and explains the disability and suggests support services that the student may need.

The Clinical Director of the Disability Service, with the assistance of other staff members in the disability office, reviews the documentation. They can either approve or reject the required support services. The request is only declined if

the documentation is inadequate or if the disability does not justify the service for that academic programme. If the documentation is approved, then support services are planned. The Disability Services can modify the requested support in the interest of curriculum requirements. Although the disability unit decides if the disability and documentation do warrant support, the Faculty Dean also has to approve each support service given to the student. This procedure recollects the point that I made in section IV of Chapter 5, in which I discuss the problem of formal rights in the context of institutional regulations.

The review committee submits its support plans to the Dean of the relevant faculty. The Dean's authorisation is required to make sure that the support service does not contravene the essential curriculum requirements. If the student is enrolled in more than one faculty, then more than one Dean will have to authorise the respective support plans from the Disability Services. If the student changes faculties, then the Dean of the new faculty will still have to approve of the disability support services. The duty of the Deans in this regard is explained by the co-ordinator as follows: "because we're centralised, we can't have an intimate grasp of the requirements of every single degree granting programme on campus. That's what the Deans do, so they can work out whether our accommodations are consistent with what they're doing, so would a student in a physical therapy programme be permitted to have extended time on practical examinations. When she is being trained to make [staff] clinical decisions with the patient and that's the Dean's role to look at the accommodation, given the requirements of the particular programme and to let us know if it is okay or needs to be modified in some way."

Once the Dean has given his approval, then the Disability Services will send a letter to the faculty staff or instructor who will be responsible for the student. The letter explains the requested support services. It is the responsibility of the

student and the faculty member to decide on support services that are best for the student without undermining the essential requirements of the academic programme. Moreover, even once the Dean has approved of the application, the student is still required to complete the "Request for Accommodations Form" each semester.

Boston University, like any other postsecondary institution that is required to comply with Section 504, has to ensure that a disability service is justified by a particular disability in relation to the programme. Central to the service is the fact that the core components of a curriculum cannot be waived because of a disability. This means that if a student with a disability cannot fulfil the core requirements of a course with or without services, then they cannot be allowed to pass the programme. However, this is not always the case. Often there are problems with support services and curriculum requirements. The 1997 lawsuit against Boston University by some students with disabilities is a popular and relevant illustration of this problem. Appendix C provides the Boston University President's response to this lawsuit and its determination, in which he argues against the extremist approach to disability support services.

(iv) Support Services

Before undergraduate students with disabilities begin their studies at Boston University, they are invited to enrol in a programme called Entry. This programme is designed to orientate and provide academic and social foundation skills for students with disabilities. In the Entry pamphlet, the philosophy and purpose of Entry is expressed as follows: "The transition from high school to college is one of the most important periods in a young person's life. For most new college students, it means living away from home for the first time, sharing life with a room mate, deciding which courses to take, developing new relationships, even doing their own laundry! For students with disabilities, the

transition can be even more challenging, as they must also learn to manage their disability, advocate for themselves on campus, and master the skills and strategies [needed] to achieve academic success" (Boston University).

The services of the Boston University Office of Disability Services focus on academic support services, architectural and programmatic accessibility, and technical support and outreach. Academic support services comprise services such as Brailing and note taking. Architectural and programmatic accessibility ensures that the campus and its activities are accessible to students with disabilities and staff. It also ensures the availability of assistive technology. Technical support and outreach provides disability awareness on campus and support for departments that need help on disability services.

Central to providing support for students with disabilities at Boston University is the fact that its disability office avoids being a clearing house for disability issues in general on campus. When I enquired why the student housing unit was responsible for the dormitory or residence accommodation of students with disabilities, the Director responded, "Compliance would be a lot easier around here if all the programmes were responsible, responsive to students with disabilities. So any place where we can avoid being a clearinghouse we do it. You see we're on the academic side... The housing office will make the decisions around how things run, or consult us to recommend what that setting should be and how it would need to be based on the disability."

As in the case of Harvard, some of the support services for students with disabilities are outsourced. For example, the co-ordinator informs, "I had a contract really with myself and one staff interpreter and I need sometimes 25 to 40 interpreters a week. I usually need 6 to 8 transcribers in a week, so I'm contracting all those people from outside."

(v) Funding

The Office of Disability Services is paid for as part of the Office of the Vice President and the Dean of Students, together with other offices, such as the Office of Career Services and the Student Activities Office. It is not specifically a disability service budget from the executive. Boston University is not as wealthy as Harvard University, but it is nonetheless wealthier than many universities around the United States of America and especially in comparison to universities in developing countries like South Africa.

Thus, like Harvard University, it is also not surprising from the interviews that Boston University does not refuse to grant access to students with disabilities on the basis of a lack of funding. However, one of the challenges that the Boston University disability office foresees is that they will need more resources to maintain quality. As the Clinical Director puts it, "I think Laura and I and Dan, the Assistant Director, have a common difficulty which is that when you do what you're doing well and you get a reputation for doing it well, that attracts students and you need to balance having the resources to deal with those students. Well, I'm getting phone calls now from parents of high school students with psychiatric disabilities who have heard that we provide good support services and you know, so I need to make sure that if we're going to be flooded, we have, you know, the resources to handle that, otherwise, you know, what we do for them isn't high enough quality."

(V) Conclusion

This chapter has examined the provision of support for students with disabilities in the United States of America. The first section highlighted the foundation of the formal support system by focusing on the University of Illinois, because it is believed to be the first American university to have provided formal support for students with disabilities. At the University of Illinois the support services for students with disabilities were founded as a result of goodwill instructions by Dr Timothy Nugent, an example of benevolence.

The second section outlined the case of the Rolling Quads within the Living Independent Movement in the 1970's and suggested that this case was a key example of the struggles that were faced by students with disabilities in the United States of America before Section 504 amended the Rehabilitation Act of 1973. We looked at the example of Ed Roberts, who fought against the government and the University of California at Berkeley in trying to secure a higher education qualification for himself as a disabled student and for other students with disabilities. This case illustrated that the major issues were funding and the practical ways of providing support for students with disabilities such as Ed Roberts. The section also highlighted the principles of the Independent Living Movement, which emphasised self-sufficiency and support for people with disabilities where needed, instead of dependence on 'normal' people. In particular, it indicated a shift away from charity and benevolence to independence, based on individual rights.

The third section has considered the challenges faced by both students and postsecondary institutions in providing support for students with disabilities, and

suggested that these challenges were also to be taken as lessons by the South African system of support for students with disabilities. The challenges that faced higher education institutions were centred on three of the four areas of support provision, namely, advocacy, curriculum flexibility, and staff development . Advocacy is used to dispel myths around disability. Curriculum flexibility means being willing to modify the curriculum to help students with disabilities without giving them unfair advantage. The challenge of staff development was to ensure that faculty members understand disability and act appropriately and normally when interacting with students with disabilities.

The fourth section illustrated some of the success and challenges after the effective date of the Rehabilitation Act of 1973. The section has suggested that, even though students with disabilities have managed to enter postsecondary education in increasing numbers, they were less likely than non-disabled students to enter for bachelor's degrees and complete their studies within the usual period. Moreover, it has also indicated the progress that has been made in terms of trying to design ways for curriculum flexibility and staff development.

The final section explored the case studies of Harvard University and Boston University to indicate the actual contemporary forms of support for students with disabilities. It looked at their support services in terms of the following: policy, disability service structure, procedures for support provision, funding, and networking. The data indicated enormous funding plus good and well-organised services that are tailor-made for specific disabilities.

What this chapter has indicated are key points in the support of students with disabilities, which seem to suggest a move away from charity towards rights. However, this shift was not smooth but characterised by struggles for disability rights. Although these rights have been legally secured as is the case of disability

support in higher education, there are often problems with their interpretation and application, as in the case of Boston University as attached in Appendix C.

The data from Boston University and Harvard University will also be used for comparison with South Africa in Chapter 10 and to develop the argument about the tensive intersection of benevolence, rights and the impasse of the social model of disability. The next two chapters (Chapters 8 and 9) will have the same structure as Chapters 6 and 7, except that they will be focusing on South Africa. The framework for providing support in South Africa is described in the next chapter, whereas the actual support is set out in Chapter 9.

CHAPTER 8

FRAMEWORK OF DISABILITY SUPPORT IN SOUTH AFRICA

(I) Introduction

This chapter provides the legal and policy frameworks within which disability rights are protected in South Africa. It also explains the value foundations upon which disability support for students with disabilities is based in the South African higher education system. In Chapter 5, I mentioned that South Africa has been part of the Independent Living Movement and the Disability Rights Movement, and indicated that its higher education disability support was based on what I term a human rights-diversity framework. This chapter expands on the principles underlying the South African framework for protecting disability rights.

As I mentioned in the preface and in Chapters 1, 2, and 5, South Africa does not have a national policy or legislation that specifically provides for students with disabilities. Higher education institutions are currently not directly obliged by national policy or legislation to provide for such students. This chapter thus tries to show how some of the existing anti-discrimination policies can be used to protect students with disabilities. Moreover, as I mentioned at the end of section III (b) of Chapter 2, the policies that I am referring to are written policies and not actual practices, because the process of transformation is still in progress and has not been fully implemented. Thus this chapter will evaluate the logic of policy, as it is written at present.

There are three sections in this chapter. The first section describes the general policies and legislation that protect the rights of disabled South Africans, in order to indicate the underlying principles of such protections. The second section describes official policies that are specific to education and disability, to try to show the principles underlying the education of South Africans with disabilities. The final part evaluates the policies that govern the education of disabled South Africans.

(II) Principles of disability rights protection

The framework for disability rights support in South Africa is underpinned by the belief in human rights values. The Constitution of South Africa "enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom" (The Constitution of the Republic of South Africa, Act No. 108 of 1996: 6). It is the Bill of Rights in the South African Constitution that protects and supports the principles of human rights in South Africa. The principles of the Constitution guide all legislation, regulation and policy.

With respect to disability rights, the *White Paper on an Integrated National Disability Strategy* (1997) highlights the situation of people with disabilities in South Africa and offers some policy guidelines. In its entirety, the White Paper pillars on three principles. The first one, as I have indicated in the above paragraph, is the belief in human rights. The White Paper affirms the rights of disabled South Africans in all spheres of life. Disabled South Africans have the right to enjoy citizenship like all other South Africans. The second principle is the belief in the social model of disability. The White Paper expressly states that reconstructing our society necessitates applying the social model of disability to promote

disability rights and the inclusion of people with disabilities in South Africa. It states, "The Social Model, therefore, implies that the reconstruction and development of our society involves a recognition of and intention to address the developmental needs of disabled people within a framework of inclusive development. Nation building, where all citizens participate in a single economy, can only take place if people with disabilities are included in the process" (Office of the Deputy President, 1997: 11). The final principle is that of participatory reconstruction. The White Paper believes that because people with disabilities have been discriminated against, dominated and excluded from all spheres of life, including their own lives, they should be involved in reconstructing their lives through consultation and participation.

The principles of human rights, the social model of disability and the approach of participatory reconstruction have not been newly introduced by the Constitution and the *White Paper on the Integrated National Disability Strategy* of 1997. These principles have a somewhat longer history. The following declarations and legislation indicate some of the official frameworks before and after the South African Constitution was passed in 1996:

- In 1992, the Disabled People South Africa and the Lawyers for Human Rights launched the Disability Rights Charter of South Africa. The charter has eighteen articles in which there are anti-discrimination and redress demands by and on behalf of people with disabilities. Of relevance is article four which demands, "Disabled people shall have the right to mainstream education with personal assistance where necessary, appropriate assistive technology and specialised teaching. Parents of disabled children shall have the right to participate in the planning and provision of their children's education" (Disabled People South Africa, 1992).

- In 1993, South African endorsed the United Nations Standard Rules on the Equalisation of Opportunities for People with Disabilities.
- Section 6 of Chapter II of The Employment Equity Act of 1998 outlaws discrimination against people with disabilities in employment policies and employment opportunities.
- The Promotion of Equality and Prevention of Unfair Discrimination Act of 2000 expands Section 9 in the constitutional provisions in prohibiting discrimination and guaranteeing equality before the law. This Act expressly prohibits discrimination on the grounds of race, gender or disability. On disability, the Act states, "no person may unfairly discriminate against any person on the ground of disability, including -

  a) denying or removing from any person who has a disability, any supporting or enabling facility necessary for their functioning in society;

  b) contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility;

  c) failing to eliminate obstacles that unfairly limit or restrict persons with disabilities from enjoying equal opportunities or failing to take steps to reasonably accommodate the needs of such persons" (Republic of South Africa, 2000: 7).

The Act also requires state departments to formulate and implement policies that will promote anti-discrimination. Thus these values and principles apply to all official documents governing disability rights in South Africa. Documents pertaining to disability and education are particularly relevant for this study.

(III) Education and Disability

(a) Three Official Documents

Three official documents look at how the education of disabled South Africans can be transformed. The first one is the *White Paper on Integrated National Disability Strategy* by the Office of the Deputy President (1997), which suggests some policy guidelines regarding all levels of education, including higher education. The White Paper believes in equal access, non-discrimination, transformation and redress in the education of disabled South Africans. In the interest of promoting diversity, the White Paper's principles on the education of disabled South Africans are that South Africans should:

1. "have access to the widest possible educational and social opportunities;
2. "receive education and training in as normal an environment as possible;
3. "be provided with the resources needed to realise their highest potential" (Office of the Deputy President, 1997: 39).

The White Paper does not, however, focus primarily on higher education. It merely states, "the implications of the above as they relate to the inclusion of students with disabilities have not been clearly defined or researched. They will receive the attention of NCSNET and NCEESS[51] (formerly TTESS)" (Office of the Deputy President, 1997: 41).

The White Paper underpins its vision with the social model of disability, arguing that disability is a human rights and development issue. It also acknowledges that there is a need for resources to create accessible environments for people

[51] National Commission on Special Needs in Education (NCSNET) and the National Committee for Education Support Services (NCESS).

with disabilities. It concludes, "The Social Model, therefore, implies that the reconstruction and development of our society involves a recognition of and intention to address the developmental needs of people with disabilities within a framework of inclusive development. Nation building, where all citizens participate in a single economy, can only take place if people with disabilities are included in the process" (Office of the Deputy President, 1997: 11).

The second document is the *National Plan for Higher Education* by the Ministry of Education (2001: 41) in which the Ministry of Education outlines guidelines on the transformation of higher education in South Africa. Unfortunately the document writes only thirteen lines on equity and students with disabilities in higher education in South Africa. In these lines it decries the lack of statistics on disability and suggests a development of regional strategies to support students with disabilities. It reveals a lack of data on students with disabilities and the development of a new system that would include students with disabilities. It estimates that there are about 1,000 students with disabilities in South African higher education institutions. It then concludes, "The Ministry recognises that it may not be possible for every institution to provide the full array of infrastructure needed to service the specific educational needs of disabled students. This provides an opportunity for institutions within each region to develop regional strategies, which would ensure that disabled students are catered for within the region. However, at a minimum, all institutions should have the basic infrastructure to allow access to the campus for disabled parents and members of the community more generally" (Ministry of Education, 2001: 41).

The third document is the *Education White Paper 6 on Special Education: Building an Inclusive Education and Training System* released by the Department of Education in July 2001. It primarily covers with the education of disabled pupils at school

level. On page 31, where it briefly mentions the education of students with disabilities in higher education, it repeats and summarises the National Plan for Higher Education. It reads, "The National Plan for Higher Education... commits our higher education institutions to increasing the access of learners with special education needs. The Ministry therefore, expects institutions to indicate in their institutional plans the strategies and steps, with the relevant time frames, they intend taking to increase enrolment of these learners" (Department of Education, 2001: 31). It thereafter mentions that the Ministry would make recommendations on the minimum level of providing support and that facilities would be organised on a regional basis because, "It will not be possible to provide relatively expensive equipment and other resources, particularly for blind and deaf students at all higher education institutions" (Department of Education, 2001: 31).

(IV) Commentary

The three documents that have been described above have three points in common. The first one is the commitment to apply democratic values to education in general. Participation and equal access are the main democratic principles underpinning the transformation and redress of education in South Africa. The second point is the recognition of the rights of disabled South Africans to access education. However, that right is restricted to the availability of appropriate resources for support. The final point is the recognition of the social model of disability to justify the rights and education of disabled South Africans.

The *White Paper on an Integrated National Disability Strategy* takes the social model of disability as one of its points of reference. However, as I have indicated in Chapter 4, the social model of disability is currently at an impasse and we need to move beyond it. The White Paper mentions the implications of the social model

but hardly mentions the complexities that might be involved. Although I understand that policies are typically vague, relying too much on articulating the social model creates the problem of the path of hope or the path of misconception in disability support, as I will argue in detail in Chapter 10.

The *National Plan for Higher Education* says nothing about the social model of disability. However, the model is implied in the document's promotion of equal access and inclusion of student with disabilities. The document does not, though, highlight or recognise the possible complexity of a systematic support provision for students with disabilities in South Africa. The provision of support for students with disabilities in developed countries shows that, unlike accessibility on the grounds of race and gender in higher education, disability requires specialization, flexibility, creativity and student input. Instead, the implied social model of disability in conjunction with equal access and non-discrimination seems to be satisfactory enough to argue and realise the support provision for students with disabilities. The mediation of specialisation, flexibility, creativity and student input are hardly mooted or even implied for institutional policy and strategy.

Surprisingly, the *White Paper on an Integrated National Disability Strategy* makes appropriate recommendations without having considered the issues at all in a complete way. It aptly recommends the development of "inclusive strategies that will:

a) remove all discriminatory practices and barriers in admission policies, examination procedures, decision-making processes, etc.;
b) place at the centre of the transformation debate the need to create an inclusive environment that caters for the diverse needs of all students. This should be done through the development and

implementation of national norms and minimum standards for barrier-free design, access to communication support, appropriate technology, etc., and

c) facilitate representation by students with disabilities as a distinct constituency on all forums an governance structures" (Office of the Deputy President, 1997: 69).

Even though these recommendations are relevant, they are typically presented in a manner that does not problematise providing support for students with disabilities. The problem with the first recommendation is that the removal of barriers in admission policies and examination procedures cannot follow seamlessly and logically from the social model of disability. It requires three considerations. Firstly, it requires overcoming the philosophical and practical challenge of the admission and examination procedures in each faculty and each department of an institution. Of course, such a challenge will be met with defences and counter-defences. Secondly, whatever resolution is reached will have transformative implications in terms of the institutional organisation and resources, which would need to be negotiated further. Finally, it should also take into account the mission statement of the institution and how this can be translated without discriminating against students with disabilities. Conversely, the support itself should consider that it does not negatively affect the ideals and goals of the institution. Such a process is hardly highlighted in the guidelines on the provision of support for the education of disabled South Africans. In summary, the White Paper needs to consider the issues of competing rights and priorities that I discussed in Chapter 5. Moreover, as Chapters 6 and 7 have indicated, even in developed countries where there are long-standing systematic support provisions for students with disabilities, there are still conflicts at the philosophical, legal and agency levels.

The problem with the second recommendation is that it does not hint at the problem of what constitutes national norms and minimum standards for barrier free design of built environments. Across the world, there are problems with this issue. Consequently, these differ among countries and among higher education institutions. In South Africa we have not yet decided what should constitute disability in higher education, much less the minimum standards and the costs of providing support.

In the South African case, the problem of minimum standard and national norms should consider the legacy of economic discrepancies. Such discrepancies have meant that disabled South Africans have not experienced disability in the same way. In other words, what might be a minimum standard for one disabled person might be a secondary need for another? The story of Simazile in Chapter 3 is an example of experiencing disability in a poverty ridden neighbourhood. The norms and standards that the White Paper suggests should not be presented as conflict-free policy guidelines. Rather the recommendations should hint at the need for discussion.

The third recommendation is a necessary one in trying to ensure that the interests of students with disabilities are represented. However, the White Paper does not state what would be the goal of such representation. In my opinion, the representation of students with disabilities' interest should pursue the embodiment of disability in higher education. By this I mean that – as Shevlin et al (2004) suggest – institutional policies should take disability into account as much as they do other factors on their campuses. As will be seen in the next chapter, the disability coordinators at South African technikons and universities carry the burden of being the disability clearing house agents. Everything that has to do with disability is dumped into the disability coordinator's office. Moreover, as will be shown, the coordinator often has to run around campus

trying to explain to academic staff members or housing officers the needs of a disabled student. The idea of the embodiment of disability is to ensure that disability coordinators are not clearing houses but rather support and development units for students with disabilities, as the case of Boston University indicates in Chapter 7.

As I have already mentioned, the *White Paper on an Integrated National Disability Strategy* did not raise any specific issues on disability and higher education before it made the recommendations. Justifiably at the time the *White Paper on an Integrated National Disability Strategy* was written there was no empirical research on higher education and disability in South Africa. The White Paper observes, "the lack of reliable information impacts severely on the planning and development of services and intervention strategies aimed not only at preventing disability, but at creating an enabling environment for the equalization of opportunities" (Office of the Deputy President, 1997: 35). It is, however, a well-known fact that the best policies are researched based. The fundamental flaw of the *White Paper on an Integrated National Disability Strategy* is its lack of data to either support its claims or make its recommendations plausible from its observations. It simply worked within the social model of disability without questioning it. The White Paper does recognise the need for further research, but the *National Plan on Higher Education* does not seem to stress the point. The CHE survey that will be discussed in the next chapter will try to close this gap and motivate for further research.

The *National Plan for higher Education* (2001) suffers from the same problem of a lack of data on disability and higher education. It recognises, "there is very little data available on the access of disabled students and the employment of disabled staff in higher education institutions as this data was not collected previously" (Ministry of Education, 2001: 41). This observation creates the

same problem of formulating a national plan without data on assessing the provision of support for students with disabilities. Hence the document, as noted above, devotes only thirteen lines to disability in a ninety-six pages document. Those thirteen lines appear as a mere repetition of the implications of the social model of disability for the education of people with disabilities. Interestingly, the National Plan for Higher Education gives considerable space and thought on access to higher education on the grounds of race and gender. Invariably, though, disability is not a priority.

The *Education White Paper 6 on Special Education* (2001) says the same as the *National Plan for Higher Education* (2001) says. It does, however, introduce some additional thoughts when it maintains, "it will not be possible to provide relatively expensive equipment and other resources, particularly for blind and deaf students, at all higher education institutions. Such facilities will have to be organised on a regional basis" (Department of Education, 2001: 31). This consideration introduces the issue of cost in supporting students with disabilities, yet a discussion on the complexities is not forthcoming in this document.

I think that cost is a legitimate concern because it means that the South African higher education community will have to decide who will be responsible for funding the support of students with disabilities. It will also have to decide how such costs should be distributed within that community. As I will show in the next chapter, funding remains a fundamental challenge in South Africa, although it should be noted that this was not a central issue for Harvard University and Boston University in Chapter 7.

The failure on the part of both government and higher education institutions is to problematise disability and higher education, especially in relation to costs, is aggravated by the fact that it has thus far been unclear who was responsible for

the process. It is interesting to note that each document relegates higher education and disability from one body to the other. In 1997, the *White Paper on an Integrated National Disability Strategy* listed the features of the special needs framework of the National Commission on Special Needs in Education (NCSNET) and the National Committee for Education Support Services (NCESS), and concluded that the implications thereof will receive the attention of the NCSNET and the NCESS because the issue had not yet been sufficiently researched.

In their discussion document, the NCSNET and the NCESSS recommended:

- "Further education programmes must be designed in such a way that they offer a range of routes to cater for diversity. This is consistent with Curriculum 2005 and [the] NQF[52]. This area requires further investigation.
- Open learning at institutions of higher education should be pursued as an approach with [the] potential to overcome barriers to access to education and training.
- Disability Studies should be considered as a field of teaching and research at undergraduate and postgraduate levels at institutions of higher education" (National Commission on Special Needs in Education and the National Committee for Education Support Services, 1997)

This recommendation is silent on who should be responsible for the three points of, respectively, catering for diversity, overcoming barriers and introducing disability studies. After the report of the NCSNE and NCESS had been incorporated in the Education White Paper 6 on Special Education, the duty of the issue of disability and higher education was relegated to the Ministry who

[52] National Qualifications Framework (NQF).

"expects institutions to indicate in their institutional plans the strategies and steps, with related time frames, they intend taking to increase enrolment of these learners. The Ministry will also make recommendations to higher education institutions regarding minimum levels of provision for learners with special needs. However, all higher education institutions will be required to ensure that there is appropriate physical access for physically disabled learners" (Department of Education, 2001: 31).

- Given the lack of a specific national policy and institutional policies and a lack of data, I echo Howell and Lazarus (2001), when they decry, "With only a vague commitment towards addressing this area of concern, little attempt has been made in the process of policy implementation to address the barriers in the education system, which continue to exclude learners with disabilities from higher education institutions and/or from the process of teaching and learning. Similarly, to date, initiatives to accommodate diversity and the building of equity have failed to specify mechanisms towards addressing the full spectrum of learning needs among the learner population" (Howell and Lazarus, 2000: 1).

(V) Conclusion

In this chapter, I have described the policies and legal frameworks within which disability rights are protected in South Africa. I have also described the democratic values underlying the transformation of education for disabled South Africans. Moreover, I have tried to show the limitations of these policies and legal frameworks. I have emphasised the need to draft a national and institutional policy on promoting access to higher education for students with disabilities.

- This chapter has identified four problems. The first one is the lack of a detailed national policy or legislation about students with disabilities in the country. The second one is the scant treatment of disability and higher education in government policy. The third one is the lack of debate about financial constraints in providing resources. The final one is the uncritical engagement with the social model of disability as an underpinning argument for support given to students with disabilities.
- These four points are problematic in three ways. Firstly, without a national policy, the higher education institutions have no obligation to provide support for students with disabilities. Secondly, the lack of resources undermines the Constitutional right to education for people with disabilities and limits the support of those who are already in higher education. Finally, the failure to engage critically with the social model of disability is very likely to be disastrous because, while other countries are beginning to move beyond this model, South Africa is still embracing the model, despite some of its inherent problems as argued in Chapter 4. Moreover, as it will be demonstrated in Chapters 9 and 10, support structures in South Africa have emerged simultaneously with disability struggles yet based on benevolence; I will argue that these two approaches cannot co-exist.

Part of the problem in South Africa is a lack of data in terms of what institutions of higher education are doing to support students with disabilities. The national survey that was commissioned by the Council on Higher Education (CHE) was intended to fill this gap. The following chapter provides some data on the provision of support for students with disabilities in South Africa. As I noted in Chapter 2 on methodology, part of the data in the next chapter has been extracted from Kathy Jagoe's documents and from the

exploratory survey of some South African universities and technikons, respectively.

CHAPTER 9

SUPPORT OF DISABLED STUDENTS IN SOUTH AFRICA

(I) Introduction

Chapter 8 set out the policy and legal framework within which disability support is provided in South Africa. This chapter has two objectives. The first one is to give a background to the actual situation in South Africa by highlighting the pioneering initiatives to support students with disabilities in the South African higher education system. The second objective is to study the survey conducted by the Council on Higher Education, which I introduced in Chapter 2 on methodology.

The data for this chapter comes from three sources. The first one are documents from Kathy Jagoe who established the Disabled Students Programme at the University of the Witwatersrand and the Disability Unit at the University of Cape Town. These are open and freely available documents in which Jagoe corresponds with sponsors about her ideas, progress and need or acknowledgement of financial assistance in establishing and running the disability support services at these higher education institutions.

The second source of data is the exploratory study that I undertook in the Western Cape and Gauteng regions in 2001. During this exploratory survey, I explored disability support at eight higher education institutions in these regions.

The final source of data is the national survey that Colleen Howell and I undertook for the Department of Education via the Council on Higher Education (CHE). The survey was conducted in 2003 by means of questionnaires that were mailed to all universities and technikons in South Africa. The survey investigated the contemporary support of students with disabilities in South Africa. In this thesis, I have used this data in two ways. Firstly, I extracted some of the data and analysed it in relation to the CHE framework and issues. Secondly, I went back to the questionnaires to produce new tables and figures and to analyse these in my own way.

(II) Disabled Students Programme

(a) The Genesis of Support

This section outlines the establishment of what is believed to be the first formal support system for students with disabilities in South Africa. It thus sketches the educational achievements and work efforts of Kathy Jagoe, first at the University of the Witwatersrand and later at the University of Cape Town. Her work is also an apt and typical illustration of the role played by benevolence in ensuring the support of people with disabilities, as I will argue later.

What appears to be the first formal unit for the support of students with disabilities in the South African higher education system was established in 1986 at the University of the Witwatersrand by Kathy Jagoe. It was called the Disabled Student Programme (DSP), and has now been renamed the Disabled Students Office. Kathy became a quadriplegic at the age of sixteen. She pursued her higher education at Rhodes University where she was granted a Bachelor of Fine Arts in 1978, a Higher Diploma in Education in 1979, a Bachelor of Education in 1981 and an honorary degree in 1991 for her work on disability in South Africa. In

1993, she received an honorary doctorate from the University of Cape Town, "In recognition of her contribution to changing attitudes towards disability in South African society in making UCT, other institutions and organisations disability-friendly environments, and in making disability studies part of the mainstream curricula at UCT" (Monday Paper, 2003).

In 1981, Kathy Jagoe moved to Johannesburg to start an Action/Research project on "The Situation of Disabled People in South Africa" and the project was accepted by the University of the Witwatersrand. In her proposal she explains, "By reason of the initiation of this project in 1981 during the International Year of Disabled Person (I.Y.D.P) and the unusual opportunity for public action and awareness created by I.Y.D.P, this action/research project proposes to focus on the following areas as pertaining to the handicapping effects of disability in the South African situation: public awareness; availability of aids and information; independent living experiences; mainstream education; consumer involvement and feed-back authorities" (Jagoe, 1982: 5).

Her involvement in the project, which was based at the University of the Witwatersrand, focused on several aspects of problems faced by people with disabilities in South Africa. Her focus on mainstreaming education for people with disabilities is of particular interest to my own study. Moreover, she looked specifically at access to higher education for students with disabilities. By mainstreaming education she meant, "Participation of disabled people with able bodied people in every sphere of life such as education". In the case of universities, she believed that people with disabilities should stop studying by correspondence due to inaccessible environments, as this increased their isolation. Being on campus "provides an opportunity for integration and

participation on a level of education rather than physical ability" (Jagoe, 1982: 8)[53].

For six-and-a-half years, while at the University of the Witwatersrand, she taught disability studies, worked with students with disabilities and acted as a consultant with respect to barrier-free design of built evnironments (Jagoe 1987). During this time there was no special unit that catered for the needs of students with disabilities on campus. Instead, Jagoe assisted students with disabilities as part of her action research on the situation of people with disabilities in South Africa through private donations. As part of her awareness programme, she taught disability studies in the disciplines of sociology, medicine, psychology, engineering and architecture at both the University of the Witwatersrand and the University of Cape Town. In fact, she had been also working with the University of Cape Town in teaching and supervising, planning barrier-free designs, advising students with disabilities, and raising awareness on disability. She worked with students with disabilities at the University of Cape Town for three to six weeks at the beginning of each year from 1982 until 1986 (Jagoe, 1987).

In 1986, as noted above, Kathy established the Disabled Students Programme (DSP) at the University of the Witwatersrand. Its purpose was to support disabled student at that university and also to be involved in the advocacy for disability rights.

[53] It should, however, be noted that the term 'mainstreaming education' has now been replaced by 'inclusive education' in South Africa to avoid the connotation of trying to make disabled people 'fit' into the system instead of providing appropriate support for equal access. When Kathy used the term "mainstream education", it was in the 1980's when the Disability Rights Movement had just begun to gain its momentum and terminology had not yet been an issue.

In the following year, 1987, Kathy moved to Cape Town where she established a Disability Unit at the University of Cape Town, which would consist of the following components:

- A Centre for Disability Studies. It was planned that the centre would run across fields such as sociology, medicine, psychology, engineering and architecture, as had been the case at the University of the Witwatersrand. There would also be a Resource Centre in the form of a disability library.
- A Disabled Students Programme. This programme would focus on supporting disabled students and promoting disability rights on campus.
- A consultancy for barrier-free design of inaccessible buildings and environments.

In her fundraising proposal, she estimated a budget of R47,000 per year for the next three years of 1988, 1989 and 1990. Moreover, the University of Cape Town had committed itself to pay her salary from 1991 (Jagoe, 1987: 1). Here it should be noted that while she was working for the University of the Witwatersrand, she had been in discussions with the Vice Chancellor of the University of Cape Town, Stuart Saunders, about the possibilities of establishing the Disability Unit; this support proved important in establishing the Disability Unit at the University of Cape Town.

Her ideas of about providing support to students with disabilities at these two universities were, to some extent, based on American programmes. Kathy had travelled to various American universities, and had adopted certain components of their programmes, one of which was the Disabled Students Programme of the University of California, Berkley. In fact when the Disability Unit at the University of Cape Town was established, the Disabled Students Programme of the University of California, Berkley celebrated its 25th Anniversary (Jagoe, 1987: 1).

As noted in Chapter 7, the American system is based on advocacy, curriculum flexibility, staff development and student life, so it is not surprising, therefore, that the South African system also developed these features, as I will elaborate below. In fact across the world the system of support provision for disabled student is based on those four pillars, which have been drawn from the Independent Living Movement and the Disability Rights Movement, as outlined in Chapter 7.

As noted above, the purpose of this chapter is firstly to outline the background of the establishment of the first separate formal support structure for students with disabilities at a South African university. This does not mean, however, that students with disabilities in South Africa only started to attend higher education institutions in 1996. In contrast, from the documents of Kathy Jagoe it is evident that there were students with disabilities in other higher education institutions in South Africa. For example, in 1965, a Cape Town newspaper reporting on UCT graduation had photo and caption, which read, "TESSA THE GUIDE DOG accompanied her master, Mr Herbert Levin, believed to be the first blind student to obtain a B.A. degree at the University of Cape Town, as he was capped by the Chancellor of the university (Mr. A. van der Sandt Centlivres) at the graduation ceremony today. There was an ovation from the crowd which packed the Jameson Hall when Mr. Levin went up to the stage" (*Cape Argus*, 1965)[54]. Even though there were students with disabilities in some higher education institutions in South Africa, Jagoe does not say how they coped without a separate disability unit or disability services. She did emphasise, though, the absence of formal structures of disability support in institutions of higher learning.

[54] Note how the part of an ovation echoes the story of Simazile and the media representation of disability in Chapter 3 and also Syndrome Seven on staff development in Chapter 7.

Similar to the experience of other countries therefore, the establishment of such disability support systems happened when students with disabilities were already on campuses. Moreover, as seen in the Jagoe case, the establishment of formal structures was undoubtedly influenced by the Independent Living Movement and the Disability Rights Movement. However, unlike other countries, South Africa in the 1990's (following initiatives like Jagoe's) has been trying to formalise these support provisions at a national level within the democratic transformation of the entire higher education system post-1994.

(b) Evaluating the Genesis of Disability Support

The most common questions in trying to understand any phenomenon are: When did it begin? Why did it happen? Who did it? Disappointingly, and yet in a manner of consolidation of science, it has been shown that with new knowledge and new evidence previous answers and assumptions are either modified or discarded. As Westaway quotes William James, "The truth of an idea is not a stagnant property inherent in it. Truth happens to an idea. It becomes true, it is made true by events. Its verity is in fact, an event, a process, the process, namely of its verifying itself" (Westaway, 1929: 50). This cannot be truer than in the social sciences in which the three questions are asked more easily than answered. My point is that the genesis of disability support in South African higher education institutions is not as clear as I have suggested in the previous section.

Some information on the establishment of formal support for students with disabilities was collected from my exploratory survey in the Western Cape and Gauteng provinces as well as from the documents of Kathy Jagoe. Even though I have tried to outline broadly how the Disabled Students Programme and the Disability Unit were created at the University of the Witwatersrand in 1986 and

the University of Cape Town in 1987, I have not been able to ascertain how students with disabilities experienced university teaching before Kathy Jagoe's initiatives. The beginnings that I have described are limited to the benevolent dedication of Kathy Jagoe to the situation of students with disabilities at the two universities. She believed in and advocated for the rights of people with disabilities, as she was disabled too. Moreover, what I have described is limited to what Jagoe has written about her initiatives and its progress and what the disability co-ordinators could answer during the exploratory survey.

With respect to the origins of disability support, in some higher education institutions the reasons and involvement are not the same as Jagoe's. For example, during the exploratory survey at one of the historically disadvantaged universities, the disability co-ordinator explained the beginnings of disability support at this university , "I was administrator of the Student Counselling. And the reason why I got involved is because we are very much involved with first year students and the students generally speaking. And I was involved in the orientation programme – which is a programme to initiate first year students to campus life – and one of the peer facilitators on that programme noticed a blind student on campus and told the student to come to me 'cause he was sure I would try and help him. And that is how I met a student who I can almost say caused this unit to be opened. He was not getting his exams in Braille. He was not getting any assistance at all. So in that first year I negotiated that I would type his papers and things and take them to the X School for the Blind and they would Braille it for me. And that is how it started." At the time of the exploratory study, the disability services in this institution were part of their Student Services and the co-ordinator also said that she wanted to establish a separate disability unit to carry the heavy load of providing disability support.

I also observed that in some institutions the beginnings of such services were unknown because of a time lag since the formal provision, or because of a lack of knowledge about the establishment of disability support programmes, as the previous staff members had left the support programme and new staff members assumed the duties where they had left off. In my exploratory survey, one co-ordinator from a historically white university claimed, "I have been here [at the university] for six years and it was even before that... there were always students with disabilities. So it is a long history." In another historically white technikon, the head of the counselling unit did not answer the question of when disability support had been established by reckoning, "I don't think there was ever any policy against it [support for students with disabilities]. We always had students with disabilities on campus... I don't talk about big numbers. I don't think we ever had more than twenty students."

From my exploratory survey, I found, though, that such services never seemed to be established due to the initiative of the university or technikon's executive, management or structure. They usually appeared to be established by one benevolent member of staff who took it upon herself (it often seemed to be a woman) to help a disabled student on campus. As the case of Kathy Jagoe illustrates, in the process of helping the student, that member of staff appears to have gradually gained the support of the institution by acquiring resources , such as assistive technology, stationery and working space. Similarly, the co-ordinator who identified a blind student on campus related, "End of '96 this unit was officially started... The year before that, I've been doing the work required by students informally, part time, lunch time and so on. So I have not been doing it officially... but because the number of students became so great the need became so great. I could no longer continue with what I was doing and they decided that they need to make this a separate unit on its own so that I devote all my time to it."

So far, therefore, from the exploratory survey and also from Jagoe's documents, I have not come across an institution in which disability support for students had been created on the initiative of the university or technikon's management or structure. However, institutions did tend to support such initiatives once started.

Another observation is that, even thought Jagoe established the Disabled Students Programme at the University of the Witwatersrand and the Disability Unit at the University of Cape Town as separate units, not all institutions followed this route. As Table 9.3 in Chapter 9 will show, out of 20 institutions that provide support for students with disabilities, 11 have a disability unit located within student services structures, whereas 9 have separate disability services units.

As I have also noted in Chapter 2, in the event of more evidence and with future intensive research, these categories of institutions – in terms of supporting students with disabilities – will either substantiate or modify my claims about the genesis of disability support. More research is needed to understand how each institution developed its disability support services. Such research projects will also need to investigate the context within which such support services have developed. Thus the next section outlines the higher education context within which the current disability support services in South Africa function.

(III) Higher Education Institutional Landscape in South Africa as of 2000

Following the Universities Extension Act of 1959, there was a deepening of the already existing racially demarcated higher education landscape. The institutional landscape of apartheid was a philosophy of 'separate but equal' development,

which, "far from extending access to higher education, on the basis of the universal values intrinsic to higher education, restricted access on race and ethnic lines. Its main purpose was two-fold. First to ensure that the historically white institutions served the educational, ideological, political, cultural, social and economic needs of white South Africa. Second, to establish institutions that would produce a pliant and subservient class of educated black people to service the fictional homelands of apartheid's imagination" (Department of Education, 2002: 1).

Higher education institutions belonged to racial and ethnic categories within the apartheid landscape[55]. Table 9.1 list the universities and technikons during the period 1959 to 1980's.

[55] In the 'homelands' the universities and technikons were reserved for a specific ethnic category within the black 'population group'. For example, Forth Hare was for Xhosa speaking people, whereas the University of the North was for Pedi speaking people.

Table 9.1: Historically White and Black University and Technikons Sub-Types to 2000

UNIVERSITIES		
University Type	University Sub-Type	University
HDU (HBU)[56]	African HDU (HBU)	Fort Hare North North West Transkei Venda Zululand
	Non-African HDU (HBU)	Durban-Westville[57] Western Cape[58]
	Special Purpose HDU (HBU)	Medunsa Vista
HAU (HWU)	Afrikaans HAU (HWU)	Free State Port Elizabeth Potchefstroom Pretoria Rand Stellenbosch
	English HAU (HWU)	Cape Town Natal Rhodes Witwatersrand
Unisa[59]		
TECHNIKONS		
Technikon Type	Technikon Sub-Type	Technikon
HDT (HBT)	African HDT (HBT)	Border Eastern Cape Mangosuthu

[56] HDU is an acronym for Historically Disadvantaged Universities. Currently it is also used interchangeably with HBU, which stands for Historically Black Universities.

[57] The University of Durban-Westville was established for the Indian 'population group'.

[58] The University of the Western Cape was established for the 'Coloured 'population group'.

[59] UNISA stands for the University of South Africa. It is a distance-learning university, similar to the Technikon SA, which was a distance learning technikon and has now merged with Unisa.

		Northern Gauteng North West
	Non-African HDT (HBT)	ML Sultan Peninsula
HAT (HWT0	HAT (HWT)	Cape Free State Natal Port Elizabeth Pretoria Vaal Triangle Witwatersrand
Technikon SA		

(Source: Cooper and Subotzky (2001: 2))

Table 9.1 is a snapshot of the higher education landscape of apartheid in South Africa in 2000. There were 36 institutions of higher education: 15 of these institutions were technikons and 21 were universities. Of the 15 technikons, 7 were historically black institutions and 7 were historically white institutions and there was one distance learning technikon. Of the 21 universities, 10 were historically white institutions, 10 were historically black institutions, and again there was one distance learning university.

According to the Department of Education's document titled *Transformation and Restructuring: A New Institutional Landscape for Higher Education* (2002), there will be a decrease in the number of institutions from thirty 36 to 21. Of these 21 institutions, 11 will be universities, 6 will be technikons and 4 will be 'comprehensive' institutions. In addition, there will also be 2 National Institutes for Higher Education to cater for two provinces that have no universities, viz. Mpumalanga and Nothern Cape

These institutional mergers were proposed to redress the inequalities of the apartheid era. The mergers were to begin in 2002 and to continue for a number

of years together with a series of other policy initiatives. They are also intended to end inefficiency and the waste of resources of supporting poorly resourced institutions that still suffer from the legacy of apartheid. Higher education institutions are to be reorganised so that they become relevant to South African society and create a strong base for teaching and research. This is in line with the *White Paper on Education and Training* (Department of Education, 1995) which promoted the transformation of the entire education system in South Africa since the start of democratisation in 1994.

During the research and writing of this thesis, the mergers were already in progress. During the CHE survey, however, which took place in 2003, data had still been collected from institutions within the old apartheid landscape of higher education. Thus the merger did not affect the data that is presented in the following section (section IV). Moreover, section IV (f) raises some issues on the potential impact of mergers on support services for students with disabilities in South Africa.

(IV) The Current Situation of Disability Support Services

Colleen Howell and I undertook a national survey on the provision of support for students with disabilities in South African universities and technikons in 2003. This survey was commissioned by the Council on Higher Education via the national Department of Education. It was conducted under the auspices of the Centre for the Study of Higher Education at the University of the Western Cape at which Howell was a senior researcher. The publication of the findings are in progress and will be released as a discussion document titled, *An Investigation of Equity of Access and Opportunity for Students with Disabilities in South African Higher Education.*

In this section, I do not intend to repeat the findings of this survey, but instead I analyse the data in relation to my key concepts of benevolence, rights and the impasse of the social model of disability. Section II above has argued that the establishment of some disability services in higher education institutions in South Africa has been based on benevolence. Chapters 5 and 8 have argued that there is some legal protection for the rights of students with disabilities to access higher education in South Africa even thought there was no national higher education policy or legislation providing specifically for such students. I termed this framework of protection the diversity-rights framework. Chapter 4 argued that the social model of disability was at an impasse and in need of operationalisation. The seven subsections below will use the CHE survey data to show some of my key concerns with regard to the core argument of my thesis. Sub-sections (a), (b), and (e) focus on the four pillars of disability support identified in Chapter 7, namely: curriculum flexibility, advocacy, staff development, and student life. Sub-sections (c), (d), and (g) focus on data relating to the rights of students with disabilities to access higher education. Sub-section (g) discusses the opportunities and challenges of mergers. These arguments will be made clear in Chapter 10, in which I compare South Africa with the United States of America and finally illustrate my argument of the tensive intersection of benevolence, rights and the impasse of the social model of disability.

The questions and sampling for the CHE survey were discussed in detail in Chapter 2 including data analysis. Thus it will not be repeated in detail in this section. The following summary thus merely outlines the methodology: Mailed questionnaires were sent to all 36 institutions and 24 responded[60]. The questionnaire focused mainly on the four pillars of disability support mentioned

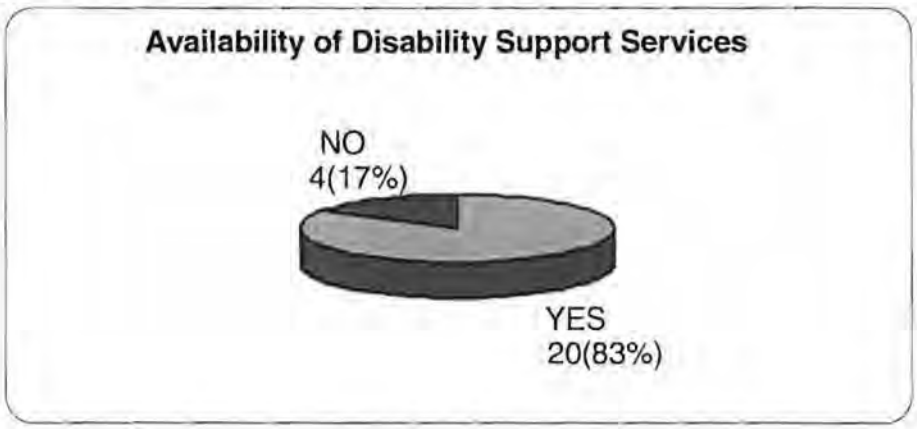
[60] The response rate was 66% (24 out of 36), which according to the rule of thumb from Payne and Payne (2004: 222) was good, because the typical rate for postal surveys is 33%. If, however, the subject is relevant for participants, then the typical rate should be 60%.

above. It contained both structured and unstructured questions. Data analysis was performed using pivot tables in Microsoft Excel. A copy of the questionnaire is in Appendix E.

(a) Availability of support services

Institutions reported a high percentage of support services for students with disabilities. The following pie chart shows the percentage of institutions that said that they provided disability support:

Figure 9.1: Percentage of institutions that provide support services and those that do not provide support services



From the twenty-four institutions surveyed, 20 (83%) said that they provided support for students with disabilities and 4 (17%0 said that they did not provide support services for students with disabilities at all. In other words, around four fifths of the respondents did provide disability support. Further, as shown in Table 9.2, 6 out of 10 HDIs said that they provided support, with all fourteen (14) HAIs (historically advantaged institutions) saying that they did so too.

Table 9.2: Number and percentage of higher education institutions[61] by type which provide support services for students with disabilities and those that do not provide support services

	Availability of services		
	YES	NO	TOTAL
HAI	14(58%)	0 (0%)	14(58%)
HDI	6(25%)	4(17%)	10(42%)
TOTAL	20(83%)	4(17%)	24(100%)

Of the 4 HDIs institutions that said that they did not provide support services for students with disabilities, 3 said that they intended to establish such services in future. One of the institutions wrote "Our Dean of Students is still investigating how other institutions deal with this [disability support provision]." Another wrote, 'Student Services is currently researching what is currently in place at other institutions of higher learning. Workshops are planned for October 2003 to train staff in the legal, physical and learning environment. Academic departments are looking at programmes especially Information, Communications Technology, that lend themselves to and appeal to disabled learners... a policy document is being developed.... future building changes and renovations are being considered to create a safe environment and... more conducive for disabled learners and staff." The third institution planned to "utilise the facilities and human resources already in place at our merger partner institutions".

Looking more closely at these responses it appears that even though a high number of institutions (83% or 20 out of 24) do provide support services for students with disabilities, the range of academic support services is not that high.

[61] Both universities and technikons.

Even the quotes in the above paragraph suggest that those institutions that plan to provide support services in future are only thinking of physically students with disabilities. Moreover, the survey revealed that institutions appear to cater mainly for students who are blind or in wheelchairs. As Figure 9.2 shows, very little is provided for students who are deaf.

Figure 9.2 Number of higher education institutions that provide academic support services for students who are blind, deaf and physically disabled

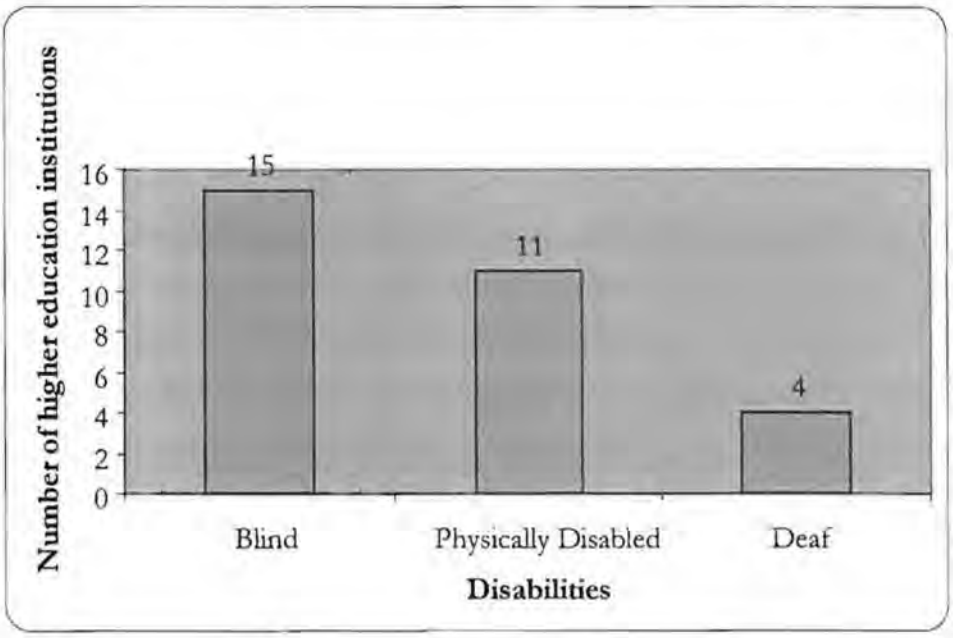


Figure 9.2 shows that 15 out of the 20 higher education institutions provide support for blind students, with 11 assisting physically students with disabilities, and only 4 providing for deaf students. Two higher education institutions that did not provide support for deaf students indicated that they had no deaf students on their campuses. However, his does not necessarily mean that, if they did have deaf students, they would provide such support. Thus, academic support services

for students with disabilities are limited to blind and physically students with disabilities with little provision being made for deaf students.

It is not surprising, however, that South Africa is mainly providing support for blind students and physically students with disabilities at higher education institutions. As noted in Chapter 3, blind people and deaf people in Europe have been received education as early as the first quarter of the nineteenth century. The case of Herbert Levin, which is summarised in the penultimate paragraph of section II (a) of this Chapter, is an apt illustration of the situation in South Africa. Moreover, the first special schools across the world were those for blind pupils and deaf pupils. It is not surprising then that even institutions with limited resources tend to focus on such students. With physically students with disabilities, it is primarily necessary to design campuses and buildings so that they are accessible. Unfortunately, due to prejudice, physically disabled people have often had to attend special schools, in South Africa and across the world. In the South African case it is interesting to note, too, that Kathy Jagoe who herself is physically disabled, established her units to cater primarily for physically disabled people.

Moreover the resources that are needed to support blind students or physically disabled students generally do not appear to cost as much as those need for deaf students or students with other learning disabilities. In addition, most of the students that do receive support seem to be concentrated in the social sciences and humanities, in which most of the study materials are in print rather than in a science laboratory or mathematics classroom. Courses such as physics and mathematics require more than Braille and an interpreter. They also require special assistive technology and a skilled person to teach the student how to use it. This requires more resources and more money, as mentioned in Chapter 7 in the case of teaching chemistry to blind students in the United States of America.

In South Africa, the situation is complicated by the fact that there is a serious lack of funding.

Even though some higher education institutions provide support services and others are planning to provide some, there are institutions that have little or no disability support services. For example, during my exploratory survey in 2001, I discovered that 3 out of 8 institutions had never heard of a disability support service in higher education or seen a disabled student on their campuses. Two of these three institutions were a historically black university and technikon. The other was a historically white technikon. Clearly, then, a lack of support services for students with disabilities is not limited to historically disadvantaged institutions.

(b) Organisational Structure

In Chapter 5, I tried to develop three international frameworks of the support structures for students with disabilities. These frameworks are: the legal mandate framework, the enforceable rights framework and the diversity-rights **framework**, which is characteristic of South Africa. I also differentiated diagrammatically between centralised and decentralised support structures that have either a single co-ordinator or more than one staff member, and made that reference **to** Boston University and Harvard University in Chapter 7. As noted in Chapter 5, there is no standard or universal manner of organising a disability support structure. Nonetheless, two types of support structures emerged from the CHE survey. One is a separate disability unit and the other operates within Student Services, Student Counselling or Student Affairs and all are centralised

The origins of these organisational structures differ with circumstances. The initial establishment of the unit depends on the availability of funding and the

convenience with which support can be provided. The cases of the Disabled Students Programme at the University of the Witwatersrand and the Disability Unit at the University of Cape Town, established by Kathy Jagoe, show that they were influenced by the typical American model, which has a separate disability support unit. In the other eleven cases – as shown in Tables 9.3 and 9.4 – from both the exploratory survey and the national survey, the support structure is conveniently situated within student services, because that is where all students go to for help, and students with disabilities are also catered for within that structure. As one psychologist in a Student Bureau at a historically white institution put it, "I think we find it works well here because it is an integrated thing we work with here. We have a learning centre, we have a career's centre, and we have the disability one and they are all part of the Student Services Bureau. So there's a lot of links between them. We don't at this stage have such huge number of disabled students that we need to have a unit as such."

From the CHE survey, I have noticed, however, that those institutions that have a separate disability support structure are likely to provide more services than those that do not. This positive relationship between disability structure and number of services is indicated in Table 9.3.

Table 9.3 Cross tabulation of number of disability services by separate disability units

		Separate Disability Unit	
		No	Yes
Disability Services	High (≥8)	2 (18.2%)	6 (66.7%)
	Low (<8)	9 (81.8%)	3 (33.3%)
		11 (100%)	9 (100%)

Moreover, based on the estimates of the number of students that they support, those institutions that have higher numbers tend to have separate support structures. This positive relationship between disability structure and number of serviced students is indicated in Table 9.4.

Table 9.4 Cross tabulation of number of serviced students by separate disability unit

		Separate Disability Unit	
		No	**Yes**
Number of Students	**High (≥45)**	2 (18.2%)	8 (88.9%)
	Low (<45)	9 (81.8%)	1 (11.1%)
		11 (100%)	9 (100%)

(c) Funding Constrains

From the onset, as the cases of the Universities of the Witwatersrand and Cape Town show with respect to the Jagoe initiatives, the first disability support structures in South Africa were paid for by private donors, outside the university. It thus does not come as a surprise that the CHE survey results suggest that funding is the most pressing problem for disability support programmes in South Africa. A section of the CHE survey gave institutions three choices for three most important constraints. Each choice listed five constraints from which

institutions had to choose. Table 9.5 shows that the most frequently chosen constraint is insufficient funding in both the first and second choice with 12 and 7 entries respectively. Cumulatively, insufficient funding ranks the most with 20 entries.

Table 9.5 Three most important constraints for disability support provision in South Africa's higher education institutions.

Constraints	1st Choice	2nd Choice	3rd Choice	Cumulative total
No Management Support	0	2	1	3
Resistance From Academics	0	3	5	8
Students Reluctance for Services	2	1	10	13
Insufficient Staff	8	6	3	17
Insufficient Funding	12	7	1	20

The most important constraint after 'insufficient' funding is 'insufficient staff' with 17 entries. This could also be partly attributed to a lack of funding to pay the staff members, which suggests that the real problem is funding.

There also appear to be two types of lack of funding. The first one emerging from the exploratory study data is lack of funding to run and expand the disability support services. For example, one co-ordinator said, "And I am possibly not politically correct, but I am very straightforward about what I think this university can make possible and what I think,this university cannot make possible. One of the things that at this point we cannot make possible is, for example, a blind student to do a physiotherapy degree. That we cannot make possible. What we can make possible is a student with visual impairments to do a physiotherapy degree. We've had three graduates and we have another three currently enrolled for the course.... The reason obviously in physiotherapy is that they will have to do a lot of close work regarding muscular build up, blood vessels... and we don't

have the equipment to make that possible." In this case, the support service is already assisting partially blind students, though in a limited way, and moreover, the possibilities of expanding the same service for blind students are narrow because of the apparent lack of funding.

The second one is lack of funding to actually set up a disability support structure. From the CHE survey, 3 institutions said that they did not have a support programme for students with disabilities because there was not funding to prioritise such services. Evidence from the CHE survey (see Table 9.2) and from my exploratory survey suggests that the historically disadvantaged institutions lack disability support services more frequently than do historically advantaged institutions. Part of the reason is that they either have no money to set up such systems, or that they know nothing about such provision. As noted, 3 out of 8 institutions during my exploratory survey said that they knew nothing about disability support services. In the CHE survey, some institutions said that having a disability support service was not a priority at that time.

A lack of funds or knowledge of support programmes is partly understandable because not only were historically disadvantaged institutions poorly funded in general, but currently in South Africa disability support is a matter of choice on the part of the HEI, with no financial involvement by the state. Historically privileged institutions are thus indeed at an advantage. Even though they are facing budget constraints, they generally have more financial resources to support students with disabilities. Funding constraints are thus at different levels of importance among institutions.

The questionnaire asked the higher education institutions if they used volunteers in providing disability support and if they paid such volunteers. Evidence from the CHE survey suggests, too, that a lack of funding and human resources is

often compensated for by the use of student volunteers. These undertake tasks such as reading notes on tapes for blind students; making photocopies; loaning out reading material in environments inaccessible to students with disabilities; and taking notes. Even though the use of volunteers is helpful in that it augments the appointed staff, it is a further indication of a lack of funding because the CHE survey showed that most of the institutions are hardly able to provide a stipend for volunteers. From the survey it seems that only a third of institutions paid volunteers, and yet about two thirds of the institutions used them.

The overall investigation (comprising the exploratory survey, Jagoe's documents and the CHE survey) suggests that three factors are important to establishing and running a disability support structure in one form or another. The first factor is whether there are students with disabilities on campus already and how many. For example, two institutions that provided support for students with disabilities indicated that they did not have services for deaf students because there were no deaf students registered on campus. Moreover, they suggested that some students did not want to ask for services for fear of the stigma attached to disability. For example, Table 9.3 above suggests that the third most important constraint for disability support is the reluctance of students to seek such services. One institution wrote that there was an "insufficient number of students to warrant it [working with academic staff on curriculum flexibility]".

The second factor seems to be whether there is an individual who is willing to be responsible for such support within the constraints of resources. There is usually no pre-established post for a disability co-ordinator unless a benevolent individual commits him- or herself first. The above section on the genesis of disability support programmes in South Africa cites examples of willing individuals, such as Kathy Jaoge and the staff member who encountered a blind student on campus and decided to help him.

The final factor, I would argue, is the gradual willingness of an institution finally to commit to paying for the support service to sustain it. As indicated above, this factor was particularly evident in the establishment of support services at the University of the Witwatersrand and the University of Cape Town. It was also evident in the case of the staff member who saw a blind student and decided to help students with disabilities on an informal basis until the demand increased and the university decided to establish a formal disability support programme.

Thus the lack of funding is not the only factor affecting the provision of support services. Although funding is fundamental for sustaining and developing these services, it is not the only important factor. As noted, the third important factor is linked to institutional policy, and this is discussed in the next section.

(d) Institutional Policy

The circumstances in which disability support services have been established in the South African higher education system make it understandable, to a certain extent, why institutions have no policies to govern such services. As Table 9.6 shows, eighteen (18) of twenty-four institutions (24), made up of 14 historically advantaged institutions and 5 historical disadvantaged ones saying that they did have such policies in place.

Table 9.6 Existence of policy by higher education institutional type

	Technikon		Universities		
	Policy	No Policy	Policy	No Policy	TOTAL
HAI	5	1	9	0	15
HDI	0	3	4	2	9
TOTAL	5	4	13	2	24

A closer analysis of their 'policies' or 'guidelines' on their websites as well as the hard copies furnished by some institutions during the national survey, reveals that these are predominantly statements of principles in providing support for students with disabilities on their campuses. The principles were equal access, equity, and the right to education and non-discrimination on the basis of disability.

In my view, these are not clear and specific policies, because a clear and specific course of action or alternative methods of action are central components of a policy. A policy tries to give a general background to a situation of interest and of the problems encountered. It also describes different perspectives or ways of thinking about the situation and then expresses its perspective. Thereafter, it proposes a course of action, taking into account alternative ways of tackling the problem. In fact, a typical policy includes both the objectives and the instruments to carry out those objectives. Moreover, even policy *guidelines* should provide some general course of action. Such features were not found in the documents that the institutions from the CHE survey called 'policies'. Although I understand that it is regarded as correct to say, "Our policy is not to discriminate against disabled students", I would argue that it is incorrect to claim that this statement is a policy. Rather, in effect, these are merely statements of principle without a clear and specific policy framework.

Moreover, I am not arguing that there is anything wrong with such principle statements in the documents of these higher education institutions. However, I do contend that they have no real substance, even though such a situation is understandable. It is understandable particularly because the support provisions were initiatives of individuals and not of a university structure. Moreover, the laws and policies of the country, as indicated in Chapter 8, never focused on ensuring access to higher education for students with disabilities. Even in the

midst of transforming higher education in South Africa, the previous chapter showed that there is no substantive national higher education policy on disability that can provide guidelines for higher education institutions to formulate their own policies. Those universities and technikons that do provide for students with disabilities are doing the best they can given their constraints and circumstances – a point I will elaborate on later in this chapter.

In summary, my argument is that a number of institutions have no substantive policies on disability support services. Yet to some extent, it seems that they are trying to do the best they can while operating in a situation where they support themselves in terms of both money and guidelines in providing support services for students with disabilities.

(e) Staff development

The lack of funding is also illustrated by the overburden that is placed on disability co-ordinators to do virtually everything regarding students with disabilities. However, I will later argue in Chapter 10 that this issue results from a combination of a lack of funding, a lack of institutional commitment and also a lack of 'embodying' disability issues on campuses. The lack of institutional commitment stems from the fact that academic staff in South African higher education essentially have a choice of whether they want to 'help' students with disabilities or not. Evidence from the CHE survey revealed the absence of institutional policies that required curriculum flexibility. Like the benevolent staff member who establishes support services, there are also some benevolent academic staff members who agree to 'help' students with disabilities, but they are not compelled to do so by the university. However, academic staff members in South Africa are largely traditionalist in that they believe in the education of the 'normal' body and the 'normal' intellect. For example, during my exploratory

study, one disability co-ordinator said, "It is an ongoing battle. It is a fight between myself and the lecturers to make work available to students. Not all of them are like this. Some lecturers I have to say are extremely very helpful, but I also have to say the fight is mainly for students with visual problems." A head of student services explained, "It is not that the student knows that there is a disability office [and says about support provision]: 'I go there from the beginning where I will be treated in a certain way and am cared for in a certain way until I leave campus'. It very much depends on the willingness and the goodness of the lecturers and whether they are able to accommodate. So the course head indicates whether they want the student or not."

The question of staff development to sensitise staff members about disability issues is an important one. Table 9.7 shows that, according to the CHE survey, 16 of the 24 respondents said that they were working with academic staff members on disability support, with the remaining 8 saying that they did not work with such staff members. One director of the services put it, "We have very close links with the staff development unit where I would present workshops or just do lectures to lecturers on how to cope with students with disabilities in classes. As a lecturer it may be the first time that you are exposed to someone with a disability and you have no idea how to teach someone who is blind, someone who is deaf."

Table 9.7: Working with staff by institutional type

	Working with staff members		
	Yes	No	Total
HAI	11	1	12
HDI	5	7	12
Total	16	8	24

However, staff development does not necessarily require academic staff to participate in the actual provision of support for students with disabilities. An academic staff member has a choice. Yet I would argue that choice and the absence of formal policy requirements effectively undermine the right of students with disabilities to access higher education. This is in contrast to the United States of America where faculty members are under legal obligation to assist students with disabilities, as seen in Chapter 7. The situation in South Africa undermines the rights of a disabled student because such support services are largely based on benevolence and, as I will show in Chapter 10, benevolence and rights are mutually exclusive.

(f) Regionalisation and mergers

As a result of a lack of resources to support students with disabilities in South African higher education, the regionalisation of support services has been mooted. The idea of regionalisation was raised during discussions at the Foundation of Tertiary Institutions of the Northern Metropolis (FOTIM), which I mentioned in both the preface and Chapter 1; this seems to be the only official body that shows some interest in disability and higher education, even though its membership is now limited to 9 public universities. Question 19 of their questionnaire indicates that all their respondents were in favour of regionalisation.

Regionalisation suggests that each region of higher education institutions should have a full service institution that provides for students with disabilities. In this way, resources would be saved and accumulated for the 'full service' higher education institution. Of course the immediate objection is that regionalisation limits the freedom of a disabled person to enrol at the institution of his or her choice. This defeats the whole argument of access and equity to higher education for students with disabilities.

Instead of regionalisation, I would rather encourage institutions of higher education to share resources with each other and with organisations for people with disabilities based on co-operation rather than region. The CHE survey revealed that two-thirds of the 24 higher education institutions collaborated with other institutions by sharing information. Similar to the CALICO library system in the Western Cape, South Africa, which allows students and academic staff to utilise the library resources of other institutions, the disability support services could also learn from such sharing of actual resources instead of sharing information only. Admittedly, a disability support service is often more difficult to share than library resources, because each disabled student has specific needs. However, where there are commonalities, then resources could be shared. For example, higher education institutions within a close distance could pool their resources to hire interpreters that would work on all their campuses according to the classroom times of deaf students in these institutions.

One potential advantage of sharing resources regards the ongoing mergers of universities and technikons. The CHE survey indicated that for some institutions the mergers are a burden because they are inheriting students with disabilities from other institutions without the resources to provide such support. On the other hand, some institutions that have previously not had the resources to provide such support will now gain such resources from the mergers. The potential gains from this situation can only be realised, however, when there is a clear and substantive policy that provides guidelines for a course of action.

Once again it should be stressed that the lack of a national policy and written guidelines on merger procedures put an undue strain on providing support for students with disabilities. A policy would at least give some answers to the issue of regionalisation versus mergers. Moreover, a policy would have to answer the

question of who is disabled and that is still a problem, in part because of a lack of statistics about students with disabilities in the South African higher education system. This general lack of statistics is examined in the next section.

(g) Lack of Statistics

As already mentioned in the previous chapter, the South African government documents dealing with disability and higher education transformation (in particular the *National Plan on Higher Education*) lament the lack of statistics on students with disabilities. This was a warning for the CHE survey that the absence of statistics would be a feature at many institutions, and indeed it was. The old South African Postsecondary Education Statistics (SAPSE) and its recent replacement, the Higher Education Management Information System (HEMIS) do not include disability in their students' enrolment statistics. HEMIS broadly reports data on the Classification of Educational Subject Matter (CESM), level of study, race, and gender. This is contrary to the case in the United State of America and the United Kingdom, whose Council on Education Statistics and Higher Education Statistics Agency, respectively, include disability in students' enrolments statistics. The crux of the matter is that statistics of students with disabilities (as well as of disability support structures) do not form part of the institutional data management system (as was found in the CHE survey). Instead, most disability support structures gave estimates of the students to whom they provide services and not the total number of students with disabilities on their campuses.

My contention is that, because students with disabilities form part of the disadvantaged groups, the transformation of higher education needs an indication of the estimates of students with disabilities participating in higher education. Moreover, it would also need to know the type of disabilities to be able to

understand the nature of the resources that are needed and to question the absence of other disabilities. It is only through such statistics that a proper policy can be formulated to tackle access to higher education for students with disabilities.

The argument about the need for statistics on students with disabilities is linked to the one Cooper and Subotzky (2001) make about race and gender equity and the increasing enrolments of black and women students in the transformation of South African higher education institutions. Based on the SAPSE statistics for 1988-1999 on race and gender, they show that, even though it is evident that black and female students' enrolments are increasing, there is a complex variation when race and gender are plotted together for African, White, Coloured and Indian populations. This complex variation in race-gender statistics leads them to argue, "In considering the new roles, missions and mandates which institutions might play within the new framework and landscape of HE [Higher Education], and key issue of redress of historical inequities, it is therefore important to identify who their immediate constituencies are in terms of the detailed analysis of students' enrolments. A key consideration, therefore, is not only the size of the constituent institutions, but the precise constitution of student enrolments in terms of key variables" (Cooper and Subotzky , 2001: 18).

I am aware that there are some objections to statistics about students with disabilities. A main problem has been that the medical model of disability has reduced people with disabilities to numbers and categories of disabilities. Thus, some proponents of the social model of disability argue that numbers and disability categories further promote stereotypes against people with disabilities. I disagree. I concur with Cooper and Subotzky (2001) that statistics are essential for operationalising policy goals, especially ones that promote greater equity. The primary problem is not the statistic or the type of disability. The issue is how

people respond to a disabled person. We need the statistics to assess the actual impairment and how it relates to the learning experience of a disabled student. We also need to know the actual numbers to be able to estimate the resources that will be needed and to find those people with disabilities who may have fallen through the cracks. In summary, we need to move beyond the social model of disability and to start thinking about ways of facilitating access to higher education for students with disabilities.

(V) Conclusion

In this chapter I have described the perceived genesis of the formal provision of support for students with disabilities in South Africa. I have also highlighted some of the results from the exploratory survey and the CHE survey to illustrate the problems faced by HEIs in this regard.

The findings suggest four factors that drive the provision of support. The first one is the willingness of a benevolent individual to kick-start the process. The second factor is the availability of students and their willingness to disclose their disabilities. The third is the willingness of the institution to support the programme financially. The final factor is the availability of funding to sustain and develop the project. Its sustainability depends primarily on funding, and yet institutions have indicated that their primary constraint was insufficient funding, followed by insufficient staff, which to some extent also translates into a lack of funding.

Even with limited resources, most of the institutions in the survey indicated that they were nonetheless providing support for students with disabilities. Most of these institutions were historically advantaged ones. Moreover, those institutions that had separate disability units tended to have more support services than those

that operated within student affairs departments. However, closer scrutiny of the types of support services offered by higher education institutions reveals that the support services catered predominantly for blind students and physically students with disabilities. There were few institutions that provided support for deaf students.

It is not only funding that appeared to be a fundamental problem, but also the lack of a policy framework. In fact, there is no policy framework guiding higher education institutions in their support services for students with disabilities. There is also no national policy framework for institutional mergers, which also poses a potential challenge for merging institutions. Higher education institutions do need real policies to guide academic staff members on how to run support programmes for students with disabilities. Exacerbating the problem is the lack of statistics on students with disabilities, which are essential for the formulation of coherent policies.

Another problem faced by disability services in the South African higher education system is the role of academic staff. Staff development is an integral part of this because, ultimately, it is the academic staff that needs to co-operate with disability service structures for the benefit of students with disabilities. However, in South Africa, academic staff members are not legally obliged to carry on this duty. They can choose to 'help' or not, which, it is my contention, limits the rights of students with disabilities to access higher education.

Returning to the central argument of the thesis, this chapter has indicated the role played by benevolence in the establishment of some disability services for students with disabilities in South Africa, even though students with disabilities have the constitutional right to access higher education (as indicated in Chapter 8). It has also shown that some of the problems, such as limited services, lack of

funding and regionalisation of resources, limit the rights of students with disabilities to access higher education. Moreover, the lack of policy direction partly hinders these institutions of higher education to move beyond the social model of disability. As I will argue in Chapter 10, such problems situate South Africa's disability support system at a tensive intersection of benevolence, rights and the impasse of the social model of disability.

Part I of the thesis has given some background to the thesis, the research methods and their philosophical assumptions. Part II analysed the concepts of benevolence, rights and the social model of disability, arguing that the social model of disability was at an impasse. Part III described the provision of disability support in the United States of America and South Africa. It examined key historical cases and statistics to indicate the level of support for students with disabilities in terms of legislation, policy, disability and support structures. Part IV, which follows in the next chapter, demonstrates what is meant by the intersection of benevolence rights and the impasse of the social model of disability. It does so by listing the similarities and differences between the American and South African experiences of disability support and argues that the American path is different to the South African one, and that South Africa has arrived at the tensive intersection of benevolence, rights and the impasse of the social model of disability.

PART IV

Benevolence, Rights & the Social Model of Disability

CHAPTER 10

THE TENSIVE INTERSECTION OF BENEVOLENCE, RIGHTS AND THE IMPASSE OF THE SOCIAL MODEL OF DISABILITY

(I) Introduction

Part III explored the background and status of disability and higher education in the United States of America and South Africa. As a section of Part IV, this chapter draws together the findings of Chapters 6, 7, 8 and 9 to compare and contrast the situation in the United States of America with that existing in South Africa. There will be two modes of comparison. The first one is with respect to the three sub-units of analysis that were mentioned in section IV (a) of Chapter 2 on methodology. These are: the national legislation or policy that provides for the support of students with disabilities; the institutional policy that guides support for students with disabilities on campus; the higher education structures of support services. The second mode of comparison will look at the concepts of benevolence, rights and the social model of disability.

This chapter thus consists of two sections. The first compares and contrasts the situations of students with disabilities in the United States of America and South Africa. The second section investigates the tensive intersection of benevolence, rights and the impasse of the social model of disability.

(II) A Comparison of the United States of America and South Africa regarding Higher Education and Disability

The American system of support for students with disability is based on legal entitlement, in terms of which federally funded institutions of higher education are legally obliged to provide disability support services in accordance with the Rehabilitation Act of 1973. In addition, the Americans with Disabilities Act of 1990 outlaws discrimination on the basis of disability. The right to such disability support services are, however, subject to the conditions mentioned in Chapters 5 and 6. In contrast, the South African system of providing support for students with disabilities is not regulated by legislation. It was only after 1994 that the higher education policy documents began to mention non-discrimination on the ground of disability. Not all institutions have policy guidelines, though, and there is no legal requirement of such policies yet. However, as mentioned in Chapter 8, the Constitution and the White Paper on an Integrated National Disability Strategy do at least provide for non-discrimination on the basis of disability.

Both the American and South African higher education disability structures operate within the same frameworks in terms of functioning and their focus on advocacy, curriculum flexibility, staff development and student life. The development of disability support services in South Africa has been influenced by the American model, as indicated in section II (a) of Chapter 9 with respect to the Kathy Jagoe initiative. Moreover, as in the United State of America, South Africa also has different types of support structures. Some are centralised, whereas others are separated. However, South Africa does not have decentralised systems as those exemplified by Harvard University. The main difference is the availability of resources, which affects the level of support. South Africa cannot afford to buy resources to match developed countries such as the United States of America. Resource constraint is thus a major problem, as stated in the higher

education policies (Chapter 8, Section II (a)), and as inferred from both the exploratory study and the CHE survey data (Chapter 9, Section II (c)). Moreover, the absence of national or institutional policies on higher education and disability mean that academic staff members are not committed to participating in supporting students with disabilities

As noted in Chapters 3, 7 and 9, both South Africa and the United States of America have been significantly influenced by the social model of disability. However, America is characterised by pragmatism rather than sociological debates around disability. Moreover, the United States of America has had the time and money to establish disability support entitlement. The central issue in the United States of America is not the social model of disability but rather the evaluation of support services and research into assistive technology and universal design. In contrast, South Africa has only been introduced to the social model of disability in the late 1980's, and this has been popularised in the 1990's within the discourse of transformation and human rights. In effect, however, both the social model of disability and disability rights have been espoused uncritically, particularly on the question of operationalising the social model of disability, as has happened in countries such as America and Britain.

The problematic nature of rights is common across the world, as I have indicated in section IV of Chapter 5. The problem is that there is a tension within the discourse of Human Rights. One of the problems is that there is a difference between rights and real rights, i.e. a difference between formal rights and the effectiveness of those rights. In the case of the United States of America, rights have replaced benevolence and have been partly restricted to the legal question and institutional interpretation. In the case of South Africa, in contrast, rights are restricted significantly by the availability of resources. Without such resources, these rights are useless, or at the very least ineffective.

(III) The Tensive Intersection of Benevolence, Rights and the Impasse of the Social Model of Disability

People with disabilities across the world have argued against charity and benevolence. In his critique of disability charity organisations, Drake (1999) observes that, like other social structures, charity organisations are characterised by power relationships in which people with disabilities are subjugated and not in control of the organisation that takes 'care' of them. The argument of disability rights movements has been that they demanded the right to self-determination with due assistance and a barrier-free society. The Disability Rights Movement and the Independent Living Movement were engaged in activism to entrench the rights of people with disabilities in their respective societies. The two movements, though practically inseparable, struggled to ensure the independence of people with disabilities and to protect their rights. It was a fight against benevolence, prejudice and inaccessible environments. It was a struggle for equal rights.

It is at this point that rights intersect with benevolence in a tensive manner. People with disabilities correctly argued for disability rights. They demanded equal access to education and other spheres of life. In higher education, a key example is the 1988 protest by students at Gallaudet University in Washington, D.C, United States (Shapiro, 1993). They demanded that the president of the university be a deaf person because the university was mainly for deaf students. This was part of the wave of protest of the post World War II Disability Rights Movement. The students correctly argued that to have a hearing university president was paternalistic, and that it created an impression that people with disabilities were incapable of taking control of their lives. This was the perfect example of the tensive intersection of benevolence and rights. Rights thus had to replace benevolence and erase the legacy of philanthropy.

Developing countries like South Africa later joined the struggle against disability oppression. In the case of South Africa, as I have already shown in the previous chapter, one of the formal support provisions for students with disabilities had been established by a disabled person who was also involved in the Disability Rights Movements. It was Kathy Jagoe's belief in disability rights that led her to want to provide support services for students with disabilities in higher education institutions. It was also her involvement in the Disabled People International organisation that led her to see what other countries were doing for their students with disabilities. Thus the struggle in the late 1980's by an emergent Disability Movement in South Africa in relation to the provision of support for students with disabilities began at a time when there was a tensive intersection between benevolence and rights for people with disabilities. Unlike the United States of America, benevolence was not replaced by rights, but rather they simultaneously constituted the support provision for students with disabilities.

However, the tensive intersection of benevolence and disability rights was not felt in South Africa at the time, because students with disabilities were not a priority for policy questions in the 1980's. While the struggle for disability rights and higher education was being waged in developed countries like the United States of America, movements in South Africa were predominantly struggling with equal access to higher education on the basis of race and later gender. So, during the time when American students with disabilities were demanding their rights to access higher education, South African students with disabilities were largely invisible and only black students were visible in the fight against apartheid education and its racially-mapped higher education landscape.

That South Africa did not feel a strong tension of the intersection of benevolence and rights has resulted in the establishment of its disability support services being

propelled primarily by benevolent individuals. As I have already suggested in the previous chapter, the establishment of support services for students with disabilities required a willing and committed individual to volunteer his or her time and resources to kick-start the process, which would later be supported by the institution. Even though Kathy Jagoe started the process in the context of international disability rights, she initially had to rely on benevolent private funding. Following her efforts, other forms of disability support services for students with disabilities were implemented, though not based on equal access and rights for students with disabilities. They were often purely an act of benevolence to help struggling students with disabilities. Although those individuals may have meant well, the same benevolence that we find in special education and in the lives of the disabled in general resurfaces. Moreover, because of a lack of national and institutional policy, only benevolent academic staff members try to 'help' students with disabilities. Thus the support services were characterised by conflicting practices of both benevolence and emancipation or empowerment of people with disabilities in general and students with disabilities in particular.

The potential problem that lay dormant was that, although developed countries could resist benevolence in favour of equal rights for people with disabilities, South Africa did not have that chance. Disabled South Africans thus experienced paternalistic benevolence as did any other disabled person in other parts of the world, as Chapter 3 indicated with regard to the relationship between disability and society. They nonetheless did have an opportunity to argue for equal rights during the 1980's and, as noted in Chapter 5, established Disabled People South Africa and produced the Disability Rights Charter of South African in 1992. However, they did not have the opportunity to argue for equal rights in higher education because the discourse of equal access to education at that time was limited to racially-based and, to a lesser extent, gender-based access. Thus, when

disability support services for disabled student in South Africa were established, they had not yet resolved the tension between benevolence and rights as developed countries had done to some extent. The South African support system for students with disabilities constitutes in itself the very seeds of the struggle of people with disabilities.

I have just mentioned that the tensive intersection between benevolence and rights in South Africa was not felt and was a potential problem lying dormant. This issue only began to surface as the process of transformation of our society gained momentum in the late 1980's. The transformation of the South African education system opened a space for the discourse of access to higher education for students with disabilities in South African. Unfortunately that space is empty, as I have demonstrated with respect to the three official documents governing access to higher education for students with disabilities. Moreover, I have yet to find a sociological study of higher education and disability in South Africa. The theoretical discourse on higher education and disability is also often empty in other parts of the world, including developed countries. The only discourse was that of rights for people with disabilities in general. Activism and policy formulation mattered, instead of an in-depth sociological engagement beyond the social model of disability, as argued in Chapter 4 on the impasse of the social model of disability.

Chapter 3, which is about the understanding of disability and society , discusses some of the problems facing the provision of disability support in South Africa. The chapter demonstrated shifts in the disability discourse from the religious, cultural, and medical model to the social model of disability. These shifts indicate the tension between understanding disability as an ideological entity, as the social model argues, and as a statistical entity, as the medical model of disability exemplifies. Although disability rights movement in South Africa understood the

ideological and political nature of disability, the dominant discourse was that of the medical model. It is therefore not surprising that the establishment of disability services is still based on benevolence and that there is no coherent framework or policy of disability support for students with disabilities ten years after the first democratic elections in South Africa. What Chapter 3 indicates for the present situation in South Africa is that the struggles for disability rights continue to highlight the need for the protection of disability rights. Moreover, while we cannot ignore disability as a statistical entity for the purpose of redress, the ideological entity continues to be the foundation for tackling the problem. Thus, the lack of balancing and interrogating both entities is partly responsible for some of the problems of disability support in the South African higher education system.

Thus, if the discourse on higher education and disability is relatively empty even in the developed world, how is it that the United States of America was able to overcome benevolence with regard to people with disabilities's rights? The answer lies partly in pragmatism, availability of money, and time for trial and error. I would argue, as I have suggested for the United States of America in Chapter 7, that the struggle for access to higher education for students with disabilities focused on practical ways to support students with disabilities in higher education. Its aim was not to advance any theory but to find practical solutions as early as the 1960's – which the copy of the pamphlet in Appendix A indicates. Moreover, the amendment of the Rehabilitation Act of 1973 to entitle students with disabilities to receive support services implies that resources were available to fulfil their rights. These practical strategies have, furthermore, been modified over time. The United States spent money on these issues over a longer period than South African has done thus far. In fact, while we were conducting the CHE survey in 2003, the United States was celebrating its 30th anniversary of officially providing support for its students with disabilities. And as noted earlier

in Chapter 7, the University of Illinois at Urbana-Champaign, which is said to be the first university in the United States to provide support for students with disabilities, has been doing so for 57 years as at 2005.

The pragmatism with which developed countries have confronted the challenge of disability in higher education is what is lacking in the transformation of higher education in South Africa. I believe that the reason why the tension between benevolence and rights began to surface in the mid-1990's is the lack of pragmatism and the uncritical reliance on the social model of disability. The social model of disability is the third factor, which intersects with both benevolence and rights in the South Africa.

The social model of disability is not a South African construction. It was transplanted from the United Kingdom to other parts of the world, including the United States of America and South Africa. Its relevance to disabled South Africans is unquestionable. I concur with Albert's (2004) argument that, although there are problems with applying models from developed countries to developing countries, there might be similarities too, where lessons could be learned. Besides, South Africa is aspiring to create a world class African higher education system. The problem is that, when the social model was introduced to South Africa, it happened in isolation, rather than as part of the quest for freedom and equal rights.

Unfortunately, the social model of disability in South Africa has not been discussed but taken as a conclusive argument. As a result, official documents on disability prelude their texts by mentioning the social model, as if that implies an obvious transformation from the social model to real rights. A central problem with this is that rights without money are meaningless. Real rights need resources to be secured. South Africa recognises the right of people with disabilities to

access higher education, but how this can be made a reality is not seriously debated and assessed.

The problem becomes clear when the social model interacts with benevolence and rights for people with disabilities to access higher education. The establishment of support services in South Africa constituted both benevolence and rights which was not supposed to happen because the struggle for disability rights were a struggle against benevolence. Yet South Africa inadvertently constituted its support services with the very seeds of the tension. For some time this was not a problem because disability was not an issue in higher education. It was only during the transformation of higher education that the tension surfaced, when the social model of disability became part of the promotion of disability support services in higher education. The social model demands rights: that students with disabilities have right to support services. Yet in the South African case, for those rights to be real and emulate those of developed countries, there is a dire need for resources, academic staff development, academic staff commitment, assistive technology and curriculum flexibility. Most importantly South Africa needs to recognise the impasse of the social model of disability as argued in Chapter 4 and to move away from uncritical reliance on the model to practical debates about the model and its implications for developing effective methods of supporting students with disabilities.

The following two diagrams show the tensive intersection of benevolence, rights and the impasse of the social model of disability. The first diagram illustrates the path followed by developed countries to resolve this issue , whereas the second one illustrates the present position in South Africa.

Diagram 10.1: The Path of Developed Countries

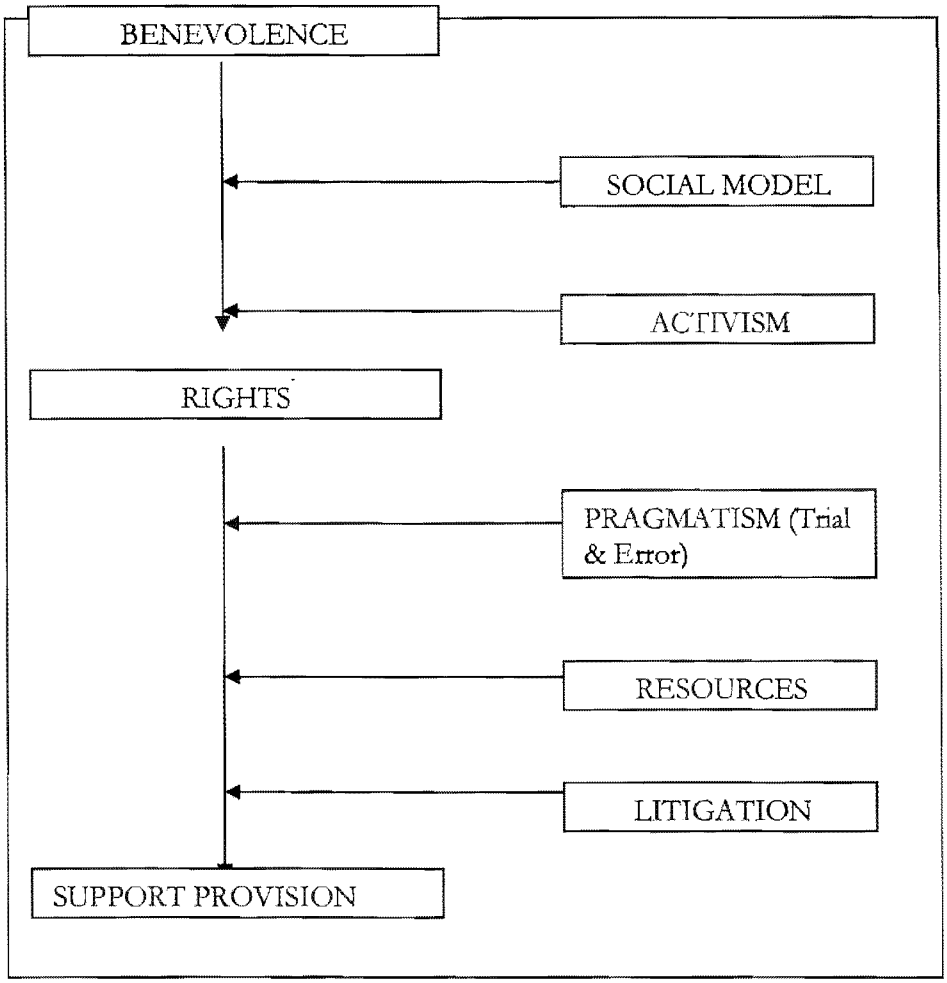
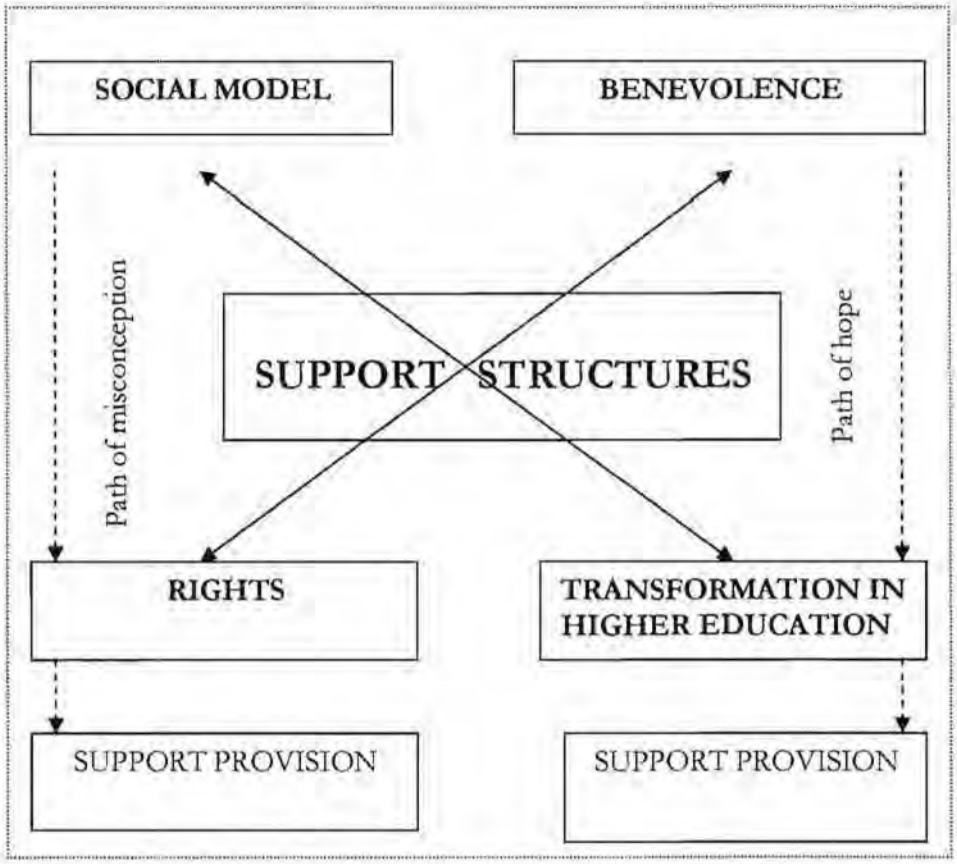


Diagram 10.1 outlines the general picture for developed countries in approaching disability in relation to higher education. The left side of the figure shows a movement away from benevolence towards equal rights for people with disabilities, which lead to the official recognition that students with disabilities in higher education institution need support structures. As I have indicated, however, this movement is not as linear and neat as it appears in the diagram. The right side of the diagram thus indicates the intervening factors that have shaped the creation of such support structures. Benevolence was resisted intellectually, especially by the arguments of the social model of

disability as indicated in Chapters 3 and 4. This intellectual struggle influenced activists who demanded rights for people with disabilities and greater independence, as indicated in Chapters 3 and 7. These rights became real rights once support structures for students with disabilities were put in place. This in turn was possible in part because of the availability of resources, the pragmatism of the approach and the fact that higher education institutions sought to avoid litigation in cases of discrimination against students with disabilities. However, the problematic nature of rights remains the same as in South Africa, as Diagram 10.2 will show.

Diagram 10.2: The South African intersection of benevolence, rights and the social model of disability



My analysis of the South African situation is depicted in Diagram 10.2. The left half of the diagram indicates the misconception that the social model of disability is used by its proponents to justify the rights of students with disabilities and that this would automatically lead to the provision of support services for students with disabilities. This was the impression conveyed by the surveys and the official documents that govern disability in the context of higher education in South Africa (see Chapter 8). The dashed arrow points downwards from social model to rights, and from rights another dashed arrow leads to disability support provision. As I have already argued, such a linear progression cannot happen without resources, discussions, compromises and policies. This is thus a path of misconception.

The right half of Diagram 10.2 indicates the path of hope, that through continued benevolence and the transformation of higher education in South Africa, the creation of support services for students with disabilities will continue and that others will be established. This is impression is also conveyed by the official documents on disability and higher education, by the current practice of support provision and by the suggestion that such support services should be regionalised. Transformation has, of course, become a powerful discourse in South Africa, so much so that if a document says that we need to transform our higher education system to ensure equal access for students with disabilities, then that is enough to convince the reader that transformation is happening and that it is a good idea. Such statements simply provide hope that someone (in this case perhaps a benevolent individual?) would do the actual work of ensuring equal access for students with disabilities. However, the reliance on the discourse of transformation does not give us answers to the course of action that would drive such transformation. It does not tell us who

would be responsible for that transformation at the level of government and higher education institutions. As I have already stated in the previous chapter, the responsibility for confronting disability in the context of higher education has changed from one document to the other, and yet this entire set of documents has three things in common, namely, higher education transformation, equal access and the unexpressed hope that some benevolent individual or the state would take responsibility for that transformation. The flaw with this idea is that hope only sustains actual action and not inaction . However, I think that transforming higher education means transforming the position and ways of disability support in higher education, to give real meaning to disability rights and equal access.

The centre of the diagram with the intersecting double-ended arrows shows the tensive intersection of benevolence, rights and impasse of the social model of disability, as the actual situation that faces support structures for disabled student in South Africa and one that I think no one is aware of or articulating. At the centre of the diagram is the actual support structure, whether in the form of a separate disability unit or a general student services office. The double-ended arrows intersect at the support structures to indicate the position in which the support structures find themselves. The double-ended arrows indicate the tension of pulling in opposite directions with the support structures. The fours corners, labelled social model, benevolence, rights and transformation respectively, are the factors in tension.

Let me explain further the double-ended (forward-slashing) arrow connecting 'benevolence' and 'rights'. I have argued that, in developed countries, disability rights activism was a struggle against benevolence for the equal rights of people with disabilities in general and students with disabilities in particular. The problem with South Africa, as I have outlined is that benevolence and disability

rights do constitute the establishment of support provision structures for higher education students with disabilities. Yet such a constitution is contradictory for two reasons. Firstly, students with disabilities cannot rely on benevolence if their rights are to be real. To assert their rights, they must be given support that is not based on benevolence but on real rights, equal access and merit. Secondly, I the benevolence of special education was based significantly on pity and exclusion and did not encourage people with disabilities to reach a higher level of education in which elitism, meritocracy and competition were the privilege of the 'normal' body and the 'normal' mind. If our support structures for students with disabilities move in the direction of benevolence, then it defeats the whole argument of equal rights and citizenship for students with disabilities. Then again, if they move in the direction of rights, then it needs human, social and physical resources that would be specifically employed for such services and not benevolent individuals who volunteer their time and services. Moreover, it would also need to engage in the problematic nature of Human Rights discourse. Such a move requires time, resources, polices, debates and compromises, which South Africa currently seems to lack.

The issue of debates and compromises is related to the double-ended (back-slashing) arrow that connects the 'social model' and 'transformation in higher education'. The social model of disability, as interpreted by its uncritical proponents, demands that students with disabilities should be provided with support services in a *laissez-faire* fashion. However, transformation, by definition requires negotiations, debates, compromises and policies, which the social model of disability is unable to operationalise automatically, as I have argued in Chapter 4. If the South African support structures for students with disabilities move in the direction of the social model, then it means amassing huge and significant resources, which we obviously do not have and which have not yet been discussed in national debates, nor have academic staff members been

conscientised. If we move in the direction of the transformation of higher education, then we risk putting disability issues at the bottom of the list in the transformation of higher education. Access to higher education has to date only prioritised race and gender and totally ignored disability as an issue, even though it cuts across race and gender.

(IV) Conclusion

In conclusion, then, the South African system of providing support for students with disabilities seems to be moving either along the path of misconception or the path of hope. Both of these are problematic. The path of misconceptions wrongly assumes that the social model of disability is a sufficient justification of rights and that it represents an entitlement to support services. The path of misconception wrongly assumes that, through benevolence and transformation, additional disability support services will be established and the existing ones will be sustained. What is wrong with this kind of thinking is that it ignores the tensions that characterises the Human Rights discourse and the social model of disability and the fact that benevolence and advocacy for rights cannot co-exist.

The position in developed countries like the United States of America is different. America's advocacy for disability rights has significantly erased benevolence by obligating state funded institutions to provide support for students with disabilities in higher education. This was not the result of a linear or smooth process, though. The tensions that characterise disability support in countries such as the United States of America relate to the limits that are put on the student's right to receive disability support services. Moreover, as I have mentioned in section (V) of Chapter 6, the separation of the Church and State in the United States of America has excluded students in religious higher education

institutions from benefiting from the rights as contained in the Rehabilitation Act of 1973.

The social model of disability has been operationalised in the United States as argued by Albrecht (2002) by being based on pragmatic intellectual traditions. For developing countries like South Africa, it is imperative that they are critical of the social model of disability by learning from developed countries and by considering the local realities of their respective countries. Moreover, disability support services must be prioritised in higher education institutions by means of greater collaboration between academic staff, government and disability organisations.

CHAPTER 11

CONCLUSION, RECOMMENDATIONS, LIMITATIONS AND FURTHER RESEARCH

(I) Conclusion

As mentioned in the preface and in section (I) of Chapter 1, given the lack of sociological studies on disability and higher education in South Africa, the aim of this thesis has been to analytically locate the position of the South African system of support services for students with disabilities in terms of benevolence, rights and the impasse of the social model of disability. To the best of my knowledge, this study and its approach is the first of its kind; it thus seeks to unearth new knowledge in the fields of disability studies and higher education studies in South Africa.

The sub-units of analysis were national legislations and policies, the policies of higher education institutions, and support structures. The main point of the thesis is that the South African system of disability support in higher education is inadvertently located at the tensive intersection of benevolence, rights and the impasse of the social model of disability.

The analysis used data from the exploratory study, the CHE survey, interviews at Boston University and Harvard University, primary documents and secondary documents, as explained in Chapter 2 on methodology. The comparison between the United States of America and South Africa has highlighted some key observations: the American system is based on legal entitlement or positive rights, whereas the South African system has no such

provision, not even in policy form, to provide support for students with disabilities; the South African model of support provision is nonetheless influenced by the American model, and like other international higher education institutions, it focuses on advocacy, curriculum flexibility, student life and staff development.

A major difference between the two countries is that South Africa cannot match the resources of developed countries, and the issue of resources is thus a real concern. Moreover, South Africa has less academic staff conscientisation on disability issues, as academic staff members are not obliged to take part in support services for students with disabilities. There is also limited networking on disability issues in higher education, as indicated by the Foundation of Tertiary Institutions of the Northern Metropolis (FOTIM) in Appendix D.

The concept of benevolence means that people with disabilities have often been treated with pity and charity, as discussed in Chapter 3. In this thesis, benevolence is identified with the apparent goodwill of those who initially establish disability support structures for students with disabilities in South Africa; Kathy Jagoe is a perfect example of this in section (II) of Chapter 9. Benevolence is then contrasted with disability rights, which are conceptually in conflict with the needs approach, in favour of a human rights approach and also justifies disability rights on the moral grounds of social justice and the legacy of discrimination. However, the human rights discourse has its own tensions both in philosophical and practical terms, as discussed in section (IV) of Chapter 5. Of primary concern to this thesis is that the justification of rights is underdeveloped in disability studies. In defence of this underdevelopment of disability rights, Campbell and Oliver wrote, "If you are struggling simply to survive, then intellectualising is the last activity that may seem relevant" (Campbell and Oliver, 1996: 125). While this is understandable, I have argued

that part of the cause of the tension within the discourse of rights as applied to disability is the social model of disability.

It is from the social model of disability that disability rights have sprung. The model is used to argue against existing oppressive social relations towards people with disabilities, i.e. the central tenet of the social model of disability is that disability is significantly shaped by societal relations. It demands rights to serve social justice in favour of people with disabilities. However, without locating disability rights within mainstream arguments about Human Rights, it would be difficult to operationalise the social model of disability in providing support for students with disabilities in South Africa. This is one of the factors that have led to the impasse of the model.

Moreover, besides the tension of rights, one of the weaknesses of the social model of disability and one that is relevant for this thesis is the scant treatment of impairments. Yes, the social model of disability differentiates impairments from disability as a social category of oppression. However, it undermines the reality of impairments and their impact in the context of developing countries like South Africa. Oliver (1999) argues that in terms of the materialist perspective, personal experiences should be changed into political activism. By that he means that, by focusing on impairments, people with disabilities may believe that their difficulties are due to their individual impairments rather than an oppressive society.

While the primary issue in developed countries seems to be citizenship, assistive technology is a basic need in developing countries. As the data from the CHE survey has indicated, resource constraints render disability rights ineffective. The primary issue in developing countries is the effect of the actual impairment on daily experience, which is of course socially exacerbated by the absence of barrier-free environments. Thus, while I agree with the materialist

understanding of disability, I cannot deny the observation that, in developing countries, basic disability resources have not yet been met as indicated in the legacy of voluntary and benevolent (rather than mandatory) establishment of support services for students with disabilities in South Africa over the past two decades.

While the South African situation displays the tensive intersection , the situation in developed countries is different. Chapter 9 shows that, partly because of the longer history of disability struggles in developed countries like America, these countries have campaigned against exclusion and benevolence in favour of rights. The availability of resources has made it possible for them to move beyond the social model of disability. Moreover, Albrecht (2002) adds that the intellectual tradition of American pragmatism has contributed towards seeing disability as social category of oppression that warrants action rather than mere intellectual inquiry.

(II) Recommendations

Access to higher education for students with disabilities in South Africa is faced with many challenges, as indicated during the FOTIM in October 2005. A summary of the proceedings is attached in Appendix E. The challenges include accessibility, awareness, policy formulation, funding and teacher training. Some of the recommendations of this thesis seek to move the process forward. Taking into consideration that this is mammoth task and that the thesis is the first of its kind, the recommendations are not concrete but they do provide a framework.

The following recommendations are directed to the Department of Education, South African higher education institutions, the Council on Higher Education, and disability studies and higher education studies in South Africa.

(a) Operationalising the Social Model of Disability

Operationalisation means defining a concept in a manner that would quantify or measure to put out something into work. Unless we move beyond the articulation of the model and begin to collect statistics, engage in discussions, and plan and strategise how to support students with disabilities, then the process is unlikely to progress.

Critical to operationalising the social model of disability is Oliver's (2004) contemplative and hopeful observation about the social model of disability. Firstly, he notes that the social model of disability mobilises disability activists. However, he also notes that the social model of disability has not made a significant impact in the disability services in Britain. Secondly, he argues that, although the humanitarian approach (which I refer to as benevolence) still persists, the compliance approach to ending discrimination against the disabled is very legalistic and filled with conflict . Finally, he suggests that we recognise the social model as a tool that can be effective if we take a citizenship approach, which respects and recognises the economic, political and moral rights of people with disabilities.

Before I embark on policy recommendations, I think that the implications of Oliver's (2004) observations for access to higher education for students with disabilities in South Africa are, firstly, that policy and legislation are part of the solution and not the entire answer, as noted in the case of American. Secondly, disability support services have to be part of institutional planning rather than the sole responsibility of disability support services units, as Boston University is trying to do. Thirdly, the social model of disability is an emancipatory and pragmatic tool whose use and effectiveness depends on contextual factors. Finally, students with disabilities are human beings first, then students, then

disabled in the context of higher education. Thus they should be treated as full citizens, just like other members of the academy.

(b) Formulating a National Policy

There are two basic considerations in formulating a National Policy on Access to Higher Education for Disabled Students (NPAHEDS). The first consideration is the CHE survey. The survey is the first of its kind and provides a baseline of descriptive data about existing support services for students with disabilities in South Africa. The survey report could form the basis for a research-based national policy in this regard.

The second consideration that the NPAHEDS should take into account is to draw on the guidelines of the Department of Education's *White Paper on the Integrated National Disability Strategy* (1997) and the *Education White Paper on a Programme for Transformation of Higher Education* (1997). These documents begin to outline, albeit very briefly, what needs to be done with regard to disability and higher education. NPAHEDS has to also consider the general situation of people with disabilities and to see how some of the aspects could be incorporated into higher education via NPAHEDS.

(c) Four Factors from the Explanatory Legitimacy Theory

One of the purposes of the Explanatory Legitimacy Theory is to "advance guidelines for professional change and social action" (DePoy and Gilson, 2004: 4). In my view, professional change and social action mean that NPAHEDS should consider: (i) who is involved in its formulation; (ii) what aspects of support service must be considered; (iii) how South African sensibilities on disability and discrimination can be entrenched, and (iv) what are the financial

implications with reference to its guidelines. Each of these four factors will be considered in turn.

(i) On the factor of representation or who should be involved, I would propose that six bodies should be represented in the formulation of the national policy . The first one should be the disability support structures from different higher education institutions. Their input is important because they can provide hands-on experience. The second body are students with disabilities, whose voices have often been ignored. They also have vital insight into what assistance they require in their daily experiences. The third body are representatives from the Council on Higher Education (CHE). Their input is important in as far as trying to locate access to higher education for students with disabilities in the context of transformation and access to higher education for other disadvantaged groups. The CHE advises the Minister of Education, thereby providing vital input into higher education policy dynamics. The fourth representatives should come from the Department of Education, which, like the CHE, would give input on the general transformation of the education system and link inclusive education and access to higher education for students with disabilities. The fifth group of representatives should be from the South African Universities' Vice-Chancellor's Association and the Committee of Technikon Principals. Such senior executive management's input on the institutional cultures and cost implications of the policy is needed for this national policy formulation. The final group should come from organisations for people with disabilities.

(ii) On the aspect of support services, the policy should be clear on the intricacies and errors of providing support and also the vital importance of context for each one of the different types of impairments. In part III, I have mentioned our focus on four areas (advocacy, curriculum flexibility, staff development, and student life). In practice, however, there is a fine line between these, and one action can

often involve all of them. For example, discussing with a student the best way of running a support service is both a learning process and involves curriculum flexibility, and also in part a form of staff development during the discussion.

Moreover, the provision of support services may seem straightforward at present because the types of disabilities that affect South African higher education institutions are usually quite traditional (e.g. physical disability, blindness, and deafness). However, if the process of inclusive education proceeds as envisaged by the Education White Paper 6 (2001), then in ten or less years time, higher education will probably experience an influx of more students with disabilities, including non-traditional types of disabilities. That does not only mean that more resources will be needed, but it also means that policies must be reviewed in the future. Consequently, the national policy must be phrased in such a way that it is flexible enough to accommodate not only more students with disabilities but also students with 'new' disabilities, who presently attend either special schools or health institutions. This indicates the need for contextual flexibility when thinking about providing support for students with disabilities in South Africa.

(iii) The third factor to consider is the South African sensibilities on disability and discrimination. South Africa's post-1994 approach to disability and discrimination is from the perspective of respecting human rights and tolerance. South Africa is trying to build a nation based on the democratic values of human dignity, equality and freedom. It is within these values that I think the policy should advance its guidelines. As I have shown in Chapter 5, developed countries have also based their disability support on equality and human rights. However, this approach should not lose sight of the issues raised in section (V) of Chapter 5, which examined tensions in the Human Rights discourse and also recognised that rights, without money or resources to make them real, are ineffective on their own. Such tensions are particularly stark in the context of a developing

post-colonial country like South Africa, in which transformation is characterised by competing priorities.

(iv) The final factor of central importance is that of financial implications for the policy guidelines. My concern for the financial implications of a policy like NPAHEDS should not be interpreted as a minimalist approach that seeks to deny students with disabilities the right to support services. Rather, I am trying to break away from both the path of hope and the path of misconception, as explained in section III of Chapter 10. These paths wrongly assume a *laissez-faire* approach that is free of conflict and tension. I am furthermore trying show that support services are about investigating the *actual* impairments and *real* assistance for students with disabilities to access higher education.

Consequently, costs matter. My suggestion is that there should be three sources of funding: (1) internal sources from higher education institutions; (2) Department of Education; and (3) private donors. I realise that the question is: Where would institutions get the money? I think that higher education institutions should make it a habit of thinking about students with disabilities in their routine planning and acquisitions. For example, time and again faculties receive funding for book acquisitions. It would be wise for faculty staff to use part of that funding to see how they can negotiate with publishers to have some publications in alternative formats that are suitable for students with disabilities.

(III) Limitations of the Thesis

In the process of this study, I have identified four limitations in linking part of my argument to parts of the data. The first one is the lack of a conclusive and thorough history on the establishment of support services for students with disabilities at South African universities and technikons. If I had an accurate history of these support units, then I believe that my points about benevolence

would either be strengthened or modified according to the data. However, such a project is separate and large on its own. Most of the people who now work in these units have no idea of their beginnings or where to find such information. Such a project would thus not be possible, given the scope and time of this thesis.

The second limitation is that there was no participatory or 'emancipatory' research process. Initially, we tried to include individuals from some people with disabilities's organisations for the survey. At the beginning of the CHE survey, we had one woman participant from a people with disabilities's organisation. However her organisation was not happy that she spent some of her working hours helping us to design the study. As a result, I think that, by not incorporating contributions from people with disabilities, there are certain questions that were not asked and which could have enhanced the results. For example, Hurst (1999) points at the need for research on disability and higher education to include students with disabilities to enhance better understanding.

The third limitation is the general factual errors and Eurocentric disability history in disability studies. I have consciously worked with the material, noting that most of my sources were from Western countries and especially Britain and the United States of America. I do not argue that the framework does not work. However, there is scant material from developing countries with which to challenge the dominant framework. Clearly, there is a need for more material, like Coleridge's *Disability, Liberation and Development.*

The final limitation is that there has been little dialogue and research on disability issues in South Africa. Disability studies in South Africa seem to be a hybrid of American pragmatism and British materialism. As Meekosha (2004) puts it, "With the emergence of disability studies a surprising contest seems to have developed between scholars in the USA, and those in Britain. In the

'periphery' of the English speaking world, Australia, Canada and so on, the approaches tend to be rather more eclectic, drawing on both metropoles and extending them through the specificity of the colonial-settler histories of their own societies" (Meekosha, 2004: 5). Although there is no problem with adopting some of the concepts, I think South Africa has yet undiscovered variations of these, as this thesis has begun to display, which could have added further material to the thesis. By trying to create something from its base, however, one risks being unable to see other factors and processes impacting on one's study. Be that as it may, I hope that this thesis will begin to lay the foundation for further discussion and research on disability in general and higher education in particular, as the following section proposes.

(IV) Further Research

Given that this thesis gave a macro-analysis of the South African system of support for students with disabilities, further research would be useful at agency level within higher education institutions, where students with disabilities interact with faculty members and other students. Macro-level studies are useful in providing an overview of the situation. However, their main importance lies in the lived experiences of human beings. Studies such as those of Chang (2004) on improving the academic achievement of students with disabilities are thus relevant and particularly necessary for South Africa.

Moreover, section IV (g) of Chapter 9 about the CHE survey data indicated the lack of statistical data on the profile of students with disabilities in South Africa. To solve this problem, research and discussions are needed into data management and criteria for statistical categorisation. Part of access to higher education for students with disabilities is to evaluate the process, and without statistical categories, the evaluation would be impossible.

The issue of the Human Rights discourse needs special attention in Disability Studies in general. This is crucial in the light of demands made by disability rights movements. It is important for disability studies to locate disability rights within the discourse, thereby being able to justify their claims in philosophical, legal, moral and practical terms.

A bigger project of research concerns the perspectives of developing countries. Third World countries need to engage in whatever aspects of disability that are important in their own contexts. I do not advocate a separate research agenda, but rather an agenda that not only informs global processes but local realities too. As mentioned at the beginning of Chapter 3 on disability and society, articles such as those of Abang (1988) and Tomlinson and Abdi (2003) on disability in Nigeria and Somaliland respectively are encouraged.

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APPENDIX A: Planning For College

PLAN WISELY FOR COLLEGE

Author: Paul L. Essert

Date: 1966

Format: Magazine article

Publication: Toomey J Gazette

Source: Gazette International Networking Institute, vol.9. Page 42-43.

(http://www.disabilitymuseum.org/lib/docs/1467card.htm, accessed 2004 April 13)

Many of the letters I have received from readers of the TjG are from paraplegics, quadriplegics and respos who want to go on with college education. This article is intended to pass on a few suggestions that will help you plan more wisely.

FIRST, be assured that if you really mean to work hard at it, do some initial research, letter writing, and personal investigation of your own, and if you have a good enough high school scholarship record to make you eligible for college entrance, you have numerous examples of "pioneer quads and respos" who have made good records in college in the face of their physical handicaps and many obstacles. Read the back issues of the TjG, particularly the Spring-Summer issue of 1962 and the Education Section of the previous issue of Spring 1965.If you are not willing or able to meet these exploratory requirements, you'd better not try to go to a college campus, since research, writing, the inquiring mind and evidence of previous scholarship are requirements of making a success of higher education

anywhere and for any student. This does not mean that you can't continue your education in profitable and interesting home-study not aimed at college credit. There are numerous ways of doing this. Later I will write a little article about them, but let's stay with the campus-bound student here.

SECOND, IF YOU WANT A SCHOLARSHIP FOR TUITION, board and room, and other aspects of scholarship grants, you will have to compete for them as any other student has to do. Consult your local high school Principal and/or your State Department of Education about types of scholarships and student aids for which you might compete. Handicapped students should never assume that their handicap is necessarily a factor in scholarship competition.

THIRD, STUDY THE FACILITIES AND SERVICES of colleges and universities that are designed to help the handicapped student in carrying on his studies. The best help available to you to make this study is a monograph entitled *Higher Education and Handicapped Students*, edited by William V. Tucker, and available from TjG. This lists by states all the higher education institutions in the USA that appears in the College Blue Book and have more than 1000 students and which responded to the questionnaire. It lists for each one, according to its own report at the time of the study, the following: housing ramps, classroom ramps, library ramps, bevelled curbs, reserved parking areas, modified toilet facilities, special counsellors, vocational rehabilitation service visits, adaptive physical education, and numbers of wheelchair and blind students. After reading this monograph, select two or three that seem to meet your needs and write to "The Registrar for a catalogue and ask to whom you should write regarding the institution's program and facilities for handicapped students. Then write to the latter for any detail not covered in the monograph described above.

FOURTH, many of you will be able to get along fairly well by yourself. Others will need to make careful investigation of the possibilities of student-attendant services. My best advice is that if this is an important factor, do everything you can to get the arrangements made definitely *before* you go to the campus. Few colleges make special dormitory or housing arrangements for the handicapped. Few of them arrange to employ students as attendants. Even if you have the money to employ a Student assistant, you may find that some institutions have trouble in recruiting the kind of person you need. When you write to the institution about this be sure to be specific about the exact duties you expect from the assistant, the amount of time and times of the day you need the assistance and any other information that would be useful in recruitment. Some of the institutions or possible attendants may be worried about their responsibility to you, legally, and suggest that you sign a waiver. Be very reluctant to sign a waiver; or, at least, consult a friendly lawyer in your community before doing so. Some have advised that you should not absolve a person from negligence, and, as long as a person exercises reasonable care, that is all that is asked of him and he cannot be held liable for anything that happens while he is exercising reasonable care. After all, this is generally the requirement that employees or assistants you have in your own home are charged with.

IF YOU NEED FINANCIAL ASSISTANCE FOP ATTENDANTS, inquire from the institution with which you are planning to study whether it is operating under the College-Work-Study Program of the Economic Opportunity Act of 1964 and whether your needs for student assistance could be financed, or partially financed, within the limitations of this program. Also write your own State Office of Vocational Rehabilitation, in your State Capitol, and ask them whether you can secure financial assistance for student assistance. Both of these agencies have limitations, but you may be able to come within

them. You also might try your local Service Clubs, such as Rotary, Lions, Kiwanis, Altrusia, etc. Very often, if they understand the situation, they will get back of an occasional need of this kind.

FINALLY, DON'T GET DISCOURAGED with a few set-backs; you're used to them and you're after a good thing here. Do all you can for yourself along the lines I've suggested. When you've done that and there are still road-blocks, write me (*care of TjG*) and we will try to do what we can to go on from there. Much of this effort of higher educational institutions to make better provisions for physically handicapped students is new to many of them. Many innovations and break-throughs are occurring, and the picture is changing slowly but favorably. Every effort you make along this line helps define *their* (the institution's) task and problems. So, even in the *trying*, you can help.

APPENDIX B: Disability Rights Chronology

Chronology of Important Events: Key dates in the journey toward the development of an international convention on the human rights of people with disabilities

1948 Adoption of the Universal Declaration of Human Rights by the UN General Assembly, claiming that all human beings are born free and equal in dignity and that everyone is entitled to all the rights and freedoms set out in the Declaration, without distinction of any kind

1971Declaration on the Rights of Mentally Retarded Persons

1975 Declaration on the Rights of Disabled Persons

1981 UN General Assembly proclaims 1981 the International Year of Disabled Persons

3 December 1982 UN General Assembly adopts the World Programme of Action concerning Disabled Persons in Resolution 37/52

1983 159 ILO Convention on Vocational Rehabilitation and Employment (Disabled Persons)

1983-1992 UN Decade for Disabled Persons

1987 Global Meeting of experts reviews the Implementation of the World Programme of Action concerning Disabled Persons and recommends that the UN General Assembly convene a special conference to draft an international convention on the rights of disabled persons

1987 Italy prepares a draft treaty outline that is submitted to the General Assembly

October 1987 42nd session of the General Assembly discusses the desirability of an international treaty, but no formal agreement to proceed

20 December 1993 UN General Assembly adopts the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

8-12 December 1998 UN convenes an Interregional Seminar and Symposium on International Norms and Standards relating to Disability, in cooperation with Boalt Hall School of Law, University of California at Berkeley at Berkeley.

September 1999 Rehabilitation International calls on UN Member States to support the drafting of a treaty on the rights of disabled people

13-17 December 1999 Interregional Seminar and Symposium on International Norms and Standards Relating to Disability in Hong Kong, cosponsored by the UN, Center for Comparative and Public Law of the University of Hong Kong

and the Equal Opportunity Commission of Hong Kong, calls for an international human rights treaty for people with disabilities

February 2000 Final report to the Commission for Social Development – Special Rapporteur Report

12 March 2000 World NGO Summit on Disability calls for an international treaty on the rights of people with disabilities

April 2000 UN Human Rights Commission Session, Special Rapporteur on Disability discusses a future treaty

August 2000 XIX World Congress of Rehabilitation International calls for an international treaty on the rights of people with disabilities in Resolution 48/96

September 2001 World Conference Against Racism, Racial Discrimination, Xenophobia and Related Intolerance recommends that the UN General Assembly consider drafting an international treaty on the rights of people with disabilities

19 December 2001 UN General Assembly adopts Resolution 56/168, calling for the establishment of an Ad Hoc Committee to consider proposals for an international human rights treaty for people with disabilities

8 April 2002 The US National Council on Disability (NCD) hosts a "Summit on Human Rights and Disability," bringing together key leaders of both the human rights and disability rights communities in the United States

11-14 June 2002 In cooperation with the UN, the Government of Mexico hosts an inter-regional expert meeting to discuss the treaty

12 June 2002 The US National Council on Disability (NCD) and the U.S. International Council on Disability host a forum of grassroots disability organizations to discuss their role in the development of an international convention on the rights of people with disabilities

29 July – 9 August 2002 The first meeting of the Ad Hoc Committee established by General Assembly Resolution 56/168 takes place at the UN in New York

15–18 October 2002 DPI 6th World Assembly takes place in Japan, also marking the end of the Asia-Pacific Decade of Persons with Disabilities

8-9 March 2003 Regional meeting on the rights of people with disabilities in the Arab World held in Manama, Bahrain

7-8 April 2003 Meeting of European NGOs held in Madrid, Spain

9-11 April 2003 Americas regional seminar and workshop on norms and standards related to the rights of persons with disabilities and development held in Quito, Ecuador

2-6 May 2003 African regional consultative conference held in Johannesburg, South Africa

27-29 May 2003 Arab Regional Meeting on Norms and Standards Related to Development and the Rights of Persons with Disabilities held in Beirut, Lebanon,

2-4 June 2003 Expert Group Meeting and Seminar on an International Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities held in Bangkok, Thailand,

16-27 June 2003 The second meeting of the Ad Hoc Committee established by General Assembly Resolution 56/168 held at the UN in New York

14-17 October 2003 UNESCAP meeting to discuss draft treaty text prepared by Prof. Andrew Byrnes, Bangkok, Thailand

20-21 October 2003 Expert dialogue and regional consultation, Amman, Jordan, convened by LSN Jordan

4-7 November 2003 UNESCAP/ CDPF regional meeting to discuss draft text from Bangkok, held in Beijing, China

3 December 2003 International Day of Disabled Persons

13-15 December 2003 Meeting of Working Group NGO representatives, Madrid, Spain

5-16 January 2004 Working Group of the Ad Hoc Committee will meet at UN headquarters, NY to draft a negotiating text for presentation to the Ad Hoc Committee in Spring of 2004

(SOURCE: HTTP://WWW.RIGHTSFORALL.ORG/CHRONOLOGY.PHP, accessed 7 April 2004)

APPENDIX C: Boston University Lawsuit

Wall Street Journal
September 3, 1997 ***By JON WESTLING***
(http://www.freerepublic.com/forum/a3780.htm)

Rule of Law

One University Defeats Disability Extremists

By JON WESTLING

Who should establish academic standards? Colleges and universities? Congress? The courts? Until recently, no one doubted that academic standards were the province of the academy. But it is increasingly argued that federal disability law requires that some students be granted degrees even when they cannot fulfill important academic requirements.

This issue was central in a recent lawsuit against Boston University. On Aug. 15, federal judge Patti Saris issued a decision in Guckenberger et al. v. Trustees of Boston University et al. that will reverberate widely--and for the most part, positively--in higher education: that disabilities law does not require universities to compromise essential academic standards. Much of the press, however, preoccupied with anecdotal understanding of learning disabilities and with Judge Saris's minor awards to six of the 10 plaintiffs, has missed that story.

The stakes in this case were high. Universities define themselves by their requirements for degrees. The public legitimately expects that graduates have the skills and knowledge specified in those requirements. Degrees do not come with fine print explaining that, in some cases, requirements were waived.

Federal law, including the 1990 Americans With Disabilities Act, which requires that people with disabilities receive "reasonable accommodations" for their conditions, has unsettled these expectations. Universities have acceded to demands from extremists to exempt students from a growing range of academic requirements. Many universities permit students who have trouble learning math to meet a math requirement by taking a nonmath course. Some permit English-language courses to substitute for foreign-language requirements. Other subversions of academic standards are more subtle. Does a medical student who is granted extra time on examinations meet the

standards for making emergency-room decisions? Is a business student who has been tested only in "distraction-free environments" ready to manage a real business?

At Boston University, one student recently sought to pass a reading comprehension test by having the text read aloud. A Naval ROTC student preparing to become a preliminary sought a notetaker for an engineering course. A graduate student in banking and securities law sought to have an editor for his examinations. We turned these requests down, but perhaps another institution would have accepted them. When that happens, students lose the opportunity to learn, and employers, graduate schools and others are misled about what the student has accomplished.

In 1995, as Boston University's provost, I tightened the university's procedures for granting academic accommodations to learning-disabled students. Regrettably, some staff members responsible for assisting those students ignored the new policy and worked what mischief they could before resigning. In 1996, 10 students sued, claiming that the university had failed to provide reasonable accommodations for their learning disabilities. Last month, Judge Saris ruled that, although they received the accommodations they sought, six of these students had suffered from the "chaos" inflicted by former learning-disability staff. She ordered the university to pay damages totaling about $30,000.

The broader importance of Judge Saris's decision, however, lies in her rejection of most of the plaintiffs' attempts to extend the scope of federal disability law. She agreed with the university's key argument: Those laws do not require universities to compromise essential academic standards. Specifically a university is not required to provide course substitutions that it "rationally concludes would alter an essential part of its academic program"; not required to waive its mathematics requirement; not required to accept outdated diagnoses of learning disabilities; and not required to accept diagnoses from unqualified or disreputable evaluators. These decisions are a crucial victory because universities now have a firm basis for saying no to the extremists' attempts to turn every intellectual deficit into a disability.

But all is not good news. Judge Saris wavered on whether Boston University could retain its 118-year old foreign language requirement. We are ordered to convene a faculty committee to consider whether mastery of a foreign language is "essential" to our version of a liberal arts education. Our language requirement may prevail, but I am deeply disturbed that a federal court would consider intruding so deeply into a university's curriculum.

The decision has other ominous notes. Judge Saris overturned the university's policy of accepting diagnoses only from physicians, licensed clinical psychologists and other appropriate specialists; in many cases, we now will have to accept diagnoses from individuals whose highest credential is a master's degree in a field such as education. Worse, Judge Saris was unpersuaded that the effects of learning disabilities may wax and wane during a student's college career; she accepted the plaintiffs' argument that the effects may vary until age 18, but not afterward.

Judge Saris's decision also reproached me for a speech I gave in which I introduced a learning-disabled student, "Somnolent Samantha," who was prone to fall asleep in class. "Somnolent Samantha," the court said, "represented Westling's belief . . . that students with learning disabilities were often fakers who undercut academic rigor." I believe nothing of the kind. "Samantha" symbolized real learning-disabled students. I altered details to preserve my students' privacy--as required by federal law and as any teacher concerned about his students would do anyway.

"Samantha" and other learning-disabled students are victims of overblown and unscientific claims by some learning disability advocates. My speech also made clear my belief that genuine learning disabilities exist, and that universities often can provide students who suffer such disabilities with reasonable accommodations that in no way compromise essential academic standards. I am committed to ensuring that my university meets its legal and ethical obligations to such students.

The larger message of Judge Saris's decision, however, is a rebuff to the learning-disabilities extremists. Academic standards have been vindicated. Universities can reject diagnoses that make no sense. Universities, not learning disability specialists, can determine appropriate academic accommodations. To uphold the integrity of academic degrees, universities need a fuller restoration of their proper academic authority, but the decision moves us in the right direction. University trustees, administrators and faculties, hearing this good news, should act to review their policies and repair the damage that has been done.

Mr. Westling is president of Boston University.

APPENDIX D: FOTIM's Research

FOTIM

ANALYSIS OF RESPONSES TO DISABILITY QUESTIONNAIRE

Questionnaires were emailed and posted (2 April 2001) to the Dean of Student Affairs at FOTIM's 16 members institutions, unless a specific contact person had been identified. Responses were received from 4 technikons and 6 universities.

ADMINISTRATION

1. Does your institution have a policy on disability?

Two technikons and 4 universities responded yes, the remaining 2 technikons and 2 universities responded no.

2. Does your institution have a disability unit?

None of the technikons have disability units, two universities have in existence and 1 is in planning phase.

3. How many students with disabilities are registered at your institution?
One technikon has 3 disabled students registered, the others did not answer the question. All universities responded positively with a range of between 16 and 639 (Unisa) students.

4. Which categories of disabilities are catered for? Give number of students.

Only one technikon caters for blind, partially sighted and deaf students, but no numbers were given. All universities cater for blind and partially sighted students, the blind range between 2 and 39, partially sighted range between 6 and 141. Four universities cater for between 2 and 55 deaf students.
Physically disabled students are catered for at 3 technikons (numbers of students not given), while all 6 universities cater for between 3 and 270 (Unisa).
Only 1 technikon caters for learning disabilities, including ADD/ADHD but 5 universities do (between 1 and 74 students)
Epilepsy and Diabetes were added by 2 universities with 2 and 4 students .

5. Does your institution provide a budget for the provision of reasonable accommodations for students with disabilities?

Three technikons do not and the one, which answered yes, indicated that the budget was inadequate. Three universities do not, and of the three, which do, one specified that funds were from bursaries, loans and contributions from RAG, while another said financial provision was made but not on a separate budget.

6. Does your institution offer financial assistance to students with disabilities?

Two technikons responded positively, one specifying a 20% rebate. Three universities offer financial assistance, one naming bursaries, loans and contributions from RAG.

ACADEMIC SERVICES

7. What academic services/resources are provided for students with disabilities?

The 4 technikons responded variously: same as for other students; life skills; special assistance regarding practical projects; with 1 in process of transcribing material for blind/deaf, investigating purchase of Braille printer and software, and developing distance education programmes.
Universities offer: services according to individual needs; Braille typewriters and scanners; reasonable accommodations to support learning and teaching; Student Support Services, Student Counseling Services, Centre for Reading and learning Development, Subject and Learning facilitators system, Academic Advisers in residences; audio cassettes, written study materials enlarged, spiral bound, electronic format, transcription of audio cassettes.

8. Have methods of teaching and assessment been modified for students with disabilities to enable participation in course work?

One technikon is in the process of modifying methods of teaching and assessment, and one allows invigilators to attend private exams.
Four of the universities provide students with material in alternate formats, one is in the process of instituting modified methods, and one indicated that lecturers give students with disabilities extra time and attention.

9. What programmes are currently available?

3 of the 4 technikons provide personal development and academic support programmes, including planning, study skills, integrated learning and peer helping.
2 universities offer programmes available to all students, 3 offer programmes specifically designed for disabled students including: study skills, language development skills, life skills, assertiveness, medical problems etc. One university indicated that no programmes are currently available.

10. Do you think an extended curriculum with reduced course loads will benefit students with disabilities?

2 technikons said yes and 2 said no – one pointing out that the students were physically disabled and able to cope mentally.
3 universities said their students would benefit, one said that it would not benefit students in *all* instances, one said it would depend on the disability and one indicated that all students could do degrees over more years.

11. What support services/recourses are provided for students with disabilities?

Of the 4 technikons, 2 provided career counseling, support groups and life skills/self awareness programmes, 1 provided intellectual assessment. None provided sport/recreation facilities.
Of the 6 universities, 5 provided career counseling, 3 provided intellectual assessment and support groups, 4 provided sport/recreation facilities and 5 provided life skills/self-awareness programmes,1 provided a medical service.

12. Does your institution have career guidance officers who are competent to provide this service to students with disabilities?

2 technikons and 4 universities responded positively.

13. Which of the following are provided at your institution:

	Tech (4)	Univ. (4)
Adaptive computer devices & prog.	1	3
Computer training	2	5
Physical orientation	2	5
Sign language interpreters	0	2
Listening devices	0	5
Note takers, reader, scribes	2	4
Relocation of an event to an accessible location	1	5
Time extension	2	6
Brailled texts	1	3
Audio taped notes	1	4

14. How are the students with disabilities integrated into the general student population?

None of the technikons indicated special programmes that facilitated integration.
4 universities said the disabled students shared facilities, residences, functions etc.
One provided volunteer programmes, residential socials, talks by disabled staff and students and awareness programmes. One said the question was non applicable since they are a distance learning institution.

15. What programmes/support are given to academic staff?

One of the 4 technikons provides support programmes under Student Academic Support.
4 of the 6 universities provide workshops/training to appreciate the needs of disabled students. One said this issue was being addressed in their new policy.

16. Is your institution physically accessible?

3 technikons responded positively, one is accessible in some regions only. One university responded negatively.

17. If not, how long will it take to achieve accessibility?

The technikon that is accessible in some regions only said it would take one year to achieve full accessibility and that budget and bureaucratic redirecting of requests is a hindrance.
The university that responded negatively said it would take 2 years to reach full accessibility.

18. What mechanisms remain to be put into place to make your institution disabled-friendly?

The technikons responded with a variety of needs: improved physical infrastructure, staff awareness training, programmes to assist with transcriptions and Braille conversions.
The universities mentioned: improved services (but money an obstacle), architects to redesign terrain for blind and wheelchair students, recruitment policy, Code of Good Conduct: Disabilities 2001, ongoing awareness programmes for staff and students, brailed signage, mechanisms for deaf students and staff.

19. What are your views on regional collaboration?

All 10 institutions responded positively, comments included: duplication of policies and infrastructure will be avoided; we should brainstorm for strategic collaboration without one feeling subsidiary to the other; good idea but the student has the right to choose the institution; services should be supportive to each other for the benefit of the student; can play a special role in the region as well as nationally in accommodation of students.

20. Do you think that a workshop on disability and the ways in which institutions might collaborate in order to cater for disabled students in the region would be valuable to your institution?

All institutions answered positively.

APPENDIX E: FOTIM Conference Proceedings

UNIVERSITY OF THE WITWATERSRAND,
JOHANNESBURG
Disabled Students' Programme

SOUTHERN AFRICAN CONFERENCE FOR THE FORMULATION OF TERTIARY EDUCATION POLICY AND PRACTICE FOR PEOPLE WITH DISABILITIES

13 - 15 October 2005
Sturrock Park Sports Precinct
University of the Witwatersrand
Johannesburg, South Africa

REPORT ON CONFERENCE

1. WELCOME AND INTRODUCTION

The conference was officially opened by the Vice-Chancellor of the University of the Witwatersrand, Professor Colin J. Bundy, who welcomed all present, especially the keynote speaker, Minister of Education, Professor Kader Asmal. Professor Bundy expressed great pleasure at the opportunity afforded the Higher Education sector to grapple with policy issues around people living with disabilities in the Higher Education environment, and stressed that the opportunity was vitally important, and long overdue. He also recorded his personal pride that the Wits' Disabled Students' Programme was host to this momentous event.

2. KEYNOTE ADDRESS

The Minister of Education, Professor Kader Asmal, delivered the keynote address where he acknowledged the importance and timeousness of the conference. The Minister made reference to the Bill of Rights and the South African Constitution,

which mandates equality for everyone. He focussed firstly on the deleterious effects of inequality and discrimination, and stressed the need to address inequalities of the past by providing educational and job opportunities for groups disadvantaged by unfair discrimination of the past. Prof. Asmal applauded those tertiary institutions that were taking positive steps in addressing transformation and diversity, especially with regard to disability, as disability has been earmarked as a national priority. The Minister announced that a centralised system of higher education statistics would soon start collecting information on students with disabilities. Data about the number of students with disabilities will have to be projected for the three-year planning cycle (2000-2002) and submitted to the Department of Education. The clear implication is that in respect of different programmes or fields of specialisation issues such as race, gender and disability imbalances, the extent of imbalances, and plans to redress the situation will have to be addressed. In addition, imbalances in relation to success rates, graduation rates of students with disabilities in different programmes, and qualifications, would also have to be evaluated. Institutions would have to assess their commitment to the needs of students with disabilities in relation to the removal of barriers, both physical and attitudinal.
Prof Asmal also articulated the importance of the need for higher education institutions to start collaborating with governmental departments in addressing challenges ahead of them and redressing the inequities. He referred to the need to examine the new funding formula, which is expected to be introduced as part of the National Plan - in response to the "*Size and Shape*" exercise - as a means of driving the system towards meeting the goals of equity, redress and development. A further area to be examined will be the National Student Financial Aid Scheme, as the primary criterion on which student aid within this Scheme is based is financial need.

The Minister referred to the Employment Equity Act (No. 55 of 1998) as confirmation of the government's commitment to address discrimination on the basis of disability. The purpose of this Act is to address discriminatory practices in employment and promote the equitable representation of historically disadvantaged groups, namely black people, women, and people with disabilities. The forthcoming Equality Act would take equality for people with disabilities further in other fields than employment, including that of education.

Prof. Asmal concluded by wishing the forum well over its deliberations, which, he hoped, would assist in realising the great potential existing in this country. He also invited the conference to begin the process of developing a National Policy on Disability in Higher Education Institutions, and expressed the belief that input generated in the conference would be extremely valuable. The possible contribution to the National Policy on Disability in Higher Education Institutions

by the Wits University's Policy was considered valuable, and was strongly supported by the conference forum.

3. SPECIAL GUEST SPEAKER

The Human Rights Commission's Commissioner Jerry Nkeli addressed the conference, -congratulating the organisers for the initiative, which he regarded as long overdue. The Commissioner expressed his pleasure for the opportunity to provide the Human Rights Commission's praise and critique of Government's contribution to redressing discrimination against people with disabilities. He gave examples of action taken by the Commission in support of the rights of people with disabilities. He also critiqued key issues which were having the effect of delaying the process of addressing disability issues and hoped that the process would be expedited, as pressure from stakeholders is imminent.

4. PRESENTATIONS:

Invited speakers presented papers on topics central to the central theme of the conference. Presentations included Students' Experiences, Copyright and Education, Fears in the Classroom, and Deaf Education. Parallel workshops were held which explored topics such as Architectural Barriers and Physical Access, Distance Learning and The Disabled, and Special Education Needs.

Outcomes and recommendations of these workshops all highlighted and made recommendations toward addressing the much-discussed problems:
financial restraints;
changes to the infra-structure of suburbs/city-centres in making buildings, streets, public transportation, etc. more accessible;
attitudes towards people with disabilities;
the need to employ modern technology in making information more user-friendly and accessible;
Governmental support, which was considered to be crucial to any change in thinking and/or the educational process.

5. INPUTTING INTO FUTURE INTERVENTIONS

Events for the final day focussed upon the conference making inputs into the future policy interventions as envisaged by the Minister.

The conference identified four key issues that were then workshopped in four workshops run by facilitators from conference delegates. Each workshop looked at one of the key issues of General Access, Networking and Developing Links, Learning Support, and Funding.

The workshop outcomes and recommendations were captured as:

Workshop 1: *'Learning Support'*

* The need to develop strategic plans to put into practice the academic, theoretical data already available in the various policy documents;
* The possibility of regional collaboration and forming links with student support centres that existed regionally;
* The need to build onto existing services within tertiary environments, State Departments, and NGO's.
* Implications of the Employment Equity Act include training and skills/qualifications acquisition;
* Policy guidelines should be replaced by clear strategic objectives that outline specific targets.
* Around overcoming barriers, time-frames for achieving objectives, the establishment of long and short term goals and the formation of appropriate support groups for lobbying purposes.

At tertiary level intervention should occur in the following ways:

* Long and short term strategies to integrate provision for students with disabilities within the broader concepts of academic and student support services;
* Addressing barriers to learning for students with disabilities, as well as awareness and sensitivity training for academic staff;
* Lobbying and providing a level of guidance to the Council for Higher Education which can advise the Minister of Education;
* Student involvement in leading and directing the process;
* Regional/National collaboration among tertiary institutions in developing and implementing policies;
* Clear time frames to be set.

Workshop 2: *'Access/Accessibility'*

* Architectural Planning / guidelines for consultants - building plans should include needs of all users, implying total access;
* Parking - dedicated parking bays for people with disabilities should be addressed in policies;

* Awareness of special needs - signage should be user-friendly;
* Changes to environment must be made known to all users to avoid accidents and injuries
* Barriers to learning - provision to be made for appropriate course materials, language policy, sign-language interpretation, Braille services, etc.
* Entrance requirements should be examined as marginalisation occurs;
* As students with learning disabilities experience difficulties working from an academic model, partnerships among various service providers are deemed necessary.
* Teacher training should incorporate skills to teach learners/students with disabilities.
* Policies to provide a barrier-free education for all to be developed.
* Intervention models should be researched to facilitate access for students with disabilities.
* An inclusivity model incorporating funding, networking, access, SAQA and National Qualifications Framework should be explored.

Workshop 3: *'Networking'*

* The concept of networking implies all stakeholders participate in decision-making processes to address transparency and accountability.
* Previously marginalised groups, as well as service providers, such as higher learning institutions, would also be included in the processes.
* Networking assists in advocating shared resources, information, expertise, technology and prevents exploitation of people with disabilities.
* National and international funding possibilities could be made more sustainable through networking and it would also provide quantitative input on policy and practice which could be presented to government departments.

* Capacity building of personnel at disabled students' programmes and the need to harness resources and opportunities is vital.

Workshop 4: *'Funding'*

* Providing reasonable accommodations, both as physical access as well as access to learning, requires urgent funding.
* A projected costing analysis is necessary to establish cost per student per degree/diploma.
* Various organisations can be approached for financial assistance including government financial aid schemes, National Research Foundation, UNESCO, WHO, and the private sector.

* Funding obtained from universities' research funds should also be used for research purposes.
* Government funding formulae should also make allowances for students with disabilities.
* In discussing cost-saving mechanisms it was suggested that appropriate strategies to run less expensive, yet excellent services be examined.
* Regional collaboration and shared resources among universities and Technikons appears to be a favourable and popular cost saving option.

6. CONCLUSION:

The conference concluded by encouraging participants to make use of conference information, resources and new networked contacts into their own institutions to promote the processes of achieving disability equality, and working toward equal participation and barrier removal.

In line with the Minister's invitation to input into disability rights, and in order for ongoing action it was suggested that the above workshop recommendations be made known to all stakeholders, including,
SAUVCA (S A Universities Vice Chancellors' Association),
Committee of Principals/ Rectors of Technikons, Regional Higher Education Consortiums, such as FOTIM, and
relevant government departments.

The conference concluded by noting that with combined effort and lobbying, a national policy for tertiary institutions from the government will be realised

APPENDIX F: CHE Survey Questionnaire

EDUCATION POLICY UNIT
University of the Western Cape

PROVISION OF TEACHING AND LEARNING SUPPORT FOR STUDENTS WITH DISABILITIES IN SOUTH AFRICAN HIGHER EDUCATION INSTITUTIONS

Education Policy Unit, University of the Western Cape, Private Bag X17, Bellville, 7535 South Africa
Tel: (27 21) 959-2580 Fax: (27 21) 959-3278 Email: epu@uwc.ac.za Website: www.epu.uwc.ac.za

INSTRUCTIONS

1. **Please answer all the questions as fully as possible**

2. **If you are unable to answer any question please indicate this by writing 'N/A' next to the question**

3. **Where the question requires you to choose a particular option (e.g. yes or no) please tick the appropriate box next to the answer of your choice (not in the margin on the right-hand side which is for office use only)**

4. **If you would prefer to complete the questionnaire in electronic form please contact us and we will e-mail you a copy. A copy of the questionnaire is also available on the *Notice Board* of the EPU website (www.epu.uwc.ac.za). This version can be downloaded from the website, completed and then returned via e-mail or through the post to the EPU.**

5. **Should you have any queries regarding the questionnaire please feel free to contact us.**

6. **We would be grateful if you could complete and return the questionnaire to us by Friday 27 June 2003. A self-addressed envelope for this purpose is enclosed for your convenience.**

7. **All queries, requests for electronic copies of the questionnaire or returned copies via e-mail can be directed to:**

Colleen Howell
Education Policy Unit
University of the Western Cape
chowell@uwc.ac.za
Phone: 021 959 2580
Fax: 021 959 3278

Thank you very much for your assistance

SECTION A: PROFILE OF INSTITUTION

For office use

A1. Name and address of institution.

Name	
Postal address	

A2. Name and position of person completing questionnaire.

Name		
Job title		
Department/ Unit		
Contact details:	Telephone:	
	Fax:	
	E-mail address:	

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For office use

SECTION B: INSTITUTIONAL POLICY

B1. Do you have any policies/guidelines in place to assist you in providing support to students with disabilities?

Yes	
No	

B2. If **Yes**, please indicate what kind of policy/guidelines you make use of.
(please tick the appropriate box or boxes if more than one answer is appropriate)

The institution has a formal policy/guidelines on providing support to students with disabilities	
We make use of informal policy/guidelines on providing support to students with disabilities	
We make use of other institutional guidelines around general student support in the institution	
We make use of guidelines provided by organisations outside the institution around support for students with disabilities	
Other guidelines (please explain)	

(If you have a formal policy/guidelines and it is not available on your Website please send us a copy by post or e-mail.)

B3. If you answered **No** to Question B1, do you feel that a policy/guidelines on providing support to students with disabilities would assist you in your work?

Yes	
No	

B4. Please explain why you feel a policy/guidelines would or would not be of assistance in your work.

B5. Using the following scale, please indicate in the table below how familiar you are with these policy documents.

For office use

1= I have read the policy and am familiar with its content
2= I have seen the document but am not really familiar with its content
3= I have heard about the document but have not seen it or read it
4= Have never heard of the policy

The Integrated National Disability Strategy (1997)	1	2	3	4
Education White Paper 6: Special Needs Education: Building an Inclusive Education and Training System (2001)	1	2	3	4
The National Plan for Higher Education (2001)	1	2	3	4

SECTION C: PROFILE OF STUDENTS WITH DISABILITIES AT YOUR INSTITUTION

C1. In the table below, please provide details (*if possible*) of the students with disabilities who are presently enrolled at your institution.

	African	Coloured	Indian	White	
Number of students with disabilities					Male
					Female
Sub total					*Total number*

(if you are unable to provide details according to race and gender, please just fill in the total number)

For office use

C2. If you were able to answer Question C1, please indicate from what source you obtained this information. (*please tick the appropriate box or boxes if more than one answer is appropriate*)

Admissions form requests students to indicate whether they have a disability	
Admissions form requests students to indicate whether they will require any assistance associated with a disability from support systems in the institution (e.g. disability unit, student affairs office etc)	
Information has been collected from tracking the number of students who have sought assistance in relation to their disability from support systems in the institution (e.g. disability unit, student affairs office etc)	
Other:	

C3. If you were able to answer Question C1, please indicate (*if possible)* the number of students with disabilities in each of the categories listed below.

		number
Undergraduate students enrolled in contact teaching programme (on campus)		
Postgraduate students enrolled in contact teaching programme (on campus)	Postgraduate diploma/honours	
	Masters	
	PHD	
Undergraduate students enrolled in distance education programme		
Postgraduate students enrolled in distance education programme	Postgraduate diploma/honours	
	Masters	
	PHD	
Other:		

C4. If you obtained the information around students with disabilities from your admissions form, please indicate (or attach a copy of the question) how this information is requested in the form.

_____

_____

_____

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SECTION D: NATURE AND STRUCTURE OF SUPPORT SERVICES OFFERED

For office use

D1. Does your institution provide any teaching and learning support services to students with disabilities?

Yes	
No	

If you answered Yes to Question D1, please now answer questions D2 to D15.

If you answered No to Question D1, please go directly to question D16

D2. In the table below please indicate what kind of teaching and learning support services you offer to students with disabilities on campus. *(please tick the appropriate box or boxes if you offer more than one kind of service)* Please briefly describe *(if possible)* the nature of the service offered in the section below the identified service).

Assistance in making print material (e.g. lecture notes, library materials) accessible to students with disabilities (e.g brailling of lecture notes, putting information on tapes)	
Nature of service:	
Sign Language interpretation facilities	
Nature of service:	
Providing personal assistants to student with disabilities to enable them to participate in lectures/seminars/tutorials (e.g. note takers)	
Nature of service:	
Direct provision of information communication technology (ICTs) (e.g computers with voice recognition software, adapted computer hardware)	
Nature of service:	

Organisation or undertaking of specific academic activities to accommodate students with disabilities (e.g organisation and administration of extra time during exams, organisation of additional tutorial assistance)	
Nature of service:	
Other services:	

For office use

D3. Please explain how the support services that you offer are organised at your institution. *(please tick the appropriate box or boxes if more than one answer is appropriate)*

The support services are offered directly through a disability unit/disability programme on campus	
The support services are offered through the student affairs division on campus	
Each faculty/department offers services directly to students with disabilities within the faculty/department	
The support services are offered through another learning support unit/programme on campus (e.g. academic development centre)	
Other:	

D4: Are any of the support services that your institution offers to students with disabilities (as indicated above) provided through an external agency/organisation? (e.g. material is brailled by an off-campus brailling service)

For office use

Yes	
No	

D5: If **Yes**, please explain.

D6. In the table below, please provide the following information for all staff members who are presently employed in a formal capacity to provide support to students with disabilities on your campus. Please fill in your own details in the first row.

Job title	Job description (main responsibilities)	Nature of contract	
		Permanent contract (two years or more)	
		One year renewable contract	
		Contract for less than one year	
		Permanent contract (two years or more)	
		One year renewable contract	
		Contract for less than one year	
		Permanent contract (two years or more)	
		One year renewable contract	
		Contract for less than one year	
		Permanent contract (two years or more)	
		One year renewable contract	
		Contract for less than one year	

For office use

D7. If your services are offered directly through a disability unit/disability programme on campus, do you have contact with/collaborate with any other learning support units on campus? (e.g. academic development programme, writing centre etc)

Yes	
No	

D8. If **Yes**, please explain how you collaborate with other learning support units/programmes on campus.

_____

_____

_____

D9. Do students pay any additional costs to use the services you provide?

Yes	
No	

D10. If **Yes**, please explain.

_____

_____

_____

D11. Do you make use of volunteers in the provision of support to students with disabilities on your campus?

Yes	
No	

D12. If **Yes**, please explain the kind of work which the volunteers do.

_____

_____

_____

D13. If you answered **Yes** to **Question D11**, please indicate whether the volunteers receive any kind of payment for their services.

Yes	
No	

For office use

D14: Do you provide any other services for students with disabilities that are not related to the direct provision of teaching and learning support? (e.g. assisting with the provision of residential accommodation for students with disabilities, acting in an advisory capacity to institution's management around disability related issues)

Yes	
No	

D15: If **Yes**, please explain.

_____

_____

_____

_____

If you have answered Questions D2 to D15, please proceed now to Section E

D16. If you answered **No** to **Question D1**, please explain how students with disabilities on your campus are supported in their studies.

_____

_____

_____

D17: If you presently have no provision to support students with disabilities in their studies, do you have any plans in place to develop any support systems in the future?

Yes	
No	

D18: If **Yes**, please explain what plans are in place.

_____

_____

_____

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SECTION E: CURRICULUM FLEXIBILITY/RESPONSIVENESS

For office use

E1. Do you undertake any work with the academic staff in supporting them/assisting them to ensure that students with disabilities are able to participate more effectively in their lectures/tutorials/seminars? (e.g using various kinds of teaching methods, different forms of assessment, organising the classroom in new ways etc)

Yes	
No	

E2. If **Yes,** please explain what kind of work you do with the academic staff.

_____

_____

_____

E3. If **No**, what has stopped you from working with the academic staff around curriculum flexibility issues? *(please tick the appropriate box or boxes if more than one answer is appropriate*)

There is insufficient capacity (human or financial) to undertake this kind of work	
This kind of work will not benefit students with disabilities	
Academic staff are resistant to being supported in this way	
Do not have sufficient management support to undertake this kind of work	
Other:	

E4: If you have filled in the table above (E3), do you have any plans in place to work more directly with the academic staff?

Yes	
No	

E5: If **Yes**, please explain what plans you have in place.

For office use

E6: If **No**, please comment.

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SECTION F: FUNDING OF SUPPORT SERVICES

F1: Does most of the funding for the services you offer (more than 50%) come directly from internal sources (within the institution) (e.g. student affairs budget), or external sources (outside the institution) (e.g. donor funding)?
(please tick the appropriate box)

Internal sources	☐
External sources	☐
Approximately half comes from internal sources and half from external sources	☐
Unsure	☐
Other source (please explain):	☐ ☐

F2: If you receive money from internal sources (within the institution), please describe where your funding comes from.

F3: If you receive money from external sources (outside the institution), please describe where your funding comes from.

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SECTION G: NETWORKING

For office use

G1. Do you collaborate with any other higher education institutions around teaching and learning support for students with disabilities? (e.g sharing information, sharing assistive devices, joint projects etc)

Yes	
No	

G2: If **Yes**, please explain the nature of your collaboration.

_____

_____

_____

G3: If **No**, do you think that collaboration between higher institutions in your region would improve the provision of support services to students with disabilities in your institution?

Yes	
No	

G4: Do you collaborate with any other organisations (e.g NGOs) regarding teaching and learning support for students with disabilities? (e.g sharing information, joint projects etc)

Yes	
No	

G4: If **Yes**, please explain the nature of your collaboration.

_____

_____

_____

G5: If **No**, do you think that collaboration between your institution and other organisations in your region would improve the provision of support services to students with disabilities in your institution?

Yes	
No	

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SECTION H: CONSTRAINTS

For office use

H1: Indicate in order of priority the three most important constraints to providing effective teaching and learning support to students with disabilities on your campus. (*indicate your choice by using the numbers from the list below*)

1	Insufficient funding
2	Lack of support from senior management in the institution
3	Resistance from academics in the institution
4	Students with disabilities are reluctant to ask for assistance
5	Insufficient staff to provide an effective service

Choice 1 (most important): _____

Choice 2 (2nd most important): _____

Choice 3 (3rd most important): _____

H2: Are there any other constraints that you feel are important to providing effective teaching and learning support to students with disabilities on your campus? Please explain.

_____

_____

_____

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SECTION I: FUTURE PLANS

For office use

I1. Do you have any plans in place to improve the provision of teaching and learning support to students with disabilities on your campus in the future?

Yes	
No	

I2. If **Yes**, please describe your plans for the future.

_____

_____

_____

_____

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SECTION J: OTHER

J1. Please feel free to comment on any issue that you think the questionnaire has not covered or make any other comments about this questionnaire.

_____

_____

_____

_____

_____

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_____