# STELLENBOSCH UNIVERSITY FACULTY OF HEALTH SCIENCES

# DEVELOPING A POLICY ANALYSIS FRAMEWORK TO ESTABLISH LEVEL OF ACCESS AND EQUITY EMBEDDED IN SOUTH AFRICAN HEALTH POLICIES FOR PEOPLE WITH DISABILITIES

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# **KEYWORDS AND KEY PHRASES:**

Disability Rights		
Equalisation of Opportunities		
Equity		
Free Health Care		
Health Policy Analysis		
Human Rights		
National Rehabilitation Policy		
People with Disabilities		
Primary Health Care		

Community Based Rehabilitation

Access

**Assistive Devices** 

Rehabilitation

# **ABSTRACT**

# **Purpose**

To date no health policy analysis tool has been developed to analyse access and equity for people with disabilities. Further, there is very little information available on health and disability policy implementation. The intention of this research is to develop a health policy framework to analyse access and equity, focussing on people with disabilities, that can be used by policy makers. This research analyses four health policies and focuses on the facilitators and the implementation barriers. The findings of this research will impact on new policies developed in the future.

#### Method

The study included both a desk - top review and a descriptive study. The desk - top review entailed the formulation of a disability - focussed framework for health policy. This was then used to analyse health policies in terms of their disability inclusiveness. Qualitative data was gathered from interviews and questionnaires and focussed on policy processes and implementation. This was incorporated into the analysis.

An ideal seven - step policy process model was developed. This was used to compare the reported policy process with the four policies followed. The four health policies used in the research are: the Primary Health Care Policy, the National Rehabilitation Policy, the Provision of Assistive Devices Guidelines and the Free Health Care Policy.

Four key informants with extensive experience and knowledge were interviewed on policy processes and implementation. Questionnaires were also sent to Provincial Rehabilitation Managers to obtain their viewpoints on barriers and facilitators to policy implementation.

#### Results

Analysis of the four health policies showed varying levels of access and equity features. In terms of policy processes: all four policies had different stakeholders who initiated the policy development process. Two of the policies viz. the National Rehabilitation Policy and the Provision of Assistive Devices Guidelines, had people with disabilities as part of the stakeholder group involved in the policy formulation. The National Rehabilitation Policy had a comprehensive monitoring and evaluation section whereas this was absent in the other three policies.

From the information gained from interviews and questionnaires, it appeared that the barriers to policy implementation included: attitudes, environmental access, human and financial resources. Facilitators to policy implementation include: policy process and design, availability of human and financial resources, support systems, management support, organisational structures and finally positive attitudes that all impacted favourably on policy implementation.

#### **Conclusions**

The developed health policy analysis framework served its purpose. Most policies did not have monitoring and evaluation guidelines that make implementation difficult to assess. Recommendations are made to improve policy design and content, specifically related to access and equity. Intersectoral collaboration and disability coordination needs to be improved. People with disabilities also need to engage with government departments, to monitor implemented policies and to advocate for change from outside the health system.

# **OPSOMMING**

# Doel

Daar is geen spesifieke analise hulpmiddel in gesondheidsbeleid om die aspekte rondom toegang en gelykheid vir gestremde persone te beklemtoon nie. Terselftertyd is daar 'n tekort aan beskikbare inligting oor die implementering van gesondheids- en gestremheidsbeleid. Die doel van die navorsing is om 'n raamwerk vir gesongheidsbeleid te ontwikkel wat gebruik kan word deur alle burokrate, beleidsmakers and administrateurs om die kritieke aspekte van toegang en gelykheid met betrekking tot persone met gestremhede beter te verstaan. Dit sal ook die uitdagings en ontsperring faktore vir implementering by vier gesondheidsbeleide ondersoek. Hierdie nuwe verstandhouding kan ook gebruik word om toekomstige beleid te verbeter. Hierdie dissertasie het ook ten doel om aanbevelings te maak.

#### Methode

Hierdie studie was deels van 'n lessenaar-af oorsig en deels 'n beskrywende studie. Die oorsig het die formulering van 'n raamwerk vir gesondheidsbeleid analise, gefokus op gestremheid, behels. Dit was toe gebruik om gesondheidsbeleid te analiseer ten opsigte van insluiting van gestremheid. Kwalitatiewe inligting, verkry vanaf onderhoude en vraelyste, is ingesluit in die analise om sodoende die beliedsprosesse en hul implementering te verstaan.

'n Ideale sewe-stap beleidsprosesmodel is ontwikkel en is vergelyk met die beleidsprosesse wat die vier beleide gevolg het. Die vier beleide ter sprake is: die Primere Gesondheidsorg Beleid, die Nasionale Rehabilitasie Beleid, die Verskaffing van Gestremde Hulpmiddels Riglyn en die Gratis Gesondheidsorg Beleid.

Onderhoude is gevoer met vier belangrikkeinformante van een provinsie om hulle kennis oor beleidsprosesse en ondervinding in implementering van beleid te bepaal. Vraelyste is ook aan die Provinsiale Rehabilitasie Bestuurders gestuur om hulle opinie te verkry oor uitdagings en ontsperring faktore vir implementering van beleid.

# **Uitslae**

Die analise van die die vier gesongheidsbeleide het verskillende vlakke van toegang en gelykheid einskappe getoon. In terme van beleidsprosesse het verskillende betrokke mense die formulering van beleidsproses in al vier van die beleide geinisieer.

In twee van die beleide, naamlik Nasionale Rehabilitasie Beleid en die Verskaffing van Gestremde Hulpmiddels Riglyn, was gestremde persone deel van die formulering van die beleid. Die Nasionale Rehabilitasie Beleid het 'n uitgebreid monitering en evaluering komponent, wat ontbreek by die ander drie beleide.

Sommige uitdagings vir beleids-implementering sluit in: houding, omgewingstoegang, menslike en finansiële hulpbronne. Ontsperring faktore vir beleidsimplementering sluit in: beleidsproses en ontwerp, beskikbaarheid van menslike en finansiële hulpbronne tesame met ondersteuning vanaf bestuur, organisatoriese strukture en ten laaste positiewe houding, wat almal 'n positiewe impak het op beleids-implementering.

# Gevolgtrekkings

Die geformuleerde raamwerk vir analise van gesondheidsbeleid voldoen suksesvol aan sy doel. Die meeste beleide het nie riglyne vir monitering en evaluering nie, wat toegang tot implementering bemoeilik. Aanbevelings is gemaak om beleidsontwerp en inhoud te verbeteer asook om toegang en gelykheid aspekte in te sluit.

Intersektorale samewerking en koordinasie met gestremdes moet verbeter. Persone met getremdhede moet ook betrokke raak met regeringsdepartmente om geimplementeerde beleide te monitor en om te vra vir veranderinge in die gesondheidsisteem.

# **DECLARATION**

I, the undersigned, hereby declare that "Developing a Policy Analysis Framework to Establish Level of Access and Equity Embedded in South African Health Policies for People with Disabilities" is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree or examination, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full name: Françoise Bernadette Law

Date: 1 September 2008

Signed .....

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# **PREFACE**

In the Code of Conduct for Public Servants, it is stated that no public servant should openly criticise the government. The researcher is a committed and dedicated public servant, who has served for many years in the Gauteng Department of Health. For the purpose of this research, the researcher took the viewpoint of a scholar.

It is therefore NOT the intention of the researcher to negatively criticise government; but rather to analyse current and past practises and offer recommendations.

There are factors that may have hindered the implementation of policies. There may also be deficiencies in the policies themselves; the reasons for these are not within the scope of this research. The researcher is merely pointing out the obvious and attempted to remain objective.

# **CONTENTS**

<b>KEYWO</b>	RDS AND KEY PHRASES:	II
ABSTR	ACT	111
OPSOM	MING	V
	RATION	
	WLEDGEMENTS	
_		
PREFA	CE	IX
CONTE	NTS	IX
ACRON	IYMS	.XV
GLOSS	ARY	.XV
CHAPTI	ER 1: INTRODUCTION AND BACKGROUND	1
1.1 I	NTRODUCTION	1
	BACKGROUND	
1.2.		
1.2.		
1.2		
1.2.		
1.2		
1.2.	~ ·	
1.2.		
1.2.		
1.2.		
	RESEARCH PROBLEM	
1.3.		
1.3		
	MOTIVATION	
1.4.		
1.4.		
1.5 F	PROJECT AIMS AND OBJECTIVES	17
1.5.	l Aim	17
1.5.	2 Specific Objectives	17
1.6	SIGNIFICANCE CLARIFIED	17
CHAPTI	ER 2: LITERATURE REVIEW	19
2.1	DEFINITIONS OF POLICY ANALYSIS	19
2.2 N	MODELS FOR POLICY ANALYSIS	20
2.2.		
2.2		
2.2		22
	DEVELOPING A FRAMEWORK MODEL FOR POLICY ANALYSIS WHICH DETERMINES	_
	EVEL OF ACCESS AND EQUITY	
2.3.		
2.3	J	24
2.3		
	IDEAL" FLOW OF POLICY DEVELOPMENT, IMPLEMENTATION AND EVALUATION	20
	RESEARCH	26

CHAP	TER 3: METHODOLOGY	28
3.1	SPECIFIC OBJECTIVES	28
3.2	RESEARCH DESIGN	
	SUBJECTS	
	ELIGIBILITY CRITERIA	
	4.1 Eligibility Criteria: Sample 1	
3.	4.2 Eligibility Criteria: Sample 2	
	4.3 Eligibility Criteria: Sample 3	31
	DATA COLLECTION METHODS	
3.6	RELIABILITY AND VALIDITY FOR DEVISED HEALTH POLICY ANALYSIS TOOL	34
3.7	PROCEDURES	35
	7.1 Piloting Of Devised Policy Analysis Framework	
	7.2 Strategy To Increase Participation In Questionnaires	
	DATA ANALYSIS	37
	8.1 Developed Health Policy Analysis Framework	
	8.2 Data Analysis of Document Reviews	
	8.3 Data Analysis of Interview Transcripts	
	8.4 Data Analysis of Questionnaires (Interview Checklists)	
	9.1 The Scientific Relevance of the Study	
	9.2 Suitability of the Investigator	
	9.3 The Relevance of the Study Rationale and the Appropriateness of the Inclusion /Exclusion Criteria	37 1 to
J.,	the South African Context:	40
3.	9.4 Informed Consent and Confidentiality:	
3.	9.5 Approval for Research Proposal	
CHVD	TER 4: RESULTS	44
СПАР		
4.1	USE OF THE DEVELOPED HEALTH POLICY ANALYSIS FRAMEWORK	
4.2		
4.3		
4.4	MECHANISMS FOR STAKEHOLDER INVOLVEMENT IN POLICY DEVELOPMENT	
4.5	POLICY IMPLEMENTATION	
4.6	MONITORING AND EVALUATION MECHANISMS FOR POLICIES	_
4.7		
	THE PRIMARY HEALTH CARE POLICY 2000 <sup>30</sup>	
	8.1 Brief Aim of the Policy	
	8.2 Problem Formation (Context)	
	8.3 Actors	
	8.4 Process of Policy Formulation and Adoption	
	8.5 Policy Content	
	8.7 Equity Impact	
	8.8 Policy Implementation	
	THE NATIONAL REHABILITATION POLICY 2000 <sup>31</sup>	61
	9.1 Brief Aim of the Policy	
4.	9.2 Problem Formation (Context)	61
4.	9.3 Actors	
	9.4 Process of Policy Formulation and Adoption	
	9.5 Policy Content	
	9.6 Accessibility of Services	
	9.7 Equity Impact	
	9.8 Policy Implementation	/ 3
4.10	A GUIDELINES FOR THE PUBLIC SECTOR 2003 <sup>32</sup>	76
1		
	10.1 Brief Aim of the Guideline	
	10.2 Problem Formation (Context)	
	10.4 Process of Guidelines Formulation and Adoption	
	10.5 Guidelines Content	
	10.6 Accessibility of Services	
	10.7 Equity Impact	

	10.8 Guidelines Implementation	82
4.11	THE FREE HEALTH CARE POLICY FOR PEOPLE WITH DISABILITIES AT THE HOSPITAL	
	LEVEL 2003 <sup>33</sup>	
	11.1 Brief Aim of the Policy	
	11.2 Problem Formation (Context)	
	11.3 Actors	
	11.4 Process of Policy Formulation and Adoption	
	11.5 Policy Content	
	11.0 Accessionity of Services	
	11.8 Policy Implementation	
	POLICY ANALYSIS	
	STAKEHOLDERS ROLES	
	COMPARISON OF POLICY ANALYSIS FOR ALL FOUR POLICIES	
	14.1 Brief Aim of the Analysed Policies	
	14.2 Problem Formation (Context)	
	14.3 Actors	
	14.4 Process of Policy Formulation and Adoption	99
	14.5 Policy Content	
	14.6 Accessibility of Services	
	14.7 Equity Impact	
CHAP	TER 5: DISCUSSION	104
5.1	IMPLEMENTATION OF POLICIES	108
5.2	GENERAL DISCUSSION OF BARRIERS TO POLICY IMPLEMENTATION	110
	2.1 Attitudinal Barriers	
	2.2 Environmental Access	
	2.3. Human Resources	
	2.4 Financial Resources	
5.3	GENERAL DISCUSSION ON FACILITATORS TO POLICY IMPLEMENTATION	
	3.1 Attitudes	
5	3.2 Political Will	122
5	3.3 Process and Product Design	122
5	3.4 Resources	122
	3.5 Management Support and Organizational Structure	122
5.4	POLICIES AND SERVICES AS EXPERIENCED BY PEOPLE WITH DISABILITIES AT THE	
	GROUND LEVEL	123
5.5	TRANSPORT AS A BARRIER TO ACCESSING HEALTH SERVICES FROM THE ENDUSER'S	
	POINT OF VIEW	125
5.6	THE WAY FORWARD	125
0114 D	TER A: DECOMMENDATIONS	407
СНАР	TER 6: RECOMMENDATIONS	127
6.1	RECOMMENDATIONS FOR POLICY PROCESSES	127
	RECOMMENDATIONS FOR POLICY ANALYSIS	
_	RECOMMENDATIONS ON ADDRESSING BARRIERS TO POLICY IMPLEMENTATION	_
	RECOMMENDATIONS ON STRENGTHENING FACILITATORS TO POLICY IMPLEMENTATION	
	RECOMMENDATIONS FOR FUTURE POLICIES IN TERMS OF CONTENT	
	TER 7: LIMITATIONS OF THIS RESEARCH AND AREAS FOR FUTURE RESEARCH	
7.1.	LIMITATIONS OF THIS RESEARCH	132
	1.1 Limitations on the Sources of Information for the Study	
7.2	AREAS FOR FUTURE RESEARCH	133
СНФЬ.	TER 8: CONCLUSION	134
J. 1/1		. 0-1
CHAP	TER 9: REFERENCES	135
A DDE	NDICES	120

# **LIST OF FIGURES**

FIGURE 1:	ALTMAN'S MODEL FOR DISABILITY DEFINITIONS	. 4
	REPRESENTATION OF THE GILSON AND WALT MODEL OF POLICY ANALYSIS	
FIGURE 3:	GILSON ET AL. ANALYTICAL FRAMEWORK MODEL	21
FIGURE 4:	REPRESENTATION OF THE PATTON AND SAWICKI MODEL OF POLICY ANALYSIS	22
FIGURE 5:	PROPOSED 7 STEP METHOD OF POLICY FORMULATION, IMPLEMENTATION AND MONITORING	3
	OF HEALTH POLICIES TO ENSURE INCLUSION OF PEOPLE WITH DISABILITIES' NEEDS	
FIGURE 6:	DEVISED POLICY ANALYSIS FRAMEWORK SENSITIVE TOWARDS ACCESS AND EQUITY	
	NEEDS OF PEOPLE WITH DISABILITIES	37
FIGURE 7:	SUMMARY OF DIFFERENT MECHANISMS WHICH ALLOW PEOPLE WITH DISABILITIES TO BE	
	INVOLVED IN POLICIES	44
FIGURE 8:	POLICY IMPLEMENTATION FROM NATIONAL DEPARTMENT TO PROVINCIAL DEPARTMENTS	
	OF HEALTH	45
FIGURE 9:	FORMULATION OF THE PRIMARY HEALTH CARE POLICY	
	: NATIONAL REHABILITATION POLICY FORMULATION METHOD	
	: FORMULATION OF THE PROVISION OF ASSISTIVE DEVICES GUIDELINES	
	: FREE HEALTH CARE POLICY FORMULATION METHOD	
	: LEVEL OF ACCESSIBILITY OF PRIMARY HEALTH CARE FACILITY PER PROVINCE IN	
	SOUTH AFRICA 2003 ACCORDING TO HEALTH SYSTEMS TRUST REPORT <sup>50</sup>	12
FIGURE 14	:GROWTH IN HUMAN RESOURCE CAPITAL OVER A TEN - YEAR PERIOD11	
	THERAPY PROFESSIONALS VACANCY RATE IN SOUTH AFRICA IN 1997 ACCORDING	
	TO DATA PROVIDED IN NATIONAL REHABILITATION POLICY. 31	15
FIGURE 16	: POTENTIAL PATIENT WORKLOAD PER REHABILITATION PROFESSIONAL PER	
	PROVINCE 1997	16
FIGURE 17	: Health Personnel Vacancy Rate per Province According to Ntuli and $Day^{52}$ . 1	17
	LIST OF TABLES	
TABLE 1:	COMPARISON OF DIFFERENT DEFINITIONS AND CONCEPTUAL MODELS FOR DISABILITY	5
TABLE 2:	INTERNATIONAL LEGISLATION AND POLICIES IN FAVOUR OF EQUITY AND RIGHT TO HEALTH	
INDEL 2.	FOR PEOPLE WITH DISABILITIES IN CHRONOLOGICAL ORDER	
TABLE 3:	SOUTH AFRICAN LEGISLATION AND POLICIES IN FAVOUR OF EQUITY AND RIGHT TO HEALTH	
.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	FOR PEOPLE WITH DISABILITIES	
TABLE 4:	HEALTH POLICIES IN SOUTH AFRICA FOR PEOPLE WITH DISABILITIES	
	SUMMARY OF INFORMATION ABOUT SUBJECTS	
	ANALYSIS OF INFORMATION SOURCES	
	SCHEMATIC REPRESENTATIONS OF RESULTS	
TABLE 9:	INTERVIEWEES VIEWPOINTS OF MECHANISMS IN PLACE TO	
	INTERVIEWEES VIEWPOINTS OF MECHANISMS IN PLACE FOR	
	RESEARCHER'S INTERPRETATION ON HOW OBJECTIVES OF NATIONAL REHABILITATION	
.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	POLICY BRINGS ABOUT ACCESS TO AND EQUITY IN HEALTH SERVICES	72
TARIF 12.	LEGISLATION AND POLICIES THAT ADVOCATE FOR FREE HEALTH CARE SERVICES	
	Comparison of Policy Process of Analysed Policies versus Researcher's	50
IADEL IO.	PROPOSED IDEAL POLICY PROCESS MODEL	በበ
	THO GOLD IDEAL FOLIOT FRODEO MODEL	50

# **LIST OF APPENDICES**

APPENDIX 1:	INTERVIEW QUESTIONS FOR INFORMANTS AT NATIONAL, PROVINCIAL, HOSPITAL	142
APPENDIX 2:	AND DISTRICT LEVELSQUESTIONNAIRE (INTERVIEW CHECKLIST) SENT TO PROVINCIAL REHABILITATION	142
ALLENDIA Z.	PROGRAMME MANAGERS	144
APPENDIX 3:	INFORMED CONSENT FORM AND INFORMATION PAGE	
APPENDIX 4:	EARLIER VERSION OF FRAMEWORK WHICH WAS PILOTED	150
APPENDIX 5:	STEPS TAKEN TO ELICIT RESPONSES FROM PROVINCIAL REHABILITATION	
	PROGRAMME MANAGERS	153
APPENDIX 6:	APPROVAL LETTERS FROM COMMITTEE FOR HUMAN RESEARCH	154
APPENDIX 7:	PRIMARY HEALTH CARE POLICY FACILITATORS AND BARRIERS TO	
	IMPLEMENTATION	157
APPENDIX 8:	NATIONAL REHABILITATION POLICY FACILITATORS AND BARRIERS TO	
	IMPLEMENTATION	•
APPENDIX 9:	STANDARDISATION OF THE PROVISION OF ASSISTIVE DEVICES FACILITATORS AND	
	BARRIERS TO IMPLEMENTATION	
APPENDIX10:	FREE HEALTH CARE POLICY FOR PEOPLE WITH DISABILITIES ON THE HOSPITAL LI	
	FACILITATORS AND BARRIERS TO IMPLEMENTATION	
APPENDIX11:	SUMMARY OF POLICY ANALYSIS	162

### **ACRONYMS**

AAC - Alternative and Augmentative Communication

ARV - Anti-Retrovirals

CBR – Community Based Rehabilitation

DART - Disability Action Research Team

DeafSA - Deaf Federation of South Africa

DPO - Disabled People's Organization

DPSA - Disabled People South Africa

FHC - Free Health Care

HIS - Health Information System

HIV - Human Immunodeficiency Virus

ICF - International Classification of Functioning, Disability and Health

INDS – Integrated National Disability Strategy

NCPPD - National Council for Persons with Physical Disabilities in South Africa

NGO - Non - Governmental Organisation

NRP – National Rehabilitation Policy

OSDP -Office on the Status of Disabled Persons

OTASA - Occupational Therapy Association South Africa

PADG - Provision of Assistive Devices Guidelines

PHC - Primary Health Care

SAIDA - South African Inherited Disorders Association

SABC - South African Broadcasting Corporation

SANCB - National Council for the Blind

SASLA – South African Speech and Language Association

SASP – South African Society for Physiotherapy

SL - Sign Language

TB - Tuberculosis

UK – United Kingdom

**UN – United Nations** 

INICEF - United Nations International Children's Fund

USA - United States of America

WHO – World Health Organisation

#### **GLOSSARY**

### ACCESS

Equal opportunities for people with disabilities to use the physical environment, transport, information and communications and public facilities and services both in urban and rural areas on an equal basis with others.<sup>8</sup>

# • EQUALISATION OF OPPORTUNITIES

"Equalisation of opportunities means the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all."<sup>31</sup>

# EQUITY

Equity may be defined as a fair distribution of benefits from social and economic development. Equity is used in different conceptual senses but in this research, equity is used in the sense of equal access to health services for all (opportunity equality).<sup>43</sup>

# HEALTH POLICY ANALYSIS

"Health Policy Analysis is the process of assessing and choosing among spending and resource alternatives that affect the health care system, public health system, or the health of the general public. Health policy analysis involves several steps: identifying or framing a problem; identifying who is affected (stakeholders); identifying and comparing the potential impact of different options for dealing with the problem; choosing among the options; implementing the chosen option(s); and evaluating the impact. The stakeholders can include government, private healthcare providers (e.g. hospitals, health plans, office-based clinicians), industry groups (e.g. pharmaceutical, biotechnology, and medical device manufacturers), professional associations, industry and trade associations, advocacy groups, and consumers."<sup>36</sup>

# PEOPLE WITH DISABILITIES

"Disability is the loss or elimination of opportunities to take part in the life of the community, equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society. These barriers may be due to economic, physical, social, attitudinal and/or cultural factors." 10

# **CHAPTER 1: INTRODUCTION AND BACKGROUND**

#### 1.1 INTRODUCTION

People with disabilities have equal human rights as do people without disabilities. However they tend to be one of the more vulnerable groups whose rights are not always acknowledged, and as a result they tend to be marginalized by society. However, with the Disability and Human Rights Movements, there is now a multitude of both national and international pieces of legislation and policies, which promote equality, inclusion of people with disabilities, and the prevention of unfair discrimination for all.

People with disabilities become ill and require health care services just like any one in the general population. Furthermore, many people with disabilities have health care needs related to their impairments (although this is not the case for all people with disabilities). There are both specific and general health policies that are in place to ensure that the rights of people with disabilities to access health care and remain in good health are realised. However, it is known that people do not access these services equally. In South Africa, the baseline survey on disability of 1998<sup>1</sup> found that different race and gender groups had different levels of access to services. In particular Whites and Indians were the most likely race groups to receive medical rehabilitation services, and Indians were the most likely to receive assistive devices services, whereas Whites were the most likely to receive educational services. These differences highlight the unequal provision of services across the race groups. Gender wise: females were also more likely to receive assistive devices services than males but the reasons for this were not clear. Respondents reported that services being too expensive and not having money (to pay for services or transport) were the biggest problems experienced with services.

With South Africa signing the United Nations Convention on the Rights of Persons with Disabilities in April 2008, it is essential that all (health) policies should take into account the needs of people with disabilities and to accommodate them into its provisions.

Having briefly introduced the topic, what follows now, in this Chapter 1, is the Background which sets the backdrop for this research and which will culminate in the motivation, aim and objectives of the study. In Chapter 2 the literature review, different models for health policy analysis are presented. Using these existing models together with the review of points from international and local legislation, considered important to ensure equity and access to health services, a health policy analysis tool will be developed which will determine the level of access and equity embedded in health policies.

In the following chapter, Chapter 3, the methodology of this dissertation is put forward. The descriptive data obtained from the interviews and questionnaires are presented in Chapter 4. The analyses of the four health policies using the devised health policy analysis framework are described in Chapter 4. The descriptive data will give the reader an understanding of health policies formulation as well as about stakeholder involvement in the policy process. Furthermore policy implementation and monitoring and evaluation processes will also be described. The barriers and facilitators to policy implementation will also be analysed according to themes for each policy and then overall in this chapter.

Chapter 5 discusses the findings presented in the previous chapter. In particular, the sources of information for the study, policy analysis and stakeholders roles are discussed. A comparison of the results of the policy analysis for all four policies are made. Policy implementation, the barriers and facilitators to this are deliberated upon. Finally the other side of policy implementation is presented, that is, from the viewpoint of the end-user. Bearing in mind that this was not the focus of the research, only two pieces of literature are presented which describes services and experiences that people with disabilities have had at the ground level. The dissertation then poses recommendations for policy analysis, as well as how to address barriers to policy implementation in Chapter 6. Recommendations are also given on the strengthening of facilitators to policy development. Limitations to the study and areas for future research are presented in Chapter 7. Having met all its objectives, the dissertation then concludes in Chapter 8.

#### 1.2 BACKGROUND

In this section, disability and various definitions thereof are explored in order to set the terms of reference as well as to review what impact the lack of consensual definitions for disability have had on policies and research. Thereafter the international legislation and policies in favour of equity and right to health for people with disabilities will be scrutinised, so that the elements of equity and access to health can be incorporated into the disability policy analysis framework. Then looking locally, policies and legislation, which also promote equity and access to health care, will be looked at and finally there is a short description of disability - specific and general health policies that will be analysed using the devised framework.

# 1.2.1 Disability and Health

Disability is not easily conceptualised and is multidimensional; as such, there is no single definition of disability as differing cultures, social institutions, and physical environments influence it. The current international guide to defining what is meant by disability is the World Health Organization's International Classification of Functioning, Disability and Health (ICF)<sup>2</sup>

The ICF presents a framework, which encompasses the complex multifaceted interaction between health conditions, and personal and environmental factors that determine the extent of disablement. The framework provides us with four classifications namely: body functions, body structure, activity and participation, and environmental factors. A person may have a health condition or impairment, which affects his/her body functions and / or body structure. The person is thereby limited in his/her activities and this has an impact on his/her participation in society. Additionally, the environmental factors interact with the person's health condition to facilitate or create barriers to participation in society. For example, stairs are a barrier to a person using a wheelchair and a ramp a facilitator for the same person.

The ICF takes cognisance that every person can have a greater or lesser deterioration in health at some point in their lives and thereby experience some disability. There is no predetermined point that separates 'disabled' from 'non-disabled', and a population can show the whole continuum from full functioning to full disability. Each person's experience of disability is different to the next person even though the other person may have exactly the same health condition, as this is dependent on the physical, social and attitudinal environment. The ICF thus provides a common language to describe this experience.

# 1.2.2 Different Approaches to Defining Disability

There is growing consensus that there is no single definition of disability and that definitions are purpose-specific.<sup>3,4</sup> Disability needs to be defined within context, rather than focussing on the inability of people that inadvertently leads to stigmatisation and categorisation.<sup>5</sup> Altman<sup>4:102</sup> suggests that when trying to make sense of disability definitions, one needs to take into consideration the following: "the structure, orientation, and source of the definitions as well as the difference between simple single-purpose statements of definition and theoretical models that map the relationship of conceptual elements seen as part of the definition and classification schemes and other forms of translating the concepts into empirical measures." Altman<sup>4</sup> developed a framework to analyse disability definitions and concepts and it is represented in Figure 1 below:

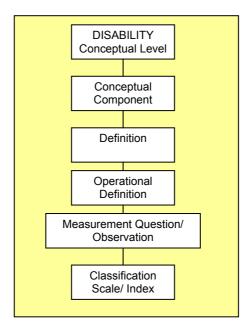


Figure 1: Altman's Model<sup>4</sup> for Disability Definitions

Table 1 below depicts a comparison between definitions for disability from six sources. The definitions for disability can be broad or specific. As can be seen from Figure 1, it is necessary to formulate operational definitions in order to narrow down the selection and to classify or categorise people as 'disabled' or 'non-disabled'; for example, for the purposes of processing applications for social assistance or for monitoring the targeted group for various policies. The first three definitions viz. those of the UN Convention, that of the Disabled People South Africa and that approved by the South African Cabinet, are broad definitions, which encompass all aspects of "disablement" but are very difficult to operationalise. The last three definitions listed in Table 1 do not address environmental issues in part to allow for a simpler operationalisation of the definitions. It is thus necessary to analyse definitions used in policies in order to see how they are going to operationalise them when targeting people with disabilities.

# 1.2.3 Disability Statistics

Reported disability prevalence rates vary widely. In many developed countries, the rates are quite high. The prevalence rates in the United States of America (USA) and Canada are 19.4% and 18.5%, respectively.<sup>6</sup> Conversely, developing countries often report very low rates. In countries such as Kenya and Bangladesh the reported rates of disability are under 1%. These rates vary for a number of reasons: differing definitions of disability, different measurement methodologies, and variance in the quality of that measurement<sup>6</sup>. In South Africa, the Census conducted by Statistics South Africa in 2001<sup>7</sup> established that the South African population was 44 819 778 with 5% being disabled,<sup>7</sup> i.e. just over 2.25 million people. The National Baseline Disability Survey1 for the Department of Health conducted in 1999 reflected a similar percentage estimate, viz. 5.7% - 6.1%.

SOURCE	UN CONVENTION 2006 <sup>8</sup>	DISABLED PEOPLE SOUTH AFRICA CONSTITUTION 2006 <sup>9</sup>	SOUTH AFRICAN CABINET <sup>10</sup>	EMPLOYMENT EQUITY ACT <sup>11</sup>	DISABILITY GRANTS APPLICATIONS <sup>10</sup>	FREE HEALTH CARE FOR PEOPLE WITH DISABILITIES 10
DEFINITION	"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."	Disability – is a social construct [and not a description of a medical condition in the individual] that represents the outcome of the interaction between impairments and the negative environmental impacts on the individual, in recognition that society is constructed, both through the characteristic of its build environment and functioning, on the one hand and the prevailing attitudes and assumptions on the other, which results in restricted opportunities for people with disabilities to participate on an equal basis, and failure of society to adapt to and accommodate their needs; and the term 'disabled' has a corresponding meaning.	"Disability is the loss or elimination of opportunities to take part in the life of the community, equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society. These barriers may be due to economic, physical, social, attitudinal and/or cultural factors."	"People who have a long-term or recurring physical or mental impairment which substantially limits their prospects of entry into, or advancement in, employment".	"A person is eligible for a disability grant if he/she has (a) a moderate to severe limitation in ability to function or ability to perform daily life activities as a result of a physical, sensory, communication, intellectual or mental impairment which makes him/her unfit to obtain by virtue of any service, employment or profession, the means needed to enable him or her to provide for his or her own maintenance; (b) income below a prescribed means level; and (c) attained the prescribed age."	"A person is eligible for free health care if he/she has (a) a moderate to severe limitation in ability to function or ability to perform daily life activities as a result of physical, sensory, communication, intellectual or mental impairment and/or psychosocial participation restriction and (b) income below a prescribed means level. The limitation or restriction needs to have lasted or has a prognosis of lasting longer than a year and which exists after maximum correction or control of the impairment."
COMMENT	Talks about the influence of the environment on people with disabilities. It is a broad definition	This definition follows that of the UN Convention. This is a broad definition that encompasses all aspect of the environment and society.	As for Disabled People of South Africa constitution.  Mention is made of the types of barriers that cause the activity limitations and participation restrictions.  This is also a broad definition.	This definition views specifically the economic participation of people specifically so that it can be applied to people with disabilities in the work environment	Takes into consideration specifically the person who is unable to work. Additional criteria are added on, as the person needs to pass the means test and be 18 years or older, in order to qualify for the Grant. No mention is made of the environment, but this is purposely as there can be many instances where people can argue that they are disabled by virtue of not being able to return to work due to environmental or attitudinal barriers e.g. if they have to work in an inaccessible building and this would mean that more people would qualify for the grant other than the targeted group. Disability Grants are merely a cash grant; they are a disincentive for people with disabilities to find work. There is a move by Social Development to look at support systems for people with disabilities to be employed especially grant recipients.	This is a specific definition. Again the means test is mentioned and the duration of the condition is mentioned to exclude people with temporary disabilities, and this makes for accurate targeting. Again the environment is left out for the same reasons as for the Disability Grant application.

**Table 1: Comparison of Different Definitions and Conceptual Models for Disability** 

The 2001 Census<sup>7</sup> found that the total number of identified people with disabilities decreased since the 1996 Census<sup>12</sup> by 1.7%. Statistics South Africa recorded 2,657,714 people with disabilities in 1996 compared to 2,255,973 in 2001. The questions and, therefore, definitions used in the Census conducted in 2001 were different to the questions and definitions used in the previous Census of 1996, which might explain the decrease in terms of lack of consistency and confusion on the definition of disability rather than real differences in estimates.

Furthermore in a study conducted by Schneider<sup>3</sup>, some physically impaired and blind respondents responded "no" to the Census 2001 question using the term "serious disability" but answered, "yes" to "Are you disabled?" It was found in focus group discussions that people had strong negative connotations with the term "disability". This discouraged respondents from identifying themselves as disabled resulting in major implications for the wording of questions used in the Census. In addition the Census<sup>7</sup>, which was conducted in South Africa in 2001, used questions and definitions which excluded persons with mild or moderate disability as well as those who suffered from chronic illness/es (e.g. epilepsy or hypertension) as the wording used in the question was "severe disability". Furthermore, it was found that high income countries (e.g. United States of America, Canada, United Kingdom) do not use the term "disability" but rather use words and phrases such as "difficulties" or "long term illness", which take the focus away from "disability".<sup>3</sup>

Hence it is not known how accurate the findings of the Census are, and it could imply that the approximately 5% figure for disability could be higher and more inclusive if a different definition and measure is used. This has ramifications on planning for programmes targeting people with disabilities.

# 1.2.4 International Legislation and Policies in Favour of Equity and Right to Health for People with Disabilities

There is a wide range of international and regional conventions, policy statements and legislation specifying commitments to people with disabilities. In general, conventions or treaties are regarded as the highest level of international and political commitments, as their adoption by a government attests that domestic practice will be held to an agreed standard and open to international monitoring of progress.

International conventions, legislation and policies that uphold the human rights of people with disabilities and which speak directly to health care are tabulated in chronological order below in Table 2. Only the clauses that are particularly relevant for health and rehabilitation for people with disabilities are included.

YEAR	POLICY DOCUMENT	CONTENT AREAS PERTAINING TO HEALTH/ ACCESS TO HEALTH SERVICES / DISABILITY
1948	United Nations Universal Declaration of Human Rights <sup>13</sup>	<ul> <li>Equality</li> <li>Article 25 (1): Right to social security in event of disability</li> <li>Article 10 (f) of Additional Protocol to the American Convention on Human Rights in the Field of Economic, Social, and Cultural Rights: "States must satisfy health needs of highest risk groups and of those whose poverty makes them the most vulnerable"</li> </ul>
1961	European Social Charter <sup>14</sup>	<ul> <li>Accessible, effective health care facilities for the entire population</li> <li>Article 13: "Any person who is without adequate resources and who is unable to secure such resources be granted adequate assistance and the care necessary in the case of sickness."</li> </ul>
1966	International Covenant on Economic, Social and Cultural Rights <sup>15</sup>	<ul> <li>Article 12: highest attainable standard of physical and mental health, to create conditions which will assure to all medical service and attention in the event of sickness.</li> </ul>
1969	Convention concerning Medical Care and Sickness Benefits <sup>16</sup>	<ul> <li>Article 8: states that "medical care shall comprise at least: a) General practitioner care; b) Specialist care at hospitals; c) pharmaceutical supplies; d) hospitalisation and e) Medical rehabilitation."</li> </ul>
1969	Declaration on Social Progress and Development <sup>17</sup>	<ul> <li>Article 10 (d) states that social progress and development should aim at the achievement of the highest standards of health and the provision of health protection for the entire population.</li> <li>Article 19 notes that free health services, adequate preventive and curative facilities, and welfare medical services are the means to achieve the above goals.</li> </ul>
1978	Declaration of Alma-Ata International Conference on Primary Health Care <sup>18</sup>	<ul> <li>Primary Health Care includes preventive, promotive, curative and rehabilitation care.</li> <li>Paragraph I: "health, a state of complete physical, mental and social well-being, is a fundamental human right."</li> <li>Paragraph II: refers to the existing "gross inequality in the health status" of persons both between developed and developing countries and within developed countries.</li> <li>Article V states that Governments are responsible for the health of their people, which can be attained by the provision of adequate health and social measures. The main social target is the "attainment of all peoples a level of health that will permit them to lead a socially and economically productive life."</li> <li>Article VII (6): states that those in need should have priority in health care</li> <li>Article VIII: urges Governments to formulate "National policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors."</li> </ul>
1981	African Charter on Human and People's Rights <sup>19</sup>	Article 18 (4): "[people with disabilities] should have the right to special measures of protection in keeping with their physical needs."
1982	United Nations World Programme of Action concerning Disabled Persons <sup>20</sup>	<ul> <li>Disability prevention</li> <li>Rehabilitation</li> <li>Equal opportunity</li> <li>Encourages the establishment and development of a public system of social care and health protection.</li> <li>Paragraph 96: programmes for prevention of disability, which includes community-based primary health care systems; health promotion</li> </ul>
1988	Convention concerning Employment Promotion and Protection against Unemployment <sup>21</sup>	<ul> <li>Article 7: Provision of benefit for prevention or cure of condition</li> <li>Article 10: "benefit shall include at least: (a) general practitioner care: (b) Specialist care at hospitals; (c) pharmaceutical supplies and; (d) Hospitalisation."</li> <li>Article 5 (4) (g): Provision of medical care to unemployed people and their dependants.</li> </ul>

Table 2: International Legislation and Policies in Favour of Equity and Right to Health for people with disabilities in Chronological Order

YEAR	POLICY DOCUMENT	CONTENT AREAS PERTAINING TO HEALTH/ ACCESS TO HEALTH SERVICES / DISABILITY
1990	Convention on the Rights of the Child (UNICEF) <sup>22</sup>	<ul> <li>Article 23 (3) "whenever possible, the [child with disabilities] should be provided health care services free of charge."</li> </ul>
1993	United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities <sup>23</sup>	<ul> <li>22 rules: support, access, equal opportunities</li> <li>Rule 3 accessible rehabilitation programmes based on actual needs; people with disabilities and families to be involved in design &amp; organization of services</li> </ul>
2006	United Nations Convention on the Rights of Persons with Disabilities <sup>8</sup>	<ul> <li>Research and development of universally designed goods, services, equipment and facilities, as well as technology</li> <li>Accessible information to people with disabilities about all support services, devices and technology</li> <li>Article 9: Accessibility detailed below in 1.3.8 a)</li> <li>Article 20: Personal mobility detailed below in 1.3.8 b)</li> <li>Article 25: Health detailed below in 1.3.8 c)</li> <li>Article 26: Habitation and rehabilitation detailed below in 1.3.8 d)</li> </ul>

Table 2 (contd): International Legislation and Policies in Favour of Equity and Right to Health for people with disabilities in Chronological Order

# 1.2.5 United Nations Convention on the Rights of Persons with Disabilities 20068

As the UN Convention on the Rights of Persons with Disabilities 2006<sup>8</sup> is the most recent convention and embodies all the proceeding pieces of legislation, it is viewed as the most pertinent. The articles concerning accessibility, personal mobility, and health will be reviewed, as these three articles are essential to the disability policy analysis framework.

# a) Accessibility (Article 9)8

Member states have to take on "appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas".

Barriers to accessibility have to be identified and eliminated. Areas that have to be looked at include: all infrastructures such as building, housing, facilities, roads and public places such as schools, medical facilities and workplaces. All services that provide information or communications and other services would also have to be scrutinised and accessibility improved upon.

Training for stakeholders on accessibility issues facing persons with disabilities has to be undertaken and guides, readers and professional Sign Language interpreters will need to be provided to facilitate accessibility to buildings and other facilities open to the public. This article is important as it deals with accessibility of services, which is one of the highlights of the framework to be devised.

# b) Personal Mobility (Article 20)<sup>8</sup>

States have to "take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities" by:

- (a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- (b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- (c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- (d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities".

This article is important for health policies, which describe the provision of assistive devices.

# c) Health (Article 25)8

This article has been extracted in full as it describes how health services should be operationalised for people with disabilities, and these points will be used in the development of the policy analysis framework.

"States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability".

# d) Habilitation and Rehabilitation (Article 26)<sup>8</sup>

Again this article has been extracted in full as it describes how rehabilitation and habilitation services should be run, and these points will be used in the development of the policy analysis framework.

- "1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
- (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
- (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
- 2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation".

# 1.2.6 Summary of International legislation and policies in favour of equity and right to health for people with disabilities

In this section, aspects of the conventions and declarations in terms of the right to health (described in 1.2.4) have been grouped into five different categories below. Some of the points described fit into more than one category. These are considered as important elements in the policy analysis framework.

# a) Equal opportunities

- All people (including people with disabilities) should be treated equally.
- Social security benefits should assist people with disabilities, and is a means for attaining a higher health status.
- Disabled people should be integrated into society and all programmes.
- Accessibility (described in detail in 1.2.5 above) to public environments, services, transport, information etc.
- There must be research and development of universally designed goods, services, equipment and facilities, as well as technology.
- Information about all support services, devices and technology must be made accessible to people with disabilities.

# b) Prevention of disability

- Disability must be prevented.
- Health promotion is necessary to prevent health conditions leading to impairments.

# c) Universal access to health care services

- There needs to be equality in services.
- The health needs of high risk groups and those made vulnerable by poverty should be addressed.
- People with disabilities should be integrated into society and all programmes.

- Community-based primary health care systems are important to ensure that all segments of the population are covered.
- Any person who is without adequate resources and who is unable to secure such
  resources should be granted adequate assistance and the care necessary in the
  case of sickness, and in case of children, wherever possible, services should be
  provided for free. This also applies to unemployed persons and their dependents.
- Health services should offer prevention or cure of condition and benefits should include at least: (a) general practitioner care: (b) Specialist care at hospitals; (c) pharmaceutical supplies; (d) Hospitalisation and (e) medical rehabilitation.

# d) Access to rehabilitation services

- There needs to be equality in service.
- Rehabilitation programme must be offered as a means to equalize opportunities, and should be accessible and based on actual needs; people with disabilities and families should be involved in design & organisation of services.
- Access to personal mobility devices (described in detail in 1.2.5 above).

# e) Access to other services

- There needs to be equality in services.
- Social security benefits should assist people with disabilities, and are a means for attaining a higher health status.
- People with disabilities should be prepared for, and also considered in terms of employment strategies.
- Information about all support services, devices and technology must be made accessible to people with disabilities.

# 1.2.7 South African Legislation and Policies in Favour of Equity and Non-Discrimination of People with Disabilities

With the unbanning of all political parties and the freeing of political prisoners in February 1990, the formation of the tripartite alliance and after many deliberations, a free and fair election took place in South Africa on the 27 April 1994. South Africa emerged from an era of apartheid during which legislation did not recognize all people (including people with disabilities), as being equal. The first thing the new government did was to establish a constitutional assembly to discuss and debate the cornerstones of democracy in South Africa.

The result of this was the new Constitution and the Bill of Rights, enshrined in it. The Bill of Rights guarantees the human rights of dignity, equality and freedom to all people, including people with disabilities. The setting in South Africa since 1994 has been of redistributive justice; not just towards those affected by apartheid but equality for all. Three previously disadvantaged groups were identified: Blacks, women and people with disabilities. The legislation, which followed, was drawn up to promote overall non-discrimination and inclusion. There is no specific legislation per se on disability, but rather legislation that appeals to the integration and inclusion of all people.

South African legislation and policies in favour of equity and right to health for people with disabilities are discussed briefly below in Table 3. Only the clauses that are particularly relevant for health and rehabilitation are included. Although the Integrated National Disability Strategy (INDS) is a strategy, it guides the government to integrate disability in their line functions. South Africa signed and ratified the United Nations Convention in April 2008. This time there are legal obligations for states and recourse mechanisms for people with disabilities through equality courts. There has been a process for government through the Office on the Status of Disabled Persons (OSDP) to re-align the INDS to the Convention.

YEAR	POLICY DOCUMENT	CONTENT AREAS PERTAINING TO HEALTH/ ACCESS TO HEALTH SERVICES/DISABILITY
1996	The Constitution of the Republic of South Africa- Bill of Rights (Act 108 of 1996) <sup>24</sup>	<ul> <li>Human dignity, equality and freedom</li> <li>Section 24 right to "environment that is not harmful to their health or well-being"</li> <li>Section 27 (1) guarantees everyone the right to have access to health care services and social security</li> </ul>
1997	The White Paper on an Integrated National Disability Strategy (INDS) <sup>25</sup>	<ul> <li>Social model of disability</li> <li>Integration of disability issues in all government development strategies, planning, processes and programmes.</li> <li>Integrated and co-ordinated management system for planning, implementation and monitoring at all spheres of government.</li> <li>Key policies include: prevention, health care, rehabilitation, public education, barrier free access, transport, communications, data collection and research, education, employment, human resource development, social welfare and community development, social security, housing and sport and recreation</li> <li>One of its strategies is "To Improve Health Services" so as to enhance prevention of disability (secondary prevention and complications thereof).</li> <li>Access to basic rehabilitation.</li> <li>Appropriate, accessible and affordable health services are essential to the equalisation of opportunities for people with disabilities.</li> </ul>
2000	The Promotion of Equality and Prevention of Unfair Discrimination Act <sup>26</sup>	<ul> <li>Cannot discriminate by:         <ul> <li>Contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility</li> <li>Failing to eliminate obstacles that unfairly limit or restrict people with disabilities from enjoying equal opportunities or failing to take steps to reasonably accommodate the needs of such people.</li> </ul> </li> </ul>
2000	The Department of Public Service Administration's Batho Pele ("People First") principles <sup>30</sup>	<ul> <li>One of the principles is of redress considers people who were disadvantaged in the past and specific mention is made to people with disabilities</li> <li>The principle of access states that "All citizens have equal access to the services to which they are entitled"</li> </ul>
2000	The Disability Rights Charter <sup>27</sup>	Article 3: "Health and rehabilitation services shall be effective, accessible and affordable to all [people with disabilities] in South Africa"
2002	National Department of Health's Patient's Rights Charter <sup>28</sup>	There is provision for the "special needs of people such as a woman in labour, a blind person or a person in pain"

Table 3: South African Legislation and Policies in Favour of Equity and Right to Health for People with Disabilities

# 1.2.8 Health Specific Policies in South Africa for People with Disabilities

There are general health policies and there are health policies, which specifically target people with disabilities. The various health policies that were established after 1994 are regarded as "current". Three disability-specific policies and one general health one were selected from those that are listed on the National Department of Health's website.<sup>29</sup> Three disability - specific policies were selected, as they were the only ones available and the one general health policy, namely the Primary Health Care (PHC) Policy, was selected as its aim is to provide basic and general health services to all including promotion and prevention (disability prevention). The aims of the selected policies will be briefly explained in Table 4 but these will be extensively analysed in the Results and Discussion section (Chapters 4 and 5 respectively).

Year	Policy Document (General or Specific)	Brief description and aim of Policy
2000	Primary Health Care <sup>30</sup> (General health)	Offers an integrated package of essential primary health care services to the entire population. It has Prevention, Promotion, Cure and Rehabilitation as its four pillars. The aim of the policy is to improve the health of the entire population and improving accessibility to services
2000	National Rehabilitation Policy <sup>31</sup> (Disability -Specific)	The goal of this policy is to improve accessibility to all rehabilitation services; it is also about equalisation of opportunities and the enhancement of human rights for persons with disabilities.
2003	Standardization of the Provision of Assistive Devices in South Africa-A Guidelines for Use in the Public Sector <sup>32</sup> (Disability - Specific)	This document provides the policy framework, which will ensure that the provision of assistive devices to people with disabilities is equitable and appropriate.
2003	Free Health Care for people with disabilities at the Hospital Level <sup>33</sup> (Disability - Specific)	The aim of the policy is to remove economic hardship on people with disabilities by making health services free, hence more accessible. Free health care services that will be provided to people with disabilities include all inpatient and out patient hospital services such as diagnosis and treatment, specialized services, rehabilitation and provision of assistive devices

Table 4: Health Policies in South Africa for People with Disabilities

# 1.2.9 Policies for Adults versus those for Children

For the purposes of this thesis, no distinction has been made between policies for adults versus those for children, as the policies apply to all people with disabilities young and old. It is noted, however, that children with disabilities are more vulnerable. There is also Free Health Care for children less than six years of age.

## 1.3 RESEARCH PROBLEM

Having given the background to this study, it is clear that there is a plenitude of international and national legislation and policies which cater for people with disabilities, each of them addressing various aspects of equity and accessibility. Four health policies have been listed in Table 4 above, but it is unclear to what extent the three disability - specific policies and the more generalised health policy, ensure full integration of people with disabilities in their provision of services and/or implementation plans. From the researcher's experience, it is evident that there are problems with services and policy implementation. The need is, therefore, to do an analysis of policies to determine if the problem is with the policy itself or the implementation. Furthermore when researching the topic, the researcher found that there is also a deficiency of information available on South African health and or disability policy implementation. Similarly there appears to be no health policy analysis tool for the purposes of highlighting access and equity issues for people with disabilities.

# 1.3.1 Focus of Dissertation and Direction of Study

The focus of this research is to devise a health policy framework, which can be used by all bureaucrats, policy makers and administrators to understand the essential features of access and equity pertaining to people with disabilities, which are contained in South African health policies. This understanding can also be used to improve on future policies. The developed tool will then be tested on four health policies to determine its ease of use and effectiveness. In addition, the study will briefly review policy implementation in South Africa, in order to identify some of the major gaps in the policies and or implementation plans so as to make recommendations for future policy formulation and implementation. Thus the intention of this dissertation is to make (evidence — based) research recommendations for policy formulation, stakeholder involvement, policy implementation and monitoring and evaluation. It is hoped that this research will thus contribute to the field of health policy analysis and implementation and result in the improvement of "disability inclusiveness" in future health policies. It is also hoped that further research in this field will be stimulated.

It should be noted that this study was undertaken from the viewpoint of the Department of Health as the policy maker and implementer. This means that the viewpoint of the end user is not extensively explored in this research due to time factor limitations. It should also be mentioned here that the study intends to do an analysis of <u>health</u> policies with a disability lens to see whether inclusion of people with disabilities is promoted. It is not a framework to analyse disability policies as such – that would be a broader exercise of which this study is only part.

Should one wish to analyse another department's policies for disability inclusion, one would need to consider other factors, for example, access to schooling or transport.

# 1.3.2 What Informed the Development of this Dissertation

Since there is no health policy analysis framework, which can analyse health policies for their "disability inclusiveness", it is difficult to determine if policies take the needs of people with disabilities into account. It is thus worthwhile to develop such a tool to inform future policy makers and implementers.

#### 1.4 MOTIVATION

# 1.4.1 Researcher's Interest

This researcher once worked as a policy maker and implementer at a provincial level and is now a policy maker and implementer at an institutional level. In the researcher's current role, it is valuable to understand facilitators and barriers to policy implementation, as this will guide the researcher in her work.

The other interest that the researcher has in the research is the actual "how to do" part of health policy analysis as the researcher has not done this before, and this will ultimately result in a more successful policy implementation. It is not just health policies that the researcher is concerned about; working in a physical rehabilitation centre, it is essential that all policies implemented and drafted address all aspects of equity and access in terms of disability.

## 1.4.2 Worthiness of Academic Contribution

As mentioned previously there is no health policy analysis tool, which includes features of access and equity, thus this research will make a much - needed contribution to the field of health policy analysis. Furthermore there is also a deficiency in the knowledge of South African health policy processes, from stakeholder involvement to monitoring and evaluation of policies. The intention of this research is to devise a health policy framework, which can be used by all bureaucrats, policy makers and administrators to understand the essential features of access and equity, which is contained in policies. This understanding can also be used to improve on future policies.

# 1.5 PROJECT AIMS AND OBJECTIVES

#### 1.5.1 Aim

The aim of this research is to develop a policy analysis framework to establish the level of access and equity embedded in South African Health Policies for people with disabilities.

# 1.5.2 Specific Objectives

The objectives of the study are as follows:

- To develop a framework that will analyse health policies in terms of their equity and accessibility features.
- To review a sample of current policies in health (both disability specific as well as general health policies) using the devised framework in order to see if and how they address issues of disability.
- To examine policy implementation barriers and facilitators.
- To make (evidence based) research recommendations for policy formulation, stakeholder involvement, policy implementation and monitoring and evaluation (M & E).

# 1.6 SIGNIFICANCE CLARIFIED

In searching through the literature, the researcher could not find any studies which looked at either the policy implementation or the analysis thereof, for the Free Health Care Policy, National Rehabilitation Policy and Assistive Devices Guidelines. The researcher found two papers which dealt with the Primary Health Care (PHC) Policy- one of the studies by Heunis et. al.,<sup>34</sup> assessed the policy implementation through interviews with PHC facility mangers and programme co-ordinators as well as through direct observations at the PHC facilities. However, it did not look at the viewpoint of people with disabilities. The second study<sup>35</sup> on the PHC Policy focussed on the end-user views of PHC.

The researcher has determined that there are several gaps in the current knowledge on health policy regarding people with disabilities. There are hardly any studies, which can answer these questions:

- How do health policies, which concern people with disabilities, get formulated and implemented? What is the "ideal" process for this?
- What are the actual gaps in service delivery (policy implementation) due to?
- What positively influences (facilitates) policy implementation?

- What exactly do health policies for people with disabilities offer in terms of access and equity?
- What health policy analysis tool should be used if analysing health policies for people with disabilities?

The study answers these questions and thus addresses these gaps in the current knowledge on health policy regarding people with disabilities in South Africa.

The developed policy analysis framework will be significant, as it will allow all stakeholders to analyse policies with a disability lens. For the first time, there will be a user-friendly tool which will shed light on the policy, and what accommodations it makes for people with disabilities. This tool can either be used before a policy is finally formulated or after, but it will allow the user to make necessary adaptations to the policy and it will point out potential problem areas. This research starts off with a narrow look at health policies in relation to disability but demonstrates that this tool can be used on other general health policies to determine the levels of access and equity contained within them.

Furthermore, it was mentioned that there is little information available on the implementation of disability - specific health policies. This research will shed some light in this field. It will also highlight shortcomings in disability policy implementation. The intention of this dissertation is to make (evidence – based) research recommendations for policy formulation, stakeholder involvement, policy implementation and monitoring and evaluation. It is NOT the intention of the researcher to negatively criticise government but rather to analyse current and past practises and offer recommendations for improvement.

# **CHAPTER 2: LITERATURE REVIEW**

The purpose of this chapter is to review literature, which will aid in the development of the policy analysis framework. This will, in turn, determine the extent to which a policy caters to the specific needs of people with disabilities. Firstly policy analysis, and then specifically health policy analysis, is unpacked so as to understand it. The concepts of equity and accessibility are then investigated and the literature is reviewed on factors promoting utilization of health services by people with disabilities. All these elements together with the review of points from international and local legislation considered as being important to ensure equity and access to health services (summarised in section 1.3.5 of the previous chapter) helped guide the building of the framework for the disability - specific health policy analysis, which is presented at the close of this chapter.

# 2.1 DEFINITIONS OF POLICY ANALYSIS

Health Policy Analysis is defined in Wikipedia<sup>36</sup> as "the process of assessing and choosing among spending and resource alternatives that affect the health care system, public health system, or the health of the general public. Health policy analysis involves several steps: identifying or framing a problem; identifying who is affected (stakeholders); identifying and comparing the potential impact of different options for dealing with the problem; choosing among the options; implementing the chosen option(s); and evaluating the impact. The stakeholders can include government, private healthcare providers (e.g. hospitals, health plans, office-based clinicians), industry groups (e.g. pharmaceutical, biotechnology, and medical device manufacturers), professional associations, industry and trade associations, advocacy groups, and consumers."<sup>36</sup>

However, having given this general definition of policy analysis, it needs to be borne in mind that the scope of policy analysis is vast. Policy analysis is important for various reasons. It can be used as a tool for research (retrospective analysis) as well as for planning (prospective analysis).<sup>37</sup> Policy analysis can be used to assist policy makers in thinking through the implications of health policies before finalisation and implementation.<sup>37:367</sup> By doing an analysis, one would be able to investigate which actors might be affected by a particular policy and the relative strengths and weaknesses of the policy can be assessed. Such an exercise would be called a prospective analysis. If such an exercise is undertaken before a policy is put into effect, it is possible to assess which groups are likely to be resistant and to plan strategies to overcome opposition, which is necessary to ensure smooth implementation. In terms of retrospective policy analysis, this is carried out on an existing policy. The analysis can be done to determine amongst other things: what the policy entails, who was involved and, what effects or impact the policy has had.

Other documents may also be found detailing the implementation of the policy and the monitoring and evaluation aspects, which, in turn can also be studied, and this can guide future policies. Other features such as levels of disability inclusiveness of the policy can also be established. As policies are dynamic documents, if the level of access or equity to services is problematic, steps can be taken so this can be addressed. For example if it is found that documents are not available in accessible format, this can be done. Similarly if the monitoring and evaluation aspects of the policy are weak, it can also be improved upon.

For the purposes of this research, the various health policies will be analysed for their content and this will be linked to accessibility and equity of services for people with disabilities. "*Policy analysis illustrates the need for interventions that highlight and address important policy issues, improve the policy implementation process and lead to better health outcomes*". <sup>38:192</sup> Portney<sup>39</sup> describes that a proposal must move through the following five stages to become a policy: problem formation; policy formulation; policy adoption; policy implementation and policy evaluation. Using this process, an "ideal" process flow will be proposed in section 2.4 below.

#### 2.2 MODELS FOR POLICY ANALYSIS

There is much literature available on general policy analysis. A resource list<sup>40</sup> providing a list of articles concerning health policy analysis did not include any explicit references to policy analysis that looked at the issue of inclusion of people with disabilities and their needs. Patton and Sawicki<sup>41</sup> argue that "the variety of public policy problems is so great that no one set of systematic procedures could be developed for dealing with all of them...[The] ...context for these problems is so far ranging that they don't have much in common, thus defying any standard approach".<sup>41</sup>

There are also other models such as that of Gilson and Walt<sup>37</sup> which analyse health policies specifically. However, there is no literature on the analysis of disability specific policies or the analysis of integration of disability into other general policies.

# 2.2.1 Gilson and Walt's model<sup>37</sup>

Gilson and Walt<sup>37</sup> have done much in relation to South African health policy analysis and proposed a model, which involves looking at the dynamic interrelationships between Context, Content Process and Actors. They derived this model by considering the effect of values and group interests of people/ stakeholders (actors) affected by the change (content) to be brought about through the policy, as well as considering the current setting or context in which the policy is based.

Gilson and Walt<sup>37</sup> believe that health policy wrongly focuses attention on policy content only. They noticed that in health policy implementation, focus is usually only on policy content, and not taking the other two components into consideration: the stakeholders and the context. Thus the policy fails. They believe that one needs to consider all elements when analysing a policy.

Figure 2 below represents the Gilson and Walt Model of this complex set of interrelationships. This can be sketched diagrammatically as follows:

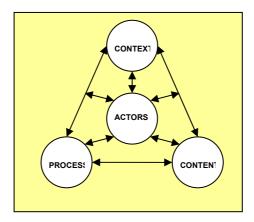


Figure 2: Representation of the Gilson and Walt Model<sup>42</sup> of Policy Analysis

A further adaptation of this model is depicted in Figure 3 below. Gilson et al.<sup>42</sup> utilised the framework depicted below in a study to determine strategies for promoting equity in community financing in three African countries.

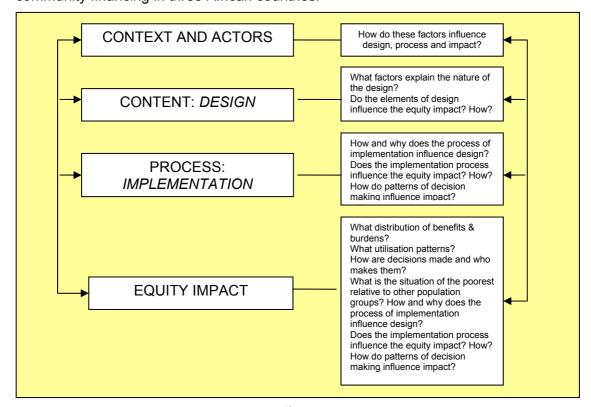


Figure 3: Gilson et al. 42 Analytical Framework Model

## 2.2.2 Patton & Sawicki's Rationalist Model<sup>41</sup>

This model is simple and relies on following a few steps: Problem definition leads to the identification and evaluation of policy alternatives followed by policy implementation. This model is more about policy formulation rather than retrospective analysis but it does have value in this study. The model can be schematically presented in Figure 4 below.

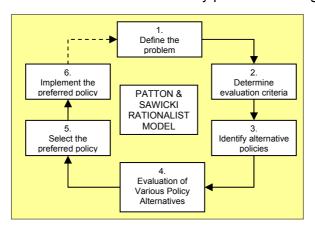


Figure 4: Representation of the Patton and Sawicki Model<sup>41</sup> of Policy Analysis

## 2.2.3 Components of Policy Analysis in Relation to Policies for People with Disabilities

The components of the Gilson and Walt model<sup>37</sup> described above will now be presented in more detail.

#### a) Actors

Actors are defined as "influenced (as individuals and as members of interest groups or professional associations) by the context within which they live and work, at both the macro government level and the micro- institutional level". 37:355 Potential actors may include: all levels of bureaucrats, medical and allied health professionals, policy makers and managers, advisors, experts, donors, financial institutions and civil society interest groups. Specifically for a policy on disability, one would expect the following to be involved: Persons with disabilities, their families, both local and national Disabled People's Organizations (DPOs), disability service providers (including organizations working for people with disability) and the various departments which have a stake in the policy implementation.

#### b) Context

When reviewing the policy context, the historical, political, economic and socio-cultural backgrounds must be considered.

Context is affected by many factors such as instability or uncertainty created by changes in politics or war; by political ideology, by history and culture. People with disabilities during the 1970s used their personal experience of disability and institutional life to form the Disability Rights Movement to show that it was not their impairments that caused the problem but the way in which society failed to make any allowances for their differences.<sup>6</sup> These activists demanded equalisation of opportunities with the prerequisite of access to health care and rehabilitation services. As a result of their efforts the Disability Rights Charter<sup>27</sup> and the UN Standard Rules<sup>23</sup> were formulated.

#### c) Content and Process

Content is simply what the policy is about, what it ensures and what is covered by the policy. The process comprises the steps that the policy went through from formulation to implementation.

## d) Relationship between Actors, Context and Content

Gilson and Walt<sup>37</sup> propose that policy analysis is a dynamic process - it is complex and the interplay of social, economic and political interactions and value systems at the time has a major influence on the implementation of the policy. The process of policy making in turn is affected by actors, their position in power structures, their own values and expectations and the relationship between these actors. The context within which policies are made, has a large influence on how the policy is implemented.

The Gilson and Walt<sup>37</sup> model for health policy analysis can be used to understand why policies were implemented in a particular way through an analysis of each of the components described above. For example, to understand why the policy for Free Health Care was not supported fully we can look at the viewpoints of one of the stakeholders (the administration clerks at the hospital). Their role is to collect revenue for the hospital and thus they do not support the idea that the services should be provided for free. Chapter 4 provides more detail on these results.

## 2.3 DEVELOPING A FRAMEWORK MODEL FOR POLICY ANALYSIS WHICH DETERMINES LEVEL OF ACCESS AND EQUITY EMBEDDED IN HEALTH CARE POLICIES

The starting point is that people with disabilities have equal rights and the aim of the policies that are going to be reviewed is that they should facilitate the realisation of these rights in relation to health care.

In order to develop this framework, one needs to review all the elements considered important to ensuring that all aspects of equity and access are covered or not covered by the policy.

## 2.3.1 Access to and Equity in Health Services

Equity and accessibility first have to be defined so that one has a good understanding of these concepts as they are used in the framework. According to the 2006 UN Convention on the Rights of Persons with Disabilities<sup>8</sup>, to ensure accessibility, member states have to consider the physical environment, transport, information and communications and public facilities and services both in urban and rural areas and to make sure that people with disabilities can access these areas on an equal basis with others.

In terms of social justice, <sup>43</sup> equity has to do, fundamentally, with a fair distribution of benefits from social and economic development. Equity, in relation to health, is used in different conceptual senses: equal access to health services for all (opportunity equality); equal resources expended for each individual (supply equality); equal resources expended for each case of a particular condition (equality of resource use based on biological need); equal healthy life gained per dollar expended (cost-effectiveness); care according to willingness to pay (economic-demand equality); care according to biological or socio-economic need; or, ultimately, equal health status for all. <sup>43</sup> In this research, equity is used in the sense of equal access to health services for all (opportunity equality). This is seen as one of the basic requirements for people with disabilities to have equal opportunities to access the health care they require.

#### 2.3.2 Factors Promoting Utilization of Health Services by People with Disabilities

In devising the framework, one needs to consider barriers to health services so as to remove these. People with disabilities need to be using health care at least as much as the general population if not more. In one study<sup>44</sup> carried out in rural Bangladesh, it was revealed that people with disabilities were fourteen times more likely than the population without disabilities to seek treatment. There was also a positive association between treatment being sought and education.<sup>44</sup> The profile of a person most likely to access these services was: a male, of an economically productive age group, who had acquired the disability and who had some belief about disability causation. Suggestions put forward by the study to promote the health of persons with disabilities, were:

- Health education and awareness of disability;
- The introduction of disability grants;
- Training of health care workers in disability issues;
- Infrastructure and;
- Intensive rehabilitation.

Social and cultural barriers prevented certain groups, notably women and people at the extremes of age i.e. those less than fifteen years of age and those more than 60 years of age, from utilizing health services. This could be used to suggest a way to 'check' policies as to their inclusion of women, people with early onset of disability, etc.

In South Africa, the baseline survey on disability in 1998<sup>1</sup>, showed that only two out of every five persons with disabilities, needing medical rehabilitation and assistive device services, actually received the service. The study also found that health services were the most received and needed service, and that welfare and educational services were the least received services. Other findings include that there was unequal provision of services across the race groups - Whites and Indians were the most likely race groups to receive medical rehabilitation services. Indians were the most likely to receive assistive devices services, and Whites the most likely to receive educational services. Females were more likely to receive assistive devices services than males but the reasons for this were not clear. Services being too expensive and people not having money (to pay for services or transport), were seen by respondents, as the biggest problems experienced with services. These barriers will need to also be addressed in the framework.

In contrast, a study conducted in Malawi<sup>45</sup> found that health services and traditional healers were found to be available for the majority of those with disabilities, with about 60% of those who needed these services having actually received it. On the other hand, there were shortcomings in vocational training and assistive device provision amongst other services.

#### 2.3.3 Elements to be Incorporated into the Framework

The policy analysis outline for the framework was modelled on the Gilson et. al model<sup>42</sup> and thereby incorporated broad sections on the context, content, actors and the process. Furthermore, the selected elements on equity and access from the review of the international legislation and policies (listed in section 1.2.6) were also incorporated into the policy analysis framework. Finally implementation barriers and facilitators are also to be considered and the resulting framework is presented in the Methodology Chapter.

## 2.4 "IDEAL" FLOW OF POLICY DEVELOPMENT, IMPLEMENTATION AND EVALUATION

The policy process for each policy will also need to be analysed. During the course of this research, the investigator has developed her own flow diagram on the process of the policy development, which is based on that of Rationalist Model of Patton and Sawick<sup>41</sup> as a skeleton and it will be referred to as the "ideal" when comparing the processes some of the analysed policies went through. The proposed policy route or cycle for policies for people with disabilities is depicted in Figure 5 below.

The policy process will be discussed individually for each policy during the analysis under section 4 of the devised framework, which relates to the policy process.

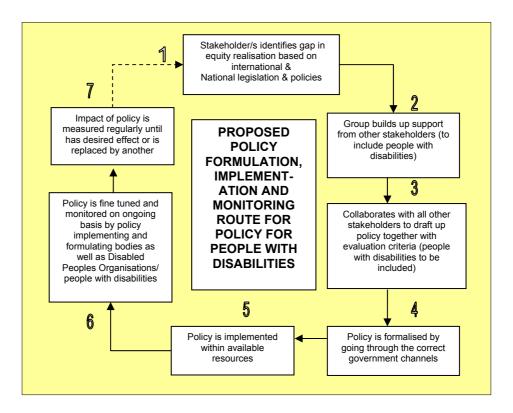


Figure 5: Proposed 7 - Step Method of Policy Formulation, Implementation and Monitoring of Health Policies to Ensure Inclusion of People with Disabilities' needs

## 2.5 SUMMARY OF MAIN POINTS FROM LITERATURE REVIEW THAT FORMS THE BASIS OF THIS RESEARCH

- Health Policy Analysis was defined to be "the process of assessing and choosing among spending and resource alternatives that affect the health care system, public health system, or the health of the general public. Health policy analysis involves several steps: identifying or framing a problem; identifying who is affected (stakeholders); identifying and comparing the potential impact of different options for dealing with the problem; choosing among the options; implementing the chosen option(s); and evaluating the impact. The stakeholders can include government, private healthcare providers (e.g. hospitals, health plans, office-based clinicians), industry groups (e.g. pharmaceutical, biotechnology, and medical device manufacturers), professional associations, industry and trade associations, advocacy groups, and consumers."<sup>36</sup>
- Policy Analysis is done for retrospective and prospective analysis. This can assist policy
  makers think through the implications before finalisation and implementation (prospective
  analysis), as well as for analysis post implementation, in order to determine shortcomings,
  facilitator and barriers to implementation (retrospective analysis). The framework which
  focuses on disability inclusiveness will be able to be used for both types of analysis.
- Some models for Policy Analysis i.e. Gilson and Walt<sup>37</sup>, Gilson et al. Analytical Framework Model<sup>42</sup> as well as the Patton and Sawicki<sup>41</sup> Models were discussed. These models were viewed in order to develop a health policy analysis framework model, which can be used for health policies for people with disabilities.
- Elements that need to be incorporated into the framework model for Policy Analysis were discussed. Access, equity and other factors promoting utilization of health services by people with disabilities were considered.
- An "ideal" seven step method of policy development, implementation and evaluation was developed. This will be for comparison of the actual policy process followed versus the "ideal", in order to determine deviations and the impact of this.

#### **CHAPTER 3: METHODOLOGY**

#### 3.1 SPECIFIC OBJECTIVES

The specific objectives of the study and the specific outcome measures are included below:

- To develop a framework which will analyse health policies in terms of their equity and accessibility features
- → Outcome measure: at the end of this research, there should be a tool, which analyses equity and accessibility features of health policies
- To review a sample of current policies in health (both disability-specific as well as general health policies) using the devised framework in order to see if and how they address issues of disability
- Outcome measure: the tool should have been tested out on a sample of health policies so that it is clear how each policy does or does not address issues of disability
- To examine policy implementation barriers and facilitators
- Outcome measure: policy implementation barriers and facilitators should be analysed for each policy and then overall to determine what the common challenges are, as well as enabling conditions to policy implementation.
- To make (evidence based) research recommendations
- Outcome measure: based on this research, recommendations for policy formulation, stakeholder involvement, policy implementation and monitoring and evaluation should have been made so that past practices can be learnt from and improved upon.

#### 3.2 RESEARCH DESIGN

The main design of the study undertaken was a desk - top review. The desk - top review aspect entailed the formulation of a framework for health policy analysis, which would be disability - focused. This devised framework was then piloted on health policies to analyse them in terms of their disability inclusiveness. This research was also in part a descriptive study. The descriptive data was derived from interviews and questionnaires in order to extract information pertaining to policy coordination and implementation as well as policy processes, which was then incorporated into the policy analysis framework.

#### 3.3 SUBJECTS

Table 5 below summarises the information regarding subjects:

	SAMPLE 1 (HEALTH POLICIES)	SAMPLE 2 (KEY INFORMANTS)	SAMPLE 3 (PROVINCIAL
	(1.2/121111 02.0120)	(1.27 61	REHABILITATION MANAGERS)
Population	All SA Health policies which have implications	Policy makers and implementers in one province	All provincial level policy implementers
	for people with disabilities	in order to collect data on the situation in that one province of South Africa	
Sample	Four health policies which have direct implications for People with Disabilities (it was not meant to be an exhaustive sample, as the focus was on testing out the devised framework)	Key Informants one representative at each level of implementation (National, Provincial, Hospital and District Rehabilitation Services)	All Provincial Rehabilitation Managers
Basis for choosing subjects	Policies which are available or exist within the Department of Health and using the eligibility criteria	Those that meet the eligibility criteria, in one province	All were selected
Eligibility criteria	See 3.4.1 below	See 3.4.2 below	All those that are appointed as Provincial Rehabilitation Managers or those who are acting in this position
Sampling methods	Purposive selection	Purposive selection	Purposive selection
Sample Size	Four	Four	Nine
Selection	Department of Health's	Based on researcher's	Based on email
process	Website, 29 researcher's	opinion on official's level of	addresses provided by
	knowledge	knowledge and experience with policies specifically for people with disabilities	National Department of Health's representative

**Table 5: Summary of Information about Subjects** 

## 3.4 ELIGIBILITY CRITERIA

## 3.4.1 Eligibility Criteria: Sample 1

Using the database listed under the policy documents tab on the National Department of Health's website (http://www.doh.gov.za/docs/index.html),<sup>29</sup> a list of all current health policies was created. This amounted to thirty three. The researcher is aware of and has worked with three other disability-specific policies before and these were not included in the database on the Department of Health's website. These three were then added to the list from which the sample selection could be made.

Sampling was then purposeful and selective, and based on criteria that were selected to fit this type of study. The criteria used were that:

- Policies be current in that they were formulated after 1994 and;
- Policies have direct relevance for access to health care services for people with disabilities.

Only three policies matched these criteria.

In recent years, it has been proposed to include people with disabilities in general development, so that they may become mainstreamed. This would also apply to health policies - there should be health policies, which should cater for the diverse needs of the entire population whether disabled or not. Hence policies should be formulated which allow universal design, access and equal opportunities for all. For this reason, a fourth general health care policy was selected to be analysed in order to compare the findings of the analysis of the disability - specific policies versus that of the general health policy. The policy that was purposefully selected was the Primary Health Care Policy as it is meant to cater for the health needs for the majority of the population. The list of policies analysed is by no means exhaustive as this was not the main aim of the study. The four health policies that were selected were thus:

- Primary Health Care-2000<sup>30</sup>
- The National Rehabilitation Policy
   2000<sup>31</sup>
- The Standardisation of the Provision of Assistive Devices in South Africa A guide for the Public Sector – 2003<sup>32</sup>
- The Free Health Care Policy for People with Disabilities at the Hospital Level-2003<sup>33</sup>

Interestingly, only one policy (Primary Health Care Policy) was listed under the policy document section of the Department of Health's website<sup>29</sup>. The National Rehabilitation Policy is not available on the Department of Health's website and a hard copy of the document was sourced from the Provincial Rehabilitation Manager's Office. The Provision of Assistive Devices Guidelines is not officially recognised as a "policy" - the title of the document is "A Guidelines for the Public Sector". The word "policy" is not mentioned. This policy is elusive to find on the website and can only be accessed via a complex search. Finally the Free Health Care Policy document can also only be accessed via a search on the website. Reasons for these policies not being on the website in the policy section may be due to non - prioritisation of disability and rehabilitation documents or this may have been an oversight by the Information Technicians. This lack of internet accessibility of documents obviously limits access to these documents.

## 3.4.2 Eligibility Criteria: Sample 2

Additional qualitative data was gathered from interviews with key informants based at various levels of policy implementation. A sample of convenience was made for the interviewees. The people were selected to be interviewed if they met the following criteria<sup>\*</sup>:

- Person to be at a National, Provincial, Institutional (Hospital) or District Level (one person per level was selected) in the one province. All participants were limited to the same province so as to allow for triangulation of information from different sources in one province. Triangulation is a long accepted technique for ensuring rigor in qualitative research.<sup>46</sup>
- They were within travelling distance from the researcher (this was included to avoid exorbitant travel costs).
- They are considered "information rich" as they have been in the public service for many years at management level hence have been exposed to all the policies. They were in the services at the time of the implementation of the policies so they were able to share their first hand knowledge/ experiences of the implementation of the policies.
- They gave permission to be interviewed.

## 3.4.3 Eligibility Criteria: Sample 3

Provincial Rehabilitation Managers were selected in all of the nine provinces using a sample of convenience. The reason for selecting all Provincial Rehabilitation Managers was to ascertain the situation in each of the provinces. This sample was thus comprehensive. Confidentiality was maintained and no specific mention is made of participants' names.

Provincial Rehabilitation Managers were considered the best candidates to answer questions on the barriers and facilitators to policy implementation. The main reasons for this are, firstly, they are responsible for policy implementation and, secondly, they are in contact with stakeholders who would give feedback to them on a regular basis regarding policy implementation.

The reason why these criteria were selected was to obtain subjects who had extensive knowledge and understanding in the policy implementation and who could thus meaningfully contribute to the information presented in this research.

#### 3.5 DATA COLLECTION METHODS

Data collection instruments were designed in a way to collect qualitative data. The following data collection tools were used:

- The developed policy analysis framework tool (refer to Figure 6) was utilised in order to perform document reviews, which accounted for the main component of this research.
- A semi structured interview tool was used to perform interviews with the key informants to complement the analysis with qualitative data (Appendix 1).
- Structured questionnaires (Appendix 2) were utilised to capture qualitative data on policy implementation barriers and facilitators. The intention of the questionnaire (interview checklist) was to guide the participants in describing the barriers or facilitators so that the researcher could understand the phenomena. Interviews with all the Rehabilitation Programme Managers could not be arranged as they are all far away from the researcher. Hence questionnaires were utilised as they could be distributed afar by means of email. It would have been desirable to have had all Provincial Rehabilitation Programme Managers to answer the tool. This would have resulted in a national picture in terms of policy implementation barriers and facilitators. Comparisons could then have been made between provinces in terms of barriers and facilitators and it could increase understanding of the nature of the barriers and facilitators as well as determine what was in place and what was not. This was a limitation of the study possibly due to reasons postulated in Chapter 7, section 7.1.1 b).
- Three sources of information were utilised in order to triangulate data. As mentioned above, this study utilised data from three sources or samples: 1) the actual policy documents; 2) Information gained from interviews with key informants; 3) Information gained from questionnaires (interview checklists) sent to the Provincial Rehabilitation Managers. Table 6 below plots the three sources of information and their utilisation:

INFORMATION	POLICY DOCUMENTS	KEY INFORMANTS AT	PROVINCIAL
SOURCE		DIFFERENT LEVELS OF POLICY IMPLEMENTATION	REHABILITATION PROGRAMME MANAGERS
Tool used	Devised Health Policy	Semi structured Interview	Structured Questionnaires
	Analysis Framework (refer to Figure 6)	Schedule (refer to Appendix 1 for interview schedule)	(refer to Appendix 2)
Purpose in	Analysis of content using	To understand the policy	Analysis of implementation
study	tool. Analysis in terms of content, stakeholders	process: how policies come about; how people with	challenges and facilitators.
	(actors), design, monitoring	disabilities were or can be	
	and evaluation, access and	included in the policy process;	
	equity features.	and the challenges and facilitators to implementation	
Structure	See Figure 4. Tool is	Questions structured to	Questionnaire (interview
	structured according to context, actors, content,	determine: definitions of disability used;	checklist) structured to determine barriers and factors
	process, access to services,	mechanisms to include people	which facilitated
	equity and barriers and	with disabilities in policy	implementation of the four
	facilitators to policy implementation	processes; policy implementation; monitoring and	(analysed) health policies in the province
		evaluation of policies and;	·
		barriers and facilitators to policy implementation	
Administration	Each policy was analysed	Interviews conducted in English	Information sheet and tool was
	using set format	at the person's place of work, in a quiet environment. All	sent to potential participant almost one month before
		interviews except for one were	administration. Tool was
		conducted in this way. One	further explained and potential
		"interview" was conducted via a questionnaire due to logistical	participants had opportunity to ask questions. Tool left with
		challenges. Participant	potential participants and tool
		responded via email. Interviews were recorded digitally and	returned in their own time with some prompting in some cases
		transcribed by researcher.	(see 3.7.2). Explanation of tool
			during a National meeting of managers
Duration	Each policy took a few	Interview lengths varied from	Sent out 23 <sup>rd</sup> May 2008 and
	hours to analyse	twenty two minutes to forty five	closing date of 14 <sup>th</sup> July 2008
		minutes. Interviews conducted during May and June 2008	(approximately seven and a half weeks)
Data	Data was entered into	As most questions were the	All responses were recorded
management	specific sections of the framework using the probing	same for all levels of implementation, contents of	for each policy and then grouped according to barrier
	questions to find the	interview transcripts could be	and facilitator themes – see
	information contained in the documents	amalgamated and data triangulated. This information	3.8.3 below.
	documento	was then summarised and	
Commont	National Dehabilitation	presented.	In the and only five
Comment	National Rehabilitation Policy not available on	Participants answered questions on implementation based on	In the end only five questionnaires were
	Department of Health's	their level of activity e.g. National	completed. Only three
	website. Free Health Care Policy appears does not	and Provincial level representatives responded on all	provinces responded (one province sent three
	appear under policies.	four policies, whereas hospital	responses). However, analysis
	Provision of Assistive Devices Guidelines can only	level did not have to respond to questions on Primary Health	of implementation challenges and facilitators was augmented
	be accessed if a search is	Care Policy as they did not have	with information gained from
	initiated	much exposure to this policy.	interviews as interviewees also
		Similarly District Rehabilitation Services representative did not	answered questions on these.
		have to respond to questions on	
		Free Health Care Policy	

**Table 6: Analysis of Information Sources** 

33

#### 3.6 RELIABILITY AND VALIDITY FOR DEVISED HEALTH POLICY ANALYSIS TOOL

The main instrument used was the developed health policy analysis framework, which has a disability focus. The information gained from the interview schedule with key informants and questionnaires (interview checklist) was integrated into the health policy analysis. Reliability and validity of the devised tool was not extensively tested, however it is the intention of this research to pilot this tool so as to determine whether it highlights valid information in the policies and meets the objectives for which it was developed.

The devised framework is based on an adapted tool of that of Gilson et al.<sup>42</sup> These researchers had already utilised the tool in another study to determine strategies for promoting equity in community financing in three African countries. The Gilson and Walt Model,<sup>37</sup> which forms the basis of the devised framework, is also a well - known and well used health policy analysis tool.

Inter - rater and intra - rater reliability was not tested. This study is thus biased to the researcher's interpretations of the analysis, which is also influenced by the researcher's experiences. It has been argued<sup>37</sup> that one of the criticisms against health policy analysis is that it could be biased and based on the analyst's viewpoints. Hence, this is acknowledged as a possible limitation of this research. The devised tool will need to be tested for reliability and validity in further research. The aim of this study was to develop a tool, which could be used by all stakeholders viz. all levels of policy implementers as well as people with disabilities. This might pose quite a challenge to test reliability at the different levels.

The questionnaire used is in essence an interview checklist: questions were posed to guide participants on the information that was needed and was not seen as requiring validation. Similar questions on policy implementation were utilised in the interview schedule. The reasons why this was done, was for triangulation purposes, in which information from different people and different sources are compared and checked for reliability. The congruence between the findings of the four interviews and the five completed questionnaires suggests that they were able to provide reliable information to the level required for the scope of this study.

#### 3.7 PROCEDURES

#### 3.7.1 PILOTING OF DEVISED POLICY ANALYSIS FRAMEWORK

The framework for the disability focused policy analysis was derived from a review of existing health policy analysis models as well as taking into consideration the elements of access and equity which international and national legislation and policies advocate. Two earlier drafts of the framework were piloted on the Free Health Care Policy and areas of the framework were refined. Refer to Appendix 4 for the piloted frameworks. In particular in the first version (refer to Appendix 4), some of the components presented in the Patton and Sawicki model<sup>41</sup> were removed as it was realised that those components are for *prospective* policy analysis and the purposes of this research was for *retrospective* policy analysis.

In the second version, the policy process of implementation was no longer included in the final tool as the researcher could not find sufficient information regarding this from the interviewees and actual policy documents. In addition, there was an absence of supporting policy documents especially with regard to implementation. The decision was thus made to discuss implementation separately and not in the framework. The final tool is presented in Figure 6 in 3.8.1.

#### 3.7.2 STRATEGY TO INCREASE PARTICIPATION IN QUESTIONNAIRES

It was the intention of this research to obtain as much participation as possible in order to develop a comprehensive overview of the nine provinces. Again it is reiterated that the purpose of this was to develop a national picture in terms of policy implementation barriers and facilitators, from which comparisons could have been across provinces.

The questionnaires were emailed to the Provincial Programme Managers using the list of e-mail addresses provided by the National Department of Health's representative. There were some provinces which had more than one contact, thus fourteen e-mails were sent. The researcher anticipated nine responses (one per province; the additional ones sent out, if answered, would be a bonus). The questionnaires were emailed on the 23<sup>rd</sup> May 2008. Information sheets and consent forms were also included in the email. The email was sent from the National Department of Health's email as a means of introduction and as a show of support for the research.

Participants could respond electronically or could return the completed forms via fax or personal pick up as it was conveyed to them that the researcher would be attending the National Department of Health's meeting with the Provincial Rehabilitation Managers almost a month later, viz. the 19<sup>th</sup> of June 2008. Of the fourteen emailed questionnaires sent out, only five questionnaires were returned. Three provinces returned the questionnaires (one province sent three different responses from three different officials). The response rate was thus 36%; while this is a low response rate it does not really affect this study as the aim was only to determine trends and not to draw any conclusive findings on policy implementation. However in a study that aims to determine more representative trends, a higher response rate would be required.

At the meeting on the 19<sup>th</sup> of June 2008, the researcher availed herself to explain the research, as well as to hand out printed consent and questionnaire forms. The researcher also tried to encourage participation by allaying any fears that the managers might have had. The Provincial Rehabilitation Managers did not have any questions for the researcher despite there being adequate time for this. The following day, the researcher returned to collect the completed forms as well as the signed consent forms. Five consent forms were collected but only one questionnaire was returned. The remaining four would – be - participants expressed the desire to return to their province to obtain wider consultation for the research questions. It was observed that two of the programme managers had partially completed their questionnaires. On follow up, only two provinces returned the questionnaires. One of the provinces sent in three responses. The researcher followed up the two provinces that did not attend the meeting with an email, which included the information sheet, questionnaire and consent forms. Refer to the flow chart in Appendix 5, which shows the steps taken to elicit responses from Provincial Rehabilitation Programme Managers.

The researcher did whatever possible to elicit a response from Provincial Rehabilitation Programme Managers but the response rate was still poor. It would appear that the use of policy analysis and disability inclusiveness are not understood and therefore not taken into account when doing analyses of policies. This highlights a strong need to show how one can do such a policy analysis and the benefits of doing so.

#### 3.8 DATA ANALYSIS

#### 3.8.1 DEVELOPED HEALTH POLICY ANALYSIS FRAMEWORK

#### 1. CONTEXT

1.1. Context; to verify, define and detail the problem: description of situation and stakeholders. Policy contexts to be considered include historical, political, economic and socio-cultural/economic contexts and practices of decision-making.

#### 2. ACTORS

2.1. Who were the stakeholders and what was their influence on the policy?

## 3. CONTENT – what is included in the actual policy on what should happen?

- 3.1. Design: what factors explain the nature of the design?
- 3.2. What definitions of disability are being used? Does it specifically mention people with disabilities or is there a general mention of all people?
- 3.3. Does the policy encourage health promotion, early identification and lead onto the prevention of disability? Or does it neglect to address the needs of people already disabled?
- 3.4. Is the policy sensitive to the general and specific health care needs of people with disabilities?
- 3.5. How does the policy integrate people with disabilities?

## 4. PROCESS - what in fact does happen?

- 4.1. How did the policy come about? The particular processes used in initiating and implementing the policies
- 4.2. Did people with disabilities participate in process?
- 4.3. Monitoring and Evaluation (M & E)
- **5. ACCESSIBILITY OF SERVICES:** What provisions are made for people with disabilities? Does it also make provisions for the following:
- 5.1. Barrier free access (physical access to facilities, are services community based, what are fee structures? Etc.)
- 5.2. Communication and information materials
- 5.3. Training of health workers
- 5.4. Is there any mention of infrastructure transportation to the service, or the placement of the service (so that it is accessible)?
- 5.5. Is there a cost involved for the service?

#### 6. EQUITY IMPACT:

- 6.1. What or how does the policy allow for the equalisation of opportunities for people with disabilities to access affordable and appropriate care?
- 6.2. What distribution of benefits & burdens?
- 6.3. What utilisation patterns?
- 6.4. How are decisions made and who makes them?
- 6.5. What is the situation of the poorest, relative to other population groups?

#### 7. BARRIERS AND FACILITATORS TO IMPLEMENTATION as described by respondents

- a. Attitudinal
- b. Environmental access buildings, transport, information
- c. Resources technology, finances, institutions
- d. Process and product design
- e. Political and economic will
- f. Other

Figure 6: Devised Policy Analysis Framework Sensitive towards Access and Equity Needs of People with Disabilities

## 3.8.2 Data Analysis of Document Reviews

Using the developed policy analysis framework (Figure 6), the four policies were analysed in terms of their content. The analysis took into account what was set out in the policy document, as this document is the backbone, or starting point, for any implementation. Therefore information contained in the documents was used to answer the questions posed by the framework. In addition, some other information was obtained from the four in-depth interviews on definitions of disability used and the historical process that lead to the policy being developed. Information gleaned from the interview schedules and questionnaires (interview checklist) was incorporated into the policy analysis. However, for the method of communication of the policies, information was gained from the National Department of Health's representative.

## 3.8.3 Data Analysis of Interview Transcripts

The qualitative data derived from the interview schedules and questionnaires (interview checklist) was analysed by way of thematic analysis.

The interview schedule allowed the researcher to explore the policy processes with the key informants as well as the barriers and facilitators to policy implementation. Information gained from the four different interview transcripts was grouped according to themes as follows:

- · Definitions of disability used
- Mechanisms for stakeholder involvement in policy development
- Policy implementation
- Monitoring and evaluation mechanisms for policies
- Barriers and facilitators to policy implementation
- Once the themes had emerged, they were incorporated into the framework.

## 3.8.4 Data Analysis of Questionnaires (Interview Checklists)

Questions contained in the questionnaires (interview checklist) guided the participant to list barriers and facilitators, hence simple coding of these two themes was utilised. Thematic analysis was utilised in order to gain an in-depth understanding of the phenomena. People expressed themselves in different ways and added different dimensions to the concepts.

Moreover, the barrier or facilitator may be experienced in different ways - participants may feel strongly about a certain issue and others may not. All these intricacies and variances may be explored with thematic analysis and it was for this reason that it was used.

Using the questionnaires and interviews, barriers and facilitators of implementation were identified and analysed and this formed part of the results. A thematic analysis of the data was performed using two initial themes of facilitators and barriers. The themes on the barriers and facilitators emerging from both the interviews and questionnaire responses were grouped broadly as:

- Attitudinal
- Environmental access physical access, buildings, information
- Resources human and financial
- Process and product design
- Management / organisational structure
- Access to and knowledge of policy
- Political and economic will
- Others which include prioritisation of rehabilitation services and or stakeholder involvement

#### 3.9 ETHICAL CONSIDERATIONS

## 3.9.1 The Scientific Relevance of the Study

This study is vital because, to the investigator's knowledge, there has been little review and uniform analyses of disability - specific as well as general health policies in South Africa in relation to their facilitation of access to health services for people with disabilities. Policy analysis is also important for various reasons. It can be used as a tool for research (retrospective analysis) as well as for planning (prospective analysis). As many people do not seem to appreciate the value of policy analysis, this review will highlight the role of policy analysis and how it can be used to understand the process, the "who" and the "how" as well as factors that will influence the implementation. Furthermore, the framework can be used as a monitoring and evaluation tool.

#### 3.9.2 Suitability of the Investigator

The information to be gained will be directly utilised by the investigator, who works as a Head of Institution within the Gauteng Provincial Department of Health. Moreover the investigator is in a good position to allow this research to take place - there are resources available within a supportive environment.

# 3.9.3 The Relevance of the Study Rationale and the Appropriateness of the Inclusion / Exclusion Criteria to the South African Context

There is little or no policy analysis framework, which analyses policies in terms of access and equity content in relation to people with disabilities. This study contributes to this field and the devised framework can be easily used to analyse other and future policies. Knowledge of this will play a role in the improvement of these features in future policies. This study also determines implementation challenges and facilitators, which has implications on future policy implementation. During the interviews, it became clear that all participants (at strategic and operational levels) were not aware of why and how one should perform a policy analysis. Thus the findings of this study will be beneficial to all concerned.

### 3.9.4 Informed Consent and Confidentiality

Those approached were consulted and informed consent was obtained from those participants. Refer to Appendix 3 for the information sheet and consent form. In reporting the results, names of interviewees and provinces are not given and quotes cannot be attributed to any one person or province. This was done to retain confidentiality of the participant's views.

#### 3.9.5 Approval for Research Proposal

The research proposal was presented to the Committee for Human Research at the University of Stellenbosch in February 2008 and permission was granted on the 5<sup>th</sup> of March 2008 (Refer to Appendix 6). The project number that was assigned to it is N08/02/052. The proposal was originally entitled "Current South African Policies in Access to and Equity in Health Services for People with Activity Limitations".

Permission was sought in August 2008 to alter the name of this title as the researcher felt that title created the impression that a comprehensive policy analysis was done for ALL health policies and this was not the case. Furthermore, the major objective of this research was to develop a policy analysis framework to analyse health policies for their disability inclusiveness, hence the researcher felt that this should be included in the title. Finally "people with activity limitations" was replaced with "people with disabilities" as it was felt that this would facilitate searches done by researchers seeking articles concerning disability. So the title was subsequently altered to: "Developing a Policy Analysis Framework to Determine Level of Access and Equity Embedded in South African Health Policies for People with Disabilities" and approval for this name change was granted on the 12<sup>th</sup> August 2008. Refer to Appendix 6 for the approval letter.

### **CHAPTER 4: RESULTS**

In this chapter, each of the four policies are analysed using the developed health policy analysis framework. Analysed policies are discussed in the following order: (1) Primary Health Care Policy, (2) National Rehabilitation Policy, (3) Provision of Assistive Devices Guidelines and (4) Free Health Care Policy. The information derived from the questionnaires (interview checklists) on the implementation facilitators and barriers is included in the last section of each policy analysis as indicated by the framework. Similarly the information gained from the interview transcripts is analysed and included in the policy analysis. Following the analysis of each health policy, a summary and comparison is then made about these analysed policies. As a means of context setting, analysed data from the interviews regarding issues on the definitions of disability, mechanisms for stakeholder involvement in policy development, policy implementation, and monitoring and evaluation mechanisms for policies, are presented prior to the policy analysis (before the policies are presented) in order to understand these better.

#### 4.1 USE OF THE HEALTH POLICY ANALYSIS FRAMEWORK

The developed Policy Analysis framework served as a guide to analysing policies in terms of their features of access and equity. The policy was first read through to in order to be familiar with its layout. Thereafter the questions posed by each component of the framework were answered by referring to all relevant sections of the policy. The questions helped to focus the researcher's attention to the details of the policy which signified access and equity features. Finally information from the interview transcripts and questionnaires, was utilised to analyse the policy implementation, using the generic headings, which again assisted in grouping findings.

## 4.2 PRESENTATION OF RESULTS

Table 7 provides a schematic representation of how the results will be presented, and sources of information used.

Section Heading and Brief Description	Source of Information	Purpose
Definitions of Disability used	Interviews	To investigate what terminology is being used and
at the Operational Level		whether this has an impact on policy implementation
Mechanisms for Stakeholder	Interviews	To investigate mechanisms which enhance people
Involvement in Policy Development		with disabilities participation in policy processes
Policy Implementation	Interviews	To understand the process of implementation, to understand mechanisms which reflect policy implementation
Monitoring and Evaluation Mechanisms for Policies	Interviews	To investigate mechanisms for monitoring and evaluation which indicates success and progress of policy implementation
Individual Policy Analysis	Documents, communi- cation section from interview	To determine levels of access and equity embedded in health policies - to examine these features in greater depth. To understand involvement of people with disabilities in the policies.
Barriers and Facilitators to Policy Implementation	Interviews and Question- naires	To learn from past experiences and to highlight challenges and offer suggestions on how to address these. To consolidate facilitating factors.

**Table 7 Schematic Representations of Results** 

It should be noted that the information gained from the interviews with the key informants can only give *tentative indications of some trends* as the sample size of interviewees was very small and, furthermore, the information given is only an indication of what is happening in that locale and may not necessarily be happening at other sites. Hence it would be dangerous to assume that viewpoints expressed are the norm for all services offered at either institutional, district, or provincial level in South Africa. Further research is required to confirm these trends with a larger sample and interviews in all provinces. Similarly the implementation barriers and facilitators presented are by no means comprehensive, given the poor response rate (36%) to the questionnaires.

## 4.3 DEFINITIONS OF DISABILITY USED AT THE OPERATIONAL LEVEL

- •
- Having discussed the importance of understanding the difference between broad and specific definitions for disability earlier in Background section 1.2.2, the interviewees were asked what definitions of disability were being used at the ground level. The responses, as presented below, indicate that the definitions of disability generally used by the Department of Health varied and are described below:
  - One source mentioned the WHO (2002) definition viz.: "Disability is any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being" which is referenced in the National Rehabilitation Policy. This is a broad definition for disability and does not take the environment into account. "Normal for a human being" is also considered medical model terminology.
  - Another definition that was used, was the definition recommended by Cabinet,
     which is "Disability is the loss or elimination of opportunities to take part in the life

of the community, equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society. These barriers may be due to economic, physical, social, attitudinal and/or cultural factors." This Cabinet definition was adopted in 2006, which was filtered down through the departments. This is a broad definition, which is based on the ICF<sup>2</sup> and it has taken cognisance of the environmental factors, the activity or participation limitations as well as that of the body impairments.

- On another operational level, it was generally mentioned that the definitions that therapists used were different and depended on their undergraduate training.
- Another source indicated that therapists were using the Free Health Care Policy definitions for people with disabilities, and as discussed previously, this is derived from the Cabinet Definition of Disability.

It appears that the information on the definition of disability is filtered down to a certain extent, but with staff turnover, there needs to be constant re-education on the need to have a common understanding of disability as well as of the terms used to describe this. The different policies have their own definitions and terms of reference and this will be discussed in each policy analysis.

#### 4.4 MECHANISMS FOR STAKEHOLDER INVOLVEMENT IN POLICY DEVELOPMENT

Based on the information gained through interviews, it would seem that people with disabilities as stakeholders can get involved at three levels viz.: at the National, Provincial and Local levels. The various vehicles for this involvement are depicted in Figure 7: Summary of Different Mechanisms Which Allow People with Disabilities to be Involved in Policies

below.

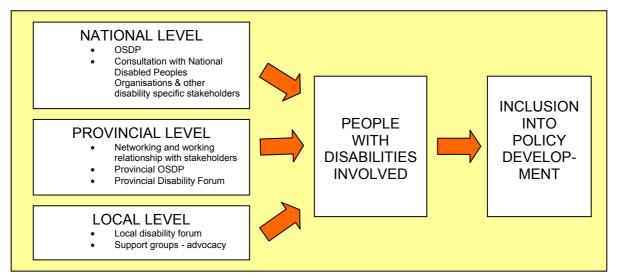


Figure 7: Summary of Different Mechanisms Which Allow People with Disabilities to be Involved in Policies

MECHANISMS FOR	RESPONDENTS' OPINION ON	TIME FRAME
INCLUSION	EFFECTIVENESS OF MECHANISM	
MENTIONED		
The Office on the Status of Disabled Persons (OSDP) in the President's Office and every Premier's Office  Consultation with National level stakeholders, such as Disabled Peoples Organisations and service rendering organisations as well as	Only mentioned by one respondent who did not seem to think it was effective due to lack of follow through. The fact that it was omitted by the other three respondents seems to echo this sentiment as it was possibly not something that they thought of as being important.  This is something that is required for policy development	Should be on an ongoing basis and for policy development but interviewee did not think that was the case.  It would seem that this was only on a consultation basis for policy development and not on an ongoing basis
disability consultants  Networking and working relationships on a provincial level	It was mentioned that not all Disabled Peoples Organisations are sufficiently empowered and that more empowered groups tend to be more actively involved. Disabled Peoples Organisations need to be sensitised towards government structures, policies and processes and other factors, so that they have a better understanding on how they can contribute. Not all people with disabilities belong to Disabled Peoples Organisations, hence they are not all represented and cannot all contribute. It was mentioned that the way forward would be to educate them.	It would seem that this was on a consultation basis for policy development as well as on an ongoing basis
Local/ Provincial Disability Forums	Provides networking opportunities but respondent seemed to think that it was more of an information-giving-session to people with disabilities so it would be effective only from an awareness raising side rather than a full dialogue.	These forums are held on an ongoing basis.
Rehabilitation support groups includes advocacy and awareness raising on policies	Mentioned as a means to increase awareness of rights but impact of this is difficult to measure.	These support groups are held regularly.

Of the various mechanisms, the interviewed officials expressed their opinions of the effectiveness of each of these mechanisms. Refer to **Error! Reference source not found.** below.

## Table 8: The Four Health Officials View on the Effectiveness of People with Disabilities Inclusion Mechanisms into Policy Development

The perspectives given here are obviously from the Health Department's point of view. A more balanced viewpoint on the effectiveness of these mechanisms would require the

opinions of people with disabilities themselves and their representative bodies. This was not within the scope of this study.

#### 4.5 POLICY IMPLEMENTATION

From the transcripts the process of policy implementation was described as depicted in Figure 8 below.

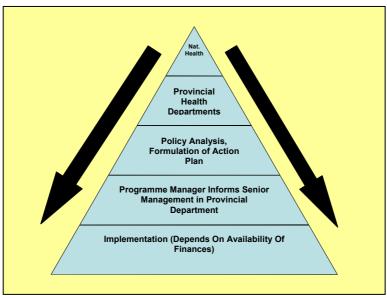


Figure 8: Policy Implementation from National Department to Provincial Departments of Health

Furthermore, the four interviewed health officials described various mechanisms for evaluation of policy implementation, and these were sited to be the following:

NATIONAL DEPARTMENT OF HEALTH	PROVINCIAL DEPARTMENTS OF HEALTH	DISTRICT REHABILITATION SERVICES	HOSPITAL LEVEL
<ul> <li>Regular contact between         <ul> <li>National Department of Health</li></ul></li></ul>	<ul> <li>Policies are discussed at Provincial Rehabilitation Forums</li> <li>Provincial circulars and addendums circulated to institutions</li> <li>Regularly discussed at meetings</li> <li>Training on policies with therapists and other stakeholders</li> </ul>	- District Rehabilitation Services meetings	- Not aware of any mechanism

Table 8: Interviewees Viewpoints of Mechanisms in Place to Ensure Policy Implementation

At a glance these mechanisms seem stronger at National and Provincial levels but this appears to evaporate at the operational levels. It was mentioned by one respondent that there were "very few methods in place – [most heads of departments]...or senior staff ...that needs to guide junior staff. Almost no training is given at [operational] level for implementation and...top management/administration in usually totally unaware of these

policies." The mechanism for policy implementation is not also done consistently with each policy.

#### 4.6 MONITORING AND EVALUATION MECHANISMS FOR POLICIES

Based on the findings of the interview transcripts, the following mechanisms were mentioned to be in place at the different levels of operation. Table 9 below represents the viewpoints of the four health officials on monitoring and evaluation of policies.

plans and targets- Indicators in Annual Performance Plans for ProvincialManual - which looks at disability managementwas of an	
Visits       to review       implementation examples include:       tions, accessibility of services at clinics, fast queues for people with policy       but the services at clinics, fast queues for people with disabilities etc.       but the services at clinics, fast queues for people with disabilities etc.       requirementation examples include:       tions, accessibility of services at clinics, fast queues for people with disabilities etc.       but the services at clinics, fast queues for people with disabilities etc.       Provice people with disabilities etc.         - no. of Community Health Centres with rehabilitation       - Indicators in Provincial Department's Annual Performance Plan       Department's Annual Centres with rehabilitation	echanism t the atistics quired under ovincial epartment of ealth is llected at spital level

Table 9: Interviewees Viewpoints of Mechanisms in Place for Monitoring and Evaluation

It would seem that even though some policies such as the National Rehabilitation Policy had a large monitoring and evaluation section, there are not enough tangible indicators or targets for provincial departments to use in their data collection and reporting. The information presented in the above table reflects that there are some indicators that provincial departments have set, but National Health has only three basic indicators on the National Health Information System (HIS).

## 4.7 BARRIERS AND FACILITATORS TO POLICY IMPLEMENTATION

In the individual policy analyses, the source of the facilitators and barriers to implementation were drawn from both sources of information – viz. the interview transcripts as well as that of the questionnaires completed by Provincial Rehabilitation Programme Managers. In this

chapter, each policy is discussed firstly in terms of facilitators to policy implementation followed by the barriers.

The categories of themes for facilitators and barriers to policy implementation were purposely made neutral and can apply to either barriers or facilitators. Furthermore, the quotes given have not been attributed to any one person due to the small number of interviews undertaken in order to retain some anonymity.

Having introduced all basic concepts for the discussion, the individual policies will now be analysed using the devised policy analysis framework (Figure 6). The source of the findings for the policy analysis is based on the actual policy document, unless otherwise specified.

## 4.8 THE PRIMARY HEALTH CARE POLICY 2000<sup>30</sup>

## 4.8.1 Brief Aim of the Policy

The Primary Health Care Policy is the policy adopted by National government as the vehicle for providing accessible and equitable health care services. The Primary Health Care Policy has four strategies: cure, prevention, promotion and rehabilitation. The Primary Health Care Policy defines what services must be rendered but it is up to the provincial and local governments to decide how the services will be provided and the level of the standard.

The Batho Pele principles underpin the Primary Health Care Policy. Public Servants should apply Batho Pele principles so that patients/clients are treated decently. Furthermore the Primary Health Care Policy also mentions the Patients Rights and Responsibilities Charter.

The Primary Health Care Policy describes what services should be available at <u>all</u> clinics. All clients / patients should go to these clinics to seek health services. The clinic will cure their illness (if possible) or will treat and manage their illness and the patient will receive basic rehabilitation services if necessary. Furthermore, health promotion ventures will take place at all clinics and surrounds in order to prevent further illnesses and impairments and to promote health.

Should the person need more services than what the Primary Health Care clinic offers, the person will be referred to the district hospital, which in turn will refer to a regional hospital if they are unable to accommodate the needs of the patient.

Regional hospitals can refer to tertiary hospitals if they too cannot offer the service the patient needs. The Rehabilitation Services described in the Primary Health Care Policy are at the clinic level.

## 4.8.2 Problem Formation (Context)

The Primary Health Care model was devised as a means to address the needs of the vast majority of the medically uninsured population of South Africa. Funds will never meet the demand for health care, hence the promotion of an egalitarian approach: financial resources will be best spent at the level of prevention of diseases and promotion of healthy lifestyles. Two of the four pillars of the Primary Health Care model stress these two very important concepts of health promotion as well as prevention of medical conditions, hence improving the health status of individuals and preventing costs for treatment and management of secondary conditions.

#### 4.8.3 Actors

The Primary Health Care document makes mention of the fact that people from the following sectors took part in the formulation of the document:

- National Department of Health
- Provincial Health Departments
- Other government departments such as Correctional Services, South African Military Health Services (SAHMS)
- Non Governmental Organisations (NGOs)
- Universities
- Private Hospitals
- Professional bodies
- Labour organisations
- South African Local Government Association (SALGA)

Even though there is a Rehabilitation programme in the Primary Health Care Strategy, people with disabilities were not consulted, and from the interviews it would seem that rehabilitation managers in the relevant departments were not consulted. This was obviously an oversight.

# 4.8.4 Process of Policy Formulation and Adoption (source are interviews and policy documents)

## a) How the Policy Came About

From the interviews, it was found that the Primary Health Care Policy was devised in the manner illustrated by Figure 9 below.

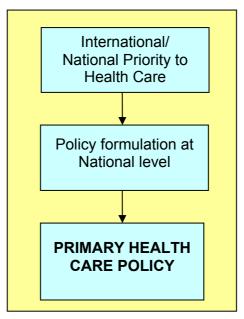


Figure 9: Formulation of the Primary Health Care Policy

Comparing this flow of policy formulation to the ideal in Figure 5 above, only 2 steps were taken as opposed to the ideal 7 steps.

## b) Involvement of People with Disabilities

It was also noted that the interviewees mentioned that the Rehabilitation Sub-directorate at National Department of Health was not consulted for input into the policy even though the policy has a large rehabilitation programme component to it. It would also seem that since people with disabilities were not listed as stakeholders in the policy document, they were not involved in the formulation of the policy. As can be seen by Figure 9, the policy adoption was done easily at the National level since it emanated from here.

## c) Monitoring and Evaluation

The policy document does not have a specific section on monitoring and evaluation but in the foreword it is mentioned that a potential use of the document is for "*local staff to help assess their own performance and that of their clinic*" as well as "by the community who are able to see the range and quality of services to which they are entitled."<sup>30:4</sup> Monitoring and evaluation for this policy is possible as there are specific norms and standards with which each programme is expected to comply with. It is further mentioned that "some provinces have set up norms and standards initiatives themselves."<sup>30:5</sup> It is thus encouraged that provinces add more to the programme. In the Community Based Rehabilitation (CBR) section, it is further mentioned that "People with disabilities [should be] involved in the planning, setting of standards and monitoring of the services of which they are the main benefactors."<sup>30:83</sup>

It was mentioned in the interview with the community based services that there is a Clinic Supervisor's Manual and the aim of this is to monitor performance of all programmes including the rehabilitation programme. This monitoring and evaluation tool is currently being upgraded to include more indicators for rehabilitation.

## 4.8.4 Policy Content

## a) Design

The design of this document is very user friendly. Each programme is clearly laid out and the structure lends to easy reading and comprehension. The Primary Health Care Policy document is virtually an instruction manual. The sections for Rehabilitation Services and for Community Based Rehabilitation services are listed as two different sections.

## b) Whether Mentions People with Disabilities and Definitions of Disability Used

It is mentioned in the Batho Pele principles embedded in the Primary Health Care that there should be "consultation", which means that "communities will be consulted about the level and quality of public services they receive and where possible will be given a choice about the services offered."<sup>30:9</sup> The policy does mention that the community should be consulted about their needs but people with disabilities are not specifically mentioned as a special and vulnerable group whose needs need to be specifically considered.

It is also mentioned that clinic staff are to work with the South African Inherited Disorders Association (SAIDA) and other Non - Governmental Organisations and Community Based Organisations to support affected individuals and families at community level.

Under mental health, staff must ensure there is no segregation or stigmatisation at the clinic of patients who have to use other services (e.g. family planning, antenatal care, etc.) and again it is mentioned that staff are to "maintain relationships with patients that are just, caring, and based on the principles of human rights." 30:55

## c) Health Promotion, Early Identification and Prevention of Disability

Prevention is one of the cornerstones for Primary Health Care. Specifically there are the following programmes, which prevent disability:

- 1. Management and Prevention of Genetic Disorders and Birth Defects: 30:18
  - Patient information would be made available in the form of posters, pamphlets and other educational materials regarding this topic to increase public awareness of these issues.
  - All patients and caretakers will receive health education on genetic disorders, birth defects and disabilities.
  - Women are encouraged to have their children at the ideal reproductive age (25-35 years) to reduce the risk of chromosomal abnormalities e.g. Down's Syndrome
  - Pregnant women are encouraged to improve / maintain their health status and that of their unborn baby by avoiding exposure to tetrogens such as alcohol, recreational drugs, chemical and infecting agents. Hence all these activities would prevent disability.

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- 2. Integrated Management of Childhood Illness<sup>30:19</sup>
  - Preventative measures would include the following actions: Monitoring and promoting growth of children (through Road to Health charts), Extended
     Programme of Immunisations, Home care counselling, De-worming, Promotion of breast feeding and the reduction in the prevalence of severe malnutrition among children less than 5 years old.

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- 3. Prevention of Hearing Impairment due to Otitis Media<sup>30:46</sup>
  - By preventing Otitis Media by early detection and management, hearing
    impairments can be reduced hence disability can be prevented.
     Opportunities are taken to inform community health committee and women
    groups that middle ear problems are very common and if not treated early can
    lead to hearing loss with effects on a child's development and language skills.

## 4. School health 30:80

 School health nurses are to visit schools and to test for basic visual acuity and hearing and physical conditions such as scoliosis. This early detection will lead to better management and hence prevention of disability (and secondary complications).

Furthermore dieticians can also visit schools and give nutritional information on healthy eating and hence reduce lifestyle diseases such as obesity, diabetes mellitus, etc.

## 5. Mental Health<sup>30:54</sup>

- Patients and their supporters are educated on how to recognise predisposing factors and conditions to prevent relapse. There is health promotion of community mental health and this is included in clinic and community based Information and Educational Communiqué.
- Primary Health Care Staff are also required to participate in community awareness programmes for mental health according to the national and international calendar.

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## 6. Rehabilitation<sup>30:67</sup>

- It is mentioned in the policy document that the "purpose of rehabilitation at clinic level is to provide a service to prevent disabling conditions, to detect disabilities early so to prevent complications and the worsening of the effects of a disability..."<sup>30:67</sup>
- It is specifically mentioned in the policy that the therapy assistant should be able to "teach prevention of pressure sores" 30:68 as well as to "teach an exercise programme for the prevention and treatment of backache." 30:68
- The visiting therapist is expected to "design and direct needs driven awareness raising, education and prevention programmes." 30:69
- The visiting Primary Health Care Doctor is also to "diagnose disabilities as early as possible…" 30:69
- Under patient education,30<sup>:70</sup> it is also indicated that patients should be educated about the prevention of bedsores.
- The policy also mentions referral pathways to and from rehabilitation services.

## d) Sensitivity to the General and Specific Needs of People with Disabilities

As this is a general health policy, it caters for the general needs of all people including people with disabilities. Additionally as there is a Rehabilitation programme within the policy, this allows the specific needs of people with disabilities to be addressed through Community Based Rehabilitation (CBR) services, which are mentioned in the policy.

#### e) Integration of people with disabilities

The Rehabilitation section of the policy document states "communities and particularly people with disabilities should be involved in designing, implementing and monitoring services for people with disabilities. This precludes a disability service from being seen narrowly as a therapy service provided only by a certain category of staff.

All health personnel in co-operation with all other sectors and the communities/people themselves are responsible for making society inclusive of all people including people with disabilities."<sup>30:67</sup> Thus the document advocates for involvement of people with disabilities.

The document also calls for collaboration and the development of a "responsive disability information system and database in consultation with Primary Health Care nurse, Generalist Doctor, Disabled People's Organisations and Community."30:70 It is also advocated in the Community Based Rehabilitation (CBR) Section 30:83 that all Community Based Rehabilitation (CBR) Health forums, hospital boards and community health committees have at least one member with a disability and that services for people with disabilities are given priority. People with disabilities are to be involved in setting up and implementing disability information systems at all levels of service provision, and this information is used to prioritise and plan services. Issues pertaining to disability are to be addressed, through intersectoral collaboration, with the community at community based service points.

## 4.8.6 Accessibility of Services

## a) General Provisions Made for People with Disabilities

As Primary Health Care is offered at the community level, it is bringing the services to the people, hence making it accessible. In the Patients Rights Charter which is embedded in the Primary Health Care Policy, it is stated that every patient has the right to access to health care and that there would be provision for the special needs of "people such as woman in labour, a blind person or a person in pain". Hence a patient with a disability is seen as having special needs that need to be addressed. In the rehabilitation section of the policy document it is mentioned that people with disabilities should be given "preference when queuing for services and, where feasible, appointments are given to patients to reduce waiting times." 30:69

## b) Barrier Free Access

Under the Mental Health programme, it is mentioned that clinic staff are to "educate the family and community to address ignorance, fear, and prejudice regarding patients with severe psychiatric conditions attending the clinic." <sup>30:56</sup> This is to try destigmatise mental health/ disability and to attempt to break down attitudinal barriers to mental health care users.

In the Rehabilitation Programme it is cited that clinics should be "accessible to wheelchairs and trolleys and have toilet facilities for people on wheelchairs." <sup>30:69</sup> Under the Community Based Rehabilitation section, it is encouraged that meetings of the Community Based Rehabilitation committees and hospital boards are conducted in barrier free circumstances.

## c) Communication and information materials

There is no specific mention of information in accessible formats. There is only general mention that educational material would be made available, but the policy does not mention that this educational material should accommodate different needs (e.g. to be in Braille for the Blind). From the interviews, it was found that this was not done due to a lack of financial resources.

## d) Training of health workers

The Primary Health Care Policy document has standards for the competence of health staff in each of the programmes described but this is for general training. The only other mention made is with reference to treating people with disabilities courteously and with dignity (i.e. like any other patient), is encompassed in the principles of Patients Rights Charter mentioned previously. However, specific training for health workers in Sign Language (SL) training is not mentioned.

#### e) Infrastructure to Services and / or Placement of Services

By being placed at the community level, this makes services so much more accessible to all. In addition, Community Based Rehabilitation (CBR) services are called for in this policy and this should make the services very accessible as the rehabilitation is to take place in the very homes of people with disabilities as well as within community structures.

#### f) Cost Involved for Services

The Primary Health Care services are provided free to all patients.

## 4.8.7 Equity Impact

## a) Equalisation of Opportunities to Access Affordable and Appropriate Care

As mentioned in the context (see section 4.8.2), the Primary Health Care Policy is an attempt to ensure accessibility of basic health services to the medically uninsured, which constitutes the majority population of South Africa.

## b) Distribution of Benefits and Burdens

As for 4.8.7 a), the health benefits are thus spread out.

## c) Utilisation Patterns

As services are made more accessible and affordable, utilisation of services is encouraged.

## d) Decision making and Decision Makers

"The philosophy of Community Based Rehabilitation (CBR) is to promote the concept of shared governance, namely the active participation of people with disabilities and their family members in:

- Developing of a vision for their lives within the society in which they live;
- Identifying the needs and resources of people with disabilities within the community;
- Planning and implementing the vision and;
- Monitoring and evaluating its implementation." 30:82

Thus the decision making is placed in the hands of people with disabilities.

## e) What is the situation of the poorest, relative to other population groups?

As the Primary Health Care services are accessible and affordable, the poorest are able to have equal access to basic health services.

## 4.8.8 Policy Implementation

This section presents the results from the interviewees and questionnaire respondents on what actually happened in the policy development and currently in implementation.

Refer to Appendix 7 for the summarised results of the facilitators and barriers of the Primary Health Care Policy which were based on interview transcripts and questionnaires.

# a) Facilitators to policy implementation

- Attitudes: There was "Community involvement and participation" for the policy.
- Resources: In order for the policy to be effected, previously scarce therapy human resources were now available in the form of community service therapists who "improved staffing substantially" and who could be retained. In some areas there were financial resources available ("sufficient budget") and some were "dedicated for assistive devices" and this improved implementation.
- Political will: For the Primary Health Care Policy, there was political will and
   "international interest" to implement the policy. Because the drive came from a
   national level, this facilitated the implementation especially since Rehabilitation
   was one of the programmes encompassed in the package:
  - "National policy that was implemented throughout, so rehabilitation part had to also be implemented"
  - "The District Primary Health Care Managers are aware that we are part of the Primary Health Care services."
- Management Organisational structure: It was reported that Primary Health Care rehabilitation services were better supported in areas which had community support systems such as "strong Home Based Care Programme" and a "structured District Health System", in which there was "appointment of provincial & district rehabilitation Managers", "support from Head Office" and "support from management in the district". This all created an enabling environment. Respondents tended to agree that the policy provided "...guidelines for service planning" and that it could be used as a "...motivating tool" and that there were "clear directions" for implementation and that the policy provided enough information to serve as "...a baseline for service implementation".

#### b) Barriers to policy implementation:

#### Attitudes:

- Non involvement of people with disabilities in decision-making: One participant felt that there was non involvement of people with disabilities in decision-making and that the therapists were still planning the rehabilitation programme according to what they thought people with disabilities needed: "Therapists decide on what the clients need and what they must get no community /family/client role involvement in decision making".
- No intersectoral collaboration: this was also listed under attitudinal barriers; it was mentioned that there was a "lack of service integration- [as departments/programmes] work in silos" hence stressing that there was no intersectoral collaboration and "poor integration of programmes" which again does not support the outlook of the INDS.
- The non prioritisation of rehabilitation services was mentioned by one of the interviewed respondents. "Space is sometimes sacrificed to other more prioritised projects such as ARV [Anti-Retroviral] clinics. And in planning for clinics, rehabilitation staff is not always consulted, hence space is poorly designed". Another comment was "Rehabilitation staff [is] expected to assist with other prioritised programmes despite the rehabilitation staff being so limited and unable to offer full rehabilitation services themselves." This is incongruent to the values of Primary Health Care rehabilitation is one of the pillars for Primary Health Care. "Rehabilitation staff [was] not involved in the formulation of the policy" and this is again surprising. This non prioritisation of rehabilitation services also had other consequences: "Lengthy and inefficient procurement processes, and non-prioritisation of rehabilitation items [creates] delay[s] when ordering assistive devices". The effect of this is that people with disabilities have to wait a long time to receive their assistive device. Assistive devices provide a significant facilitator for many people with disabilities.
- Environmental Access: It is of concern that the environmental barriers limit people with disabilities from freely accessing health services at the Primary Health Care level. Many clinics "may have ramps but gradient is too steep, or may not have handrails." And there is a lack of accessible toilets. The requirement of accessible buildings is not covered in the policy.
- Other policy design oversights include the "poor definition of the role of disability and rehabilitation in Primary Health Care" and clear guidelines on "management issues …no standards /clarity on issues such as acceptable patient caseload".
- Resources in General: This seemed to be very problematic and a significant barrier as it was mentioned by all interviewees and also information contained in the questionnaires. Lack of adequate and suitable equipment, facilities, finances,

- safety and security, staffing, communication and transport resources were listed as constraints to full policy implementation.
- <u>Human Resources:</u> This was mentioned by all respondents as a barrier for the implementation of the Primary Health Care Policy.

- The comments on human resources were very broad, ranging from failure to recruit and retain staff, lack of training for Community Rehabilitation Workers, to issues around community service as well as staff rotation. Another issue raised was the mindset barrier in which there were two schools of thought: those that thought therapists should only be based at an institution as opposed to those who thought that therapists should be at the community or primary health care level.
  - "As services are run by community service therapists there is a lack of continuity of services" not only because of the turnover of staff but also because the supply of community service therapists is not always constant. Hence a district may have such staff for the year and may be allocated less or no community service staff the next year and this has an impact on the rehabilitation services offered. Having community service therapists is a way of recruiting staff to the services. However, in order for this to become a reality, the therapists have to be exposed to Community Based Rehabilitation (CBR) at an undergraduate level and also so that they may be encouraged to apply for such placements:
  - "Recruiting and retaining staff Not enough exposure of community rehabilitation to students hence they do not know what it is about and do not want to work there". Because there is no stable complement of staff, staff have to rotate in order to gain exposure and to cover all areas. This staff rotation has an impact on service in that the "...clinic nurses do not have opportunity to build relationships with therapists."
  - At the Primary Health Care level, therapy assistants are necessary for services, however the "salary levels for [therapy assistants]" and "human resources [esp. therapy assistants]" was listed as a challenge. It is assumed that either the staff establishments do not have opportunities for career progression or that the therapy assistants who graduate after a two year diploma are expected to start at a level lower than what can be expected for a person who has studied. Also, the training of physiotherapy and speech therapy assistants has been stopped or is non existent ["No training institution for [therapy assistants]"). Hence, there is no new staff being recruited into posts.
  - Training for Community Rehabilitation Facilitators / Workers was also halted by the Health Professionals Council, hence again, staff recruitment is problematic and the impact of this on service is that "...[people with disabilities] cannot [be facilitated to] form support groups /self - help groups".
  - The lack of a community level post structure was again mentioned by a respondent in that there are "...no posts in clinics".

- <u>Transport for the Rehabilitation Staff:</u> This was mentioned by four of the eight respondents. Respondents mentioned that "Access to transport [is a barrier.

  There is] no dedicated transport so unable to do many home visits" and this implies that the service is compromised.
- Access to and Knowledge of Policy: it was stated that the "policy [was] not known at times" and that the Primary Health Care "policies [were] not displayed" and there was an "unavailability of policy"- this is in contrast to the other policies in which the policies were printed extensively in pamphlet/booklet and / or poster form. This unavailability of the policy was further exacerbated as it was mentioned that there was a general lack of communication facilities and this includes the internet: "No internet to access policy" was mentioned as a barrier. It was mentioned by one respondent that "each district has their own view" and that "training [was] needed".
- Organisational / management Structure: The Reporting and Management structures in the District Services were crucial to the success of the programme. It was mentioned that reporting lines were problematic as "Nursing managers ... do not understand rehabilitation...".
- Other: "Poor referral systems" and "Non inclusion in the national data" were mentioned as additional other barriers.

# 4.9 THE NATIONAL REHABILITATION POLICY 2000<sup>31</sup>

Again most of the findings are based on the actual policy document review, unless otherwise specified.

# 4.9.1 Brief Aim of the Policy

The aim of the National Rehabilitation Policy has been to be a formal policy guideline for rehabilitation programme implementation in South Africa, in order to achieve equitable services across all provinces as well as meeting the basic standards required for rehabilitation service provision. The principles of development, empowerment and social integration of people with disabilities are seen as the backbone for the document.

# 4.9.2 Problem Formation (Context)

Rehabilitation according to the World Programme of Action<sup>20</sup> is defined as a "goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change his or her own life.

It can involve measures intended to compensate for a loss of function or a functional limitation (for example technical aids) and other measures intended to facilitate social adjustment or readjustment."

The White Paper on an Integrated National Disability Strategy<sup>25</sup> proposes the development of national policy guidelines. It also proposed that Community Based Rehabilitation should serve as the basis for the national rehabilitation strategy as this would ensure that the services would be available locally and hence be accessible. These services would be supported by secondary and tertiary rehabilitation services. Furthermore, it also calls for the involvement of people with disabilities and their families in rehabilitation. This is in line with the provisions of the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities<sup>23</sup>.

There was no Policy guideline or strategy for rehabilitation in South Africa prior to this document. This implied that Rehabilitation Programmes were implemented haphazardly and in a non-uniform manner throughout South Africa. This resulted in huge variances in the services provided to people with disabilities as well as the approach to the services.

The National Rehabilitation Policy mentions that a technical committee appointed by the National Department of Health conducted a situational analysis on the status of rehabilitation services for people with disabilities in South Africa in 1998. The services offered prior to the advent of the National Rehabilitation Policy were at the discretion of the person delivering the services and not based on the verbalised needs of people with disabilities. Services and stakeholder involvement were also not clearly defined. Services were underdeveloped or non-existent in many parts of the country. Even where there were services, there was disparity in resources. Hence persons with activity limitations could be receiving no services in some areas and just by moving elsewhere or across a provincial boundary, could access more medical rehabilitation services.

Rehabilitation was seen as a health issue only, with some involvement by the Department of Social Development in the provision of disability grants (both for adults and children). Furthermore, people just carried out rehabilitation programmes without even knowing if they were effective or not, i.e. there was no monitoring and evaluation of the programme. As a result, the National Rehabilitation Policy was conceptualised in order to address the shortcomings in service provision of rehabilitation services. From the interviews it was found that the National Rehabilitation Policy was formulated after two groups of stakeholders lobbied for this document. The two stakeholders were rehabilitation professionals and people with disabilities.

Therapists lobbied government as they wanted a guideline for service provision. Service users and people with disabilities also wanted to know what they could expect from Government so that they could lobby for further services if there were any gaps. As a result of these efforts, a policy was drafted by provinces and this was circulated, reformulated and the final draft presented to the Ministerial Committee for approval.

#### 4.9.3 Actors

In the acknowledgements of the Policy, the following stakeholders were named as playing a significant role in the development of the document:

- State Departments
  - Department of Welfare (now called Social Development)
  - Department of Education (DoE)
  - Department of Labour (DoL)
  - Office on the Status of Disabled Persons (OSDP)
  - Provincial Health Departments
- Professional Associations/Societies
  - Occupational Therapy Association of South Africa (OTASA)
  - South African Society for Physiotherapists (SASP)
  - South African Speech-Language-Hearing Association (SASLA)
- Non-Governmental Organisations
  - Disabled People South Africa (DPSA)
  - National Council for Persons with Physical Disabilities in South Africa (NCPPD)
  - Deaf Federation of South Africa (DeafSA)
  - National Council for the Blind (SANCB)
- Private Sector
  - Hospital Association of South Africa
  - Physical Rehabilitation
  - Libertas Hospital

There seemed to have been wide consultation. People with Disabilities were well represented through their Disabled Persons Organisations.

# 4.9.4 Process of Policy Formulation and Adoption (sources are policy document and interviews)

# a) How the Policy Came About

According to the policy document, the National Department of Health's Directorate: Chronic Diseases, Disabilities and Geriatrics developed the policy. The Sub-directorate: Disabilities (and Rehabilitation) embarked on a process to develop this policy. A technical committee consisting of stakeholders such as governmental departments, professional associations, Disabled Peoples Organisations, Non-Governmental Organisations, disability rights movement and the private sector, was appointed to devise the content of the policy. (See 4.9.3 Actors for the detailed list of stakeholders)

The technical committee did a desktop situational analysis and identified major policy areas. Subsequently, task teams focused on developing specific areas of the policy. Others were also consulted before it was finalised. Furthermore the National Baseline Disability study<sup>1</sup> was commissioned to inform future policy development.

From the interview transcripts, the policy formulation method was described as depicted below in

Figure 10.

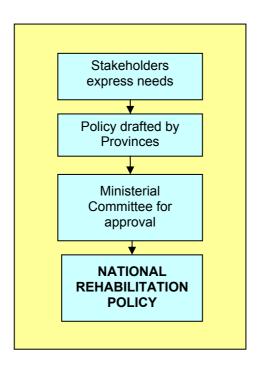


Figure 10: National Rehabilitation Policy Formulation Method

Comparing this flow of policy formulation to the ideal in Figure 5 above, only 3 steps were taken as opposed to the ideal 7 steps.

#### b) Involvement of People with Disabilities

Within the policy under the "Guidelines for Establishing a Rehabilitation Programme", it is also mentioned that people with disabilities should participate in "planning, implementing and monitoring rehabilitation."<sup>31:8</sup> Further on in the policy, it is mentioned that there should be direct involvement of persons with disabilities in decision making.

#### c) Monitoring and Evaluation

This policy is more of a guideline and does not state exact evaluation criteria but does give quite a lot of guidance as indicated below. In several sections, reference is made to principles and strategies. There is a separate monitoring and evaluation section, which is broad and encompasses the rationale, principles and strategies for monitoring and evaluation. There are strategies which are identified which are broad and make reference to the project / programme so is by no means specific.

The goal of monitoring and evaluation is stated as follows: "To institute appropriate monitoring and evaluation procedures for all rehabilitation programmes and projects in all practice settings and at all levels of health care in the relevant public sectors involved in rehabilitation, and to ensure that the information yielded from such procedures will be used to develop appropriate, effective, sustainable and cost-effective rehabilitation services for all people in South Africa who are in need of such services."<sup>31:23</sup>

The rationale as well as the principles and strategies for monitoring and evaluation are given: in order to evaluate specific projects and programmes, all components are to be evaluated; these are inputs, outputs and outcomes. Descriptions are given in the policy of which each component consists. Briefly, the inputs are the resources required, and the outputs would be measured against specified quantitative and qualitative standards. Outcomes would have to be clearly stated in qualitative and quantitative terms and evaluation would be against these in relation to cost and time.

It is also mentioned in monitoring that data should be collected using indicators which can measure for "productivity, appropriateness, safety, continuity, accessibility and acceptability". It is also suggested that a minimum data set pertaining to disability and rehabilitation needs to be determined at a national and provincial level for research and budgetary purposes. However there is no specific implemented criteria to evaluate.

#### 4.9.4 Policy Content

#### a) Design

As this was the first document post 1994 to discuss rehabilitation services, it is a broad all encompassing strategic document to describe where and what rehabilitation services should be provided. It was influenced by the Integrated National Disability Strategy (INDS) and it talks extensively about intersectoral collaboration.

#### b) Whether Mentions People with Disabilities and Definitions of Disability Used

Disability is defined in the National Rehabilitation Policy using the World Health Organisation (WHO) 1980's<sup>31</sup> definition: "Disability is any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (for example, difficulty in speaking, hearing or walking)."<sup>31:31</sup> At the time, that was probably the most popular definition, but it sees people with disabilities through the medical model and being "abnormal" because of their impairments. No mention is made of the societal and environmental barriers in this definition. People with disabilities are mentioned everywhere in the document.

# c) Health Promotion, Early Identification and Prevention of Disability

The National Rehabilitation Policy defines prevention as "measures aimed at preventing the onset of mental, physical and sensory impairments (primary prevention) or at preventing impairment, when it has occurred, from having negative physical, psychological and social consequences". 31:31

The National Rehabilitation Policy makes the following two recommendations as a strategy to build capacity of rehabilitation professionals: a) "there should be a portfolio for disability prevention and rehabilitation services at provincial level to ensure development and coordination of services" and "each district should have a disability prevention and rehabilitation services coordinator". 31:16

Further on in the document under the Finance section, it is again mentioned that funding must be made available for employing "staffing for health promotion, disability prevention, rehabilitation..." as well as for the training of disability prevention and rehabilitation personnel and also calls these funds "the disability prevention and rehabilitation budget". 31:17

The National Rehabilitation Policy considers Disability Prevention to be a component of Rehabilitation and has a dedicated section for this purpose. It calls on the Department of Health to be the leading department, and the Department of Welfare (Social Development), Labour, Education, Minerals and Energy Affairs, Transport, Environmental Affairs, Safety and Security to have strongly supporting roles. Strategies identified for preventing these impairments and disabilities include any of the following:

- Community based campaigns;
- Media awareness and educational campaigns;
- Screening programmes for high risk groups to facilitate early detection;
- Sufficient length of hospital stay to achieve rehabilitation goals;
- Family involvement in rehabilitation and education on prevention;
- Follow up and evaluation;
- Support programmes for people with disabilities and their families;
- Functional assessments:
- Health education to empower people with disabilities to make informed decisions about their own health and lifestyles;
- Disability education for the entire population
- Specific educational campaigns aimed at high risk groups e.g. birth defects
- Counselling and psychological support programmes;
- Effective referral systems so that clients will be followed up in their communities post discharge and;
- Campaigns and workshops to socially integrate people with disabilities into schools, the workplace, recreational and other social activities.

#### d) Sensitivity to the General and Specific Needs of People with Disabilities

People with disabilities are the focus of this policy. They were involved in the policy development process as the stakeholders. All aspects of the policy talks to people with disabilities and their needs, as well as how to improve services to them.

#### e) Integration of People with Disabilities

The policy talks about integration of people with disabilities into society. It mentions that people with disabilities should be mainstreamed and people with disabilities should be encouraged to participate in their integration or re-integration into society and this should be the ultimate goal of rehabilitation.

#### 4.9.6 Accessibility of Services

#### a) General Provisions Made for People with Disabilities

"Rehabilitation for All" is the vision of the National Rehabilitation Policy. This implies that services should be accessible to all people and also equally available to all. The goal of the National Rehabilitation Policy is stated as "to improve accessibility to all rehabilitation services in order to facilitate the realisation of every citizen's constitutional right to have access to health care services. This policy should also serve as a vehicle to bring about equalisation of opportunities...". 31:2

Under the section titled: "Guidelines for Establishing a Rehabilitation Programme", it is specifically mentioned that rehabilitation services that are provided should be "equitable, affordable and accessible to all". 31:8

#### b) Barrier Free Access

The policy document in the preamble makes mention that service providers need to "pay particular attention to external factors such as environmental barriers and societal attitudes because of the potential of such factors to limit the success of rehabilitation processes." Thus it is recognised that these barriers need to be overcome in order to make services more accessible. This is an acknowledgement of the role of environmental factors even if these are not mentioned specifically in the definition.

# c) Communication and Information Materials

Specific mention of communication and strategies for this is also made. This document is available only in printed format. These documents were distributed to Provincial Rehabilitation Programme Managers who in turn disseminated these to all services. This policy is the only one of the four analysed policies that does not appear on the website of the Department of Health. The document is available in English only.

# d) Training of health workers

In almost every section of the policy, training of health workers is mentioned:

- Objective 4 of the National Rehabilitation Policy is to develop human resources which takes into account the needs of both the service providers and the consumers.
- It is also mentioned that staff should be trained and developed and reoriented toward the new ethos of service provision in the public sector in the context of intersectoral collaboration.
- It is also recommended that the curricula for rehabilitation personnel be reviewed in order to incorporate the primary health care principles.
- "Education and training programmes should aim to recruit and develop personnel who are competent to respond appropriately to the health needs...of people with disabilities" 31:14 is listed as a principle under Education and Training of Human Resources. Thereafter it specifically mentions that personnel training for rehabilitation services must take place in the Primary Health Care setting.
- It is also listed as a strategy to provide Medical Rehabilitation and Therapeutic
  Devices and that rehabilitation personnel should be equipped with the skills and
  tools necessary to design effective treatment programmes and to provide
  appropriate therapeutic devices.
- As for assistive devices, the National Rehabilitation Policy suggests that training workshops be held in order to provide skills to health professionals so that they can provide the appropriate assistive device.
- Training of health professionals is further promoted so that staff can offer quality vocational rehabilitation and psychosocial rehabilitation.

#### e) Infrastructure to Services and / or Placement of Services

No mention is made of transportation to the service. However, as the National Rehabilitation Policy advocates for Community Based Rehabilitation (CBR) services, this would mean that the services would have to be placed in the community and hence would be very local and assumedly more accessible to users. This is interesting in view of the refusal of the statutory professional bodies for Physiotherapy, Occupational Therapy, and Speech Therapy and Audiology to recognise Community Based Rehabilitation workers. This is also complicated by the virtual non existent training facilities for such cadres of personnel.

#### f) Cost Involved for Services

The National Rehabilitation Policy talks about "affordable" rehabilitation services. It also talks about the provision of assistive devices to be conducted in the spirit of the Primary Health Care model and again mentions "affordability" and also says that free health care to children under six should include basic assistive devices.

It also mentions that there should be a list of basic assistive devices, which should be provided for free or at a nominal fee. It also talks about a uniform billing system for services. The National Rehabilitation Policy predated the Free Health Care Policy for people with disabilities and it could be that the Free Health Care Policy was an attempt to deal with making rehabilitation services affordable.

# 4.9.7 Equity Impact

#### a) Equalisation of Opportunities to Access Affordable and Appropriate Care

Equality, social justice and equity, integration and participation are listed as the principles which underpin the National Rehabilitation Policy. It is mentioned that "equal access to services …should be available at various levels…". <sup>31:5</sup> Furthermore the policy calls for mainstreaming of disability in community life.

The objectives of the National Rehabilitation Policy are sevenfold and the researcher has interpreted these as to how they could bring about access to and equity in health services and this is presented in Table 10 below.

NATIONAL REHABILITATION POLICY OBJECTIVE	ACCESS AND EQUITY EFFECTS
To improve accessibility of rehabilitation services	By improving accessibility to rehabilitation services, this would mean that the end user would be able to enhance his/her chances of re-integration into society as equal members after undergoing rehabilitation.
To promote intersectoral collaboration so that a comprehensive rehabilitation service could be offered	By involving other departments, this would mean that the person with disabilities is catered for in all aspects of his/her life and would have a greater chance of re-integration into society. It would mean that the limited resources are used wisely.
To ensure that resources are properly allocated and utilised	If the resources are properly allocated and utilised, then people with disabilities would receive a better health service and assistive devices which could mean better opportunities for re-integration hence achieving equalisation of opportunities.
To develop human resources so that better services can be offered	By developing human resources, Rehabilitation services could run optimally and people with disabilities would get good quality services and this means that more people with disabilities can benefit from the services, hence could gain better access to these services.
5. To encourage the development and implementation of monitoring and evaluation strategies for rehabilitation programmes	By developing monitoring and evaluation strategies, this would ensure accountability of the services, hence better service delivery – hence there might be better access to services too.
6. To ensure participation of persons with disabilities in planning, implementation and monitoring of rehabilitation programmes	By being consulted and involved, would inform how the Rehabilitation process would happen for others, thereby tailor making and directing the rehabilitation programmes so that the programmes would run more effectively and would be more accessible
7.To encourage research initiatives in rehabilitation	Research would point the way forward in terms of how to make services more accessible and what services to offer which would bring about equalisation.

Table 10: Researcher's Interpretation on How Objectives of National Rehabilitation Policy Brings about Access to and Equity in Health Services

Community Based Rehabilitation (CBR) was also identified in the National Rehabilitation Policy as a rehabilitation strategy to employ. This would be offered at the level of the community, making services affordable as Primary Health Care / Clinic services are for free. Furthermore, as it would be taking place at a community level, people with disabilities would not have to travel far thus saving on the costs of transport. It is also mentioned that there should be equitable distribution of health personnel in the country thereby bringing about equity of service provision.

# b) Distribution of Benefits and Burdens

The National Rehabilitation Policy's goal<sup>31:2</sup> mentions the following as benefits of the policy:

- "To improve accessibility to all rehabilitation services"
- "Right to have access to health care services"
- "Equalisation of opportunities"
- "Enhance human rights for persons with disabilities"
- "Addressing issues of poverty and disparate socio-economic circumstances."

#### c) Utilisation Patterns

By making services appropriate, affordable and accessible, the National Rehabilitation Policy is trying to encourage utilisation of services. The National Rehabilitation Policy promotes intersectoral collaboration through the usage of services not only of Department of Health, but of other departments, such as the Department of Labour; Education; and Social Development.

# d) Decision making and Decision Makers

The National Rehabilitation Policy talks about Community Based Rehabilitation (CBR) and the principle behind this is that people with disabilities and their families as well as their communities are the decision makers. In the guidelines for establishing a rehabilitation programme, it is also mentioned that members of the community need to be empowered to play a more "direct and meaningful role" in the rehabilitation process. It is also remarked that people with disabilities should participate in planning, implementing and monitoring rehabilitation and they should also be given opportunities to "influence policy formulation and to participate in the whole process of programme development and implementation". 31:8

# e) What is the situation of the poorest, relative to other population groups?

It has been mentioned in 4.9.6 f) that some services / assistive devices should be free or offered at a nominal rate. However it is stated in the goal of the policy that "persons with disabilities are among the poorest of the poor" and that "a person's ability to pay for services should therefore not be a prerequisite for him/her to access services." Hence poor people with disabilities will be allowed access to services and will be catered for.

#### 4.9.8 Policy Implementation

Refer to Appendix 8 for the summarised results of the facilitators and barriers of the National Rehabilitation Policy, which was based on interview transcripts and questionnaires.

#### a) Facilitators to policy implementation:

- <u>Attitudes:</u> "Intersectoral collaboration between all departments" was rated as having a positive effect on policy implementation.
- Environmental Access: a participant felt that having "basic Sign Language training for first line workers" also provided environmental access to the services. This is important as services should cater for all categories of disability.
- Policy Process and Design: The National Rehabilitation Policy too was regarded as an "enabling policy used for advocacy, to lobby for resources, changes in behaviour etc." as well as a "framework document [and] not [an] instruction manual". The policy "focus[es] on disability as a human rights issue" and is "congruent with the INDS" and hence this creates political will to implement the policy. It was regarded as having "some monitoring tools for the services".
- Access to and Knowledge of Policy: Another positive factor influencing the implementation of this policy was the fact that it was "always available" as the National Department of Health had printed, distributed and re-distributed the policy document, hence it is a highly accessible document.

# b) Barriers to policy implementation:

- Attitudes: A lack of intersectoral collaboration was mentioned by two respondents. It is noted that one respondent mentioned the opposite of this (see facilitators above)
  - Environmental access: "Our services are inaccessible for Deaf and blind people lack of [Sign Language] interpreters at entry points and no Brailed information leaflets/pamphlets" this limits health promotional material and health services information being disseminated to people with disabilities who could/should access services. Furthermore, as there are generally no Sign Language interpreters for the Deaf at facilities, the Deaf are not properly serviced and may have to bring along another person (at their own cost) to assist communication in the health facility. This leads to increased cost to the people with disabilities and could be a barrier to accessing services. It was noted under facilitators that one respondent mentioned that they did have personnel who were skilled in basic Sign Language hence the availability of Sign Language interpreters is variable from place to place.

- Process and product design: It was reported that there was "No people with disabilities' involvement/participation in planning, implementing and monitoring of Rehabilitation Programme" which again is of concern since the actual needs of people with disabilities were not taken into account. Furthermore, the "non inclusion in the national data" set implies that there is no monitoring for the rehabilitation services that is supposed to be rendered. Hence it is not known if the services are up to standard and no one is taking account (responsibility) for the services. This further compromises the programme as it might as well be considered "non-essential". The outcome is that it will not be prioritised in the provinces and districts.
- Resources financial: The National Rehabilitation Policy rehabilitation programme "does not enjoy appropriate budget allocation" and there is a "lack of budget for key services e.g. provision of assistive devices". This has an obvious negative effect on service provision.
- Resources human resources: In terms of staff necessary to effect the National Rehabilitation Policy there is a "scarcity of personnel" as well as a "high turnover of staff" and there is difficulty in "recruitment and retention of staff especially of specialist therapists". "Staffing, space and equipment shortages" is also mentioned as a barrier. "Lack of [Community Rehabilitation Worker's] training" for the purposes of rendering Community Based Rehabilitation services as mentioned in the National Rehabilitation Policy is again mentioned as a barrier. If there is no training for such a cadre of staff, the whole concept of Community Based Rehabilitation is doomed for failure.
- Rehabilitation Policy did not have "...clear guidelines" and that "each district has their own view". A "shortage of documents" was also reported, however as mentioned under facilitators. It was also mentioned that there was "no provincial rehabilitation policies in place" which are based on the National Rehabilitation Policy, thereby making implementation of the National Rehabilitation Policy problematic and ineffective. It was also listed that there was "Limited knowledge of [Community Based Rehabilitation] approach". Community Based Rehabilitation (CBR) is mentioned as a strategy in the National Rehabilitation Policy but if there is no training for such workers of the model; if the strategy is not promoted and work-shopped; and there are no clear guidelines; then the Community Based Rehabilitation approach cannot succeed.

# 4.10 THE STANDARDISATION OF THE PROVISION OF ASSISTIVE DEVICES IN SOUTH AFRICA - A GUIDE FOR THE PUBLIC SECTOR 2003<sup>32</sup>

#### 4.10.1 Brief Aim of the Guideline

The aim of the guide is to set guidelines which will ensure that the provision of assistive devices is equitable and appropriate, as well as for advocating the maintenance of assistive devices.

# 4.10.2 Problem Formation (Context)

The government took cognisance of the link between poverty and disability and ensured that the Integrated National Disability Strategy<sup>25</sup> highlighted this trend.

Part of the rehabilitation process encompasses the provision of an assistive device. This compensates for the loss of function or functional limitation and hence increases the functional level of the person.

As stated in the guide, assistive devices can "open doors to learning, employment and social participation". According to the National Baseline Disability study<sup>1</sup>, assistive devices services were one of the services reported as needed most often. However only 40% needing these services, received the service. The National Baseline Disability study<sup>1</sup> also found that there was disparity in the provision of the assistive devices as the majority of assistive devices users live in formal metropolitan and urban areas.

The National Baseline Disability study<sup>1</sup> also reported that study participants "spoke of the crippling cost of their medical equipment", which jeopardised their financial resources, affected their families and also resulted in them not being able to obtain what they needed. Furthermore, whether or not the person had an assistive device and personal assistance had a significant impact on how respondents rated their activity limitation: the number of respondents who said their disability was "severe" was 58% with no assistance. When an assistive device was used, the percentage rating their disability as "severe" dropped to 5%.

#### 4.10.3 Actors

In the acknowledgements, reference has been made to the following stakeholders:

- National Council for Persons with Physical Disabilities in South Africa (NCPPD)
- National Council for the Blind (SANCB)
- Deaf Federation of South Africa (DeafSA)

- Disability Action Research Team (DART)
- Disabled People South Africa (DPSA)
- Department of Health, Limpopo Province

It would thus seem that Non Governmental Organisations and Disabled People's Organisations were involved in the formulation of the document. Furthermore, the Disability Action Research Team was also included and information based on its research, specifically pertaining to disability prevalence rates was utilised in the guide. The fact that information provided by research, is being utilised in this guide, is to be commended.

# 4.10.4 Process of Guidelines Formulation and Adoption (source are interviews and guide)

#### a) How the Guidelines Came About

From the interviews, it was found that the Assistive Devices Guidelines was devised in the manner illustrated by Figure 11 below.

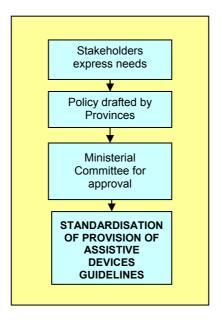


Figure 11: Formulation of the Provision of Assistive Devices Guidelines

Comparing this flow of guide document formulation to the ideal in Figure 5 in section 2.4, the initial steps of stakeholder's involvement and the passing of the guidelines through the correct channels were adhered to but in terms of the implementation of the guide as well as the monitoring and evaluation, this has not been congruent to the proposed model. From the interviews and the questionnaires, it is clear that financial resources are a challenge.

The challenge lies in the resources required to implement this "policy" and a possible reason why this document was never made official as a "policy" was because a "policy" is more legally binding on provinces.

This would amount to large financial and personnel resources being required to fully implement this guide and even the well - resourced provinces would be unable to cope with the demand.

#### b) Involvement of People with Disabilities

As for 4.10.3, Disabled Peoples Organisations (DPOs) were involved in the formulation of the guide document.

# c) Monitoring and Evaluation

There is no mention of this in the document. It is mentioned that there should be budgets for assistive devices and that this should be based on the actual need, hence this would require record keeping on the need of assistive devices as well as those issued. This is the only aspect of monitoring mentioned in the document.

#### 4.10.5 Guidelines Content

#### a) Design

The guideline talks about assistive devices in general and so this makes it difficult to pinpoint exactly what assistive devices should be issued and what is expected for each assistive device. For example, it is mentioned that "instant access to assistive devices for infants, children and adults with feeding and swallowing difficulties, e.g. cleft palate, stroke and cerebral palsy, should be guaranteed" but which specific assistive devices are referred to, is unclear. The guideline has many of these gaps and this would make the guideline easily open to interpretation and hence different implementation.

#### b) Whether Mentions People with Disabilities and Definitions of Disability Used

People with disabilities are specifically mentioned as they are the targeted population. However, somewhat surprisingly, no actual definition of disability is provided.

#### c) Health Promotion, Early Identification and Prevention of Disability

No mention is made of these aspects but an assistive device "prevents disability" in the sense that it compensates for a loss of function or functional limitation and thereby enhances the person with disability's prospects of employment, education and/or participation.

# d) Sensitivity to the General and Specific Needs of People with Disabilities

This guide is targeting the specific need of people with disabilities for assistive devices.

# e) Integration of People with Disabilities

As mentioned in the foreword and introduction to the guidelines, an assistive device can open the doors to learning, employment and social participation and thereby promote integration of people with disabilities.

# 4.10.6 Accessibility of Services

# a) General Provisions Made for People with Disabilities

The guideline does not make much mention of accessibility of services apart from what is contained in points below.

# b) Barrier Free Access

The guideline does not mention anything about the physical accessibility of the facilities that are providing the assistive devices. It does however mention that "personal assistants, such as those for the blind, people with locomotor disability, and the Deaf (Sign Language Interpreters), shall be made available by institutions to assist the public to access health services." <sup>32:16</sup>

# c) Communication and Information Materials

As for b) above. The guideline is only available in English and the printed format was sent to Provincial Rehabilitation Programme Managers to distribute. It is only available on the Department of Health website if a search is performed and does not appear under "policy document".

#### d) Training of Health Workers

The guidelines make mention that "assessment and prescription for assistive devices shall only be done by appropriately trained rehabilitation providers" and that "newly trained graduates should be specifically trained in the issuing of assistive devices after the commencement of employment." Furthermore "training/rehabilitation should be done by an appropriately trained rehabilitation provider." 32:9

# e) Infrastructure to Services and or Placement of Services

No specific mention is made about the placement of services. It is only mentioned that items for Alternative and Augmentative Communication (AAC) be made available at a tertiary level. It is also stated that "essential accessories shall be obtainable and/or available at every level of service delivery" but does not give a list of the essential accessories. It is also cited that "the client should be issued with the required assistive device by the institution/organisation discharging the client to his home ...or the referral facility doing the rehabilitation." It is also vaguely stated that "accessories for assistive devices and non-tender wheelchair accessories and items (e.g. gloves, commodes, etc.) should be budgeted for at relevant levels" but there is no list of these items. So it is not clear what exactly is on the list and what service level should be providing these (e.g. wheelchair gloves). This is open to interpretation and subsequently implemented differently in each province.

#### f) Cost Involved for Services

The guideline states that "payment for assistive devices should be done according to a Uniform Patient Fee System" 32:12 and that "assistive devices should be part of the service package offered free of charge to qualifying members (e.g. children under six and [people with disabilities] qualifying for free health care)." 32:13 So there is a cost involved which is nominal for the device/s but if the person qualifies for Free Health Care, the assistive device is for free.

#### 4.10.7 Equity Impact

#### a) Equalisation of Opportunities to Access Affordable and Appropriate Care

Should the person with disability qualify for Free Health Care services, then the assistive device is for free. However, it is known that not all assistive devices are available at all levels of care; for example, a prosthetic limb can only be accessed from specific hospitals and these hospitals may be some distance away from the client's home. It is known from the researcher's experiences that a client will need to attend at least three appointments with a medical orthotist and prosthetist before he/she can get the assistive device. This may entail large financial costs for transport to these specialised workshops. The guideline does not actually mention that its intention is to increase access to assistive devices but rather to govern more the practical provision or issue of them. In the introduction it is remarked that the "guideline puts forward proposals that will have a direct, practical benefit for people with disabilities with <u>due</u> consideration to cost implications to the State."

# b) Distribution of Benefits and Burdens

Should a person obtain an assistive device, he/she will derive some benefit.

# c) Utilisation Patterns

Utilisation patterns should increase with the implementation of this guideline. However, this guideline is rather general as it does not specifically mention to which assistive devices people with disabilities are entitled, making it difficult for service users to lobby for them.

#### d) Decision making and Decision Makers

No specific mention is made of people with disabilities being involved in decision making. In terms of budgeting, the guideline refers to those who are directly involved with the issuing of the devices. It is suggested that these people should be involved in the budgeting of the assistive devices.

#### e) Situation of the poorest, relative to other population groups

Only if the person qualifies for Free Health Care or is under six years of age, will the assistive device be provided for free. Others who receive assistive devices are expected to pay a fee.

# 4.10.8 Guidelines Implementation

Refer to Appendix 9 for the summarised results of the facilitators and barriers of the Provision of Assistive Devices Guidelines, which was based on interview transcripts and questionnaires.

# a) Facilitators to Guidelines Implementation:

- Attitudes: In terms of the actual provision, "therapists' attitudes and commitment to policy" takes the guidelines a long way, in that there is "creativity and innovation of health personnel". Some provinces have taken the lead in terms of maintenance of the assistive devices by "...supplying the repair parts for recycling" and "...appointing people with disabilities for repair workshops in the institutions". Furthermore there is a "loan system for those who need [assistive devices] temporarily [which] uses recycled items]" (for example spare parts of wheelchairs can be used in other wheelchairs).
- <u>Guidelines Process and Design:</u> The Standardisation of Assistive Devices Guidelines "facilitate[s an] equitable way of providing assistive devices" due to features in the document design itself that make it "user friendly". It "outlines generic criteria" for the provision of assistive devices. As there are obvious direct cost implications, it was necessary that there should be an adequate "dedicated budget at the provincial level" as well as "additional funding or resources from [National Department of Health] and donations". Some "...province[s] ha[ve] introduced database[s] for [Assistive Devices] that will help them to draw a report to motivate for the budget".
- Other Ease of order of Assistive Devices: In order to operationalise the policy, assistive devices needs to be bought and this is facilitated by National/Provincial assistive device contracts: "assistive device supplier contracts offers a variety of devices and simplifies ordering".

#### b) Barriers to Guidelines Implementation:

- Process and product design: This guideline was devised before the policy of Free Health Care but the Free Health Care Policy indicates that assistive devices should be provided for free (if the person qualifies for it). This has obvious cost implications on services and provinces. So even though the devices should be provided for free, "some therapists use discretion ... due to the [Free Health Care Policy] issue".
- Resources Financial: This barrier was extensively mentioned by respondents (7 of the 9 mentioned this as a barrier). As mentioned in the point above, there are cost implications especially if the devices have to be provided for free under the Free Health Care Policy: "Free Health problems" was listed as a barrier. There is an obvious increased demand for assistive devices, so much so that "...demand exceeds budget available", and so many provinces may "only issue the basic [assistive devices and] not [all that] is appropriate ... especially motorised [wheel]chairs and mattresses to try and cover a bigger number" of requests. Additionally the human resource shortage has a detrimental effect on the budget for assistive devices as "due to [therapist] shortage[s], the therapists do not have time to log in the clients in the database, [so] the province struggle[s] to get [proof] to motivate for a better budget". The reason for the "... minimal budget at district & institution level [is because rehabilitation services are] not life saving".
- Resources Human Resources: It was mentioned that because of the "scarcity of personnel, newly trained graduates work alone so they are compelled to issue [assistive devices]" but they may not necessarily have the skills to do so. Therapists are not adequately equipped at undergraduate level with wheelchair/ buggy seating skills to make the best choices for patients especially if they are also not familiar with the ordering procedures and or what devices are available of procurement contracts. Due to the "high staff turnover...[staff have to be constantly] retrain[ed]" on the guidelines and criteria for issuing of assistive devices as well as the ordering procedures and procurement contracts. In terms of assistive device repairs, an additional barrier faced is "...no dedicated working space [workshop] and personnel for repairs in some of the institutions". This leads to a weak implementation of this part of the policy.
- Access to and Knowledge of "Policy": The one respondent seemed to think that there were "no clear guidelines" and that "each district has their own view". This could be the case because the "policy" is not an actual policy but rather guidelines
   the exact title is "The Standardisation of the Provision of Assistive Devices in South Africa a GUIDELINE for the Public Sector".

The reason given for why the document is not a policy is because the Minister of Health cannot force provinces to provide assistive devices x,y,z because financially, some provinces cannot afford to do this. There would be many cases of litigation if this document were a policy. It is known that more resourced provinces provide more assistive devices whereas other provinces have a waiting list and may also depend on National Department of Health for additional funding (as mentioned under facilitators for this policy).

- Procurement Process for Assistive Devices: "Inefficient and lengthy procurement processes results in waiting lists for assistive devices despite having adequate budget procurement process can take as long as six months". Having sufficient budget for purchasing assistive devices is not the sole solution to guidelines implementation; there needs to be a whole system that is streamlined to deliver a service. Other stakeholders, like the procurement personnel and the actual procurement system, need to be sensitive to the needs of the programme/policy/end user and vice versa.
- Monitoring and Evaluation: Under this section, two respondents felt that the "lack of monitoring mechanisms at all levels" was a barrier to the guidelines being implemented, presumably because there is no one who will react if the "policy" is not being implemented as it is only a guideline. At the National level, the only information required is the actual number of wheelchairs, walking aids and hearing aids issued. The indicator does not contain any other information such as what number of devices was required in comparison to the numbers issued and also how long people had to be on the waiting list before they received their devices. Other assistive devices such as artificial limbs and motorised wheelchairs are not included in the national dataset.
- Other: One respondent listed the following as a barrier: "Billing system by admin classification of patients". It is presumed that the person meant that the administration clerks themselves acted as a barrier to services. For example they may turn people away from services if they have not settled their accounts. It is however also possible that the participant may have meant that the billing system was a problem as people receiving assistive devices have to pay a certain percentage of the purchase price of the assistive device. It may be possible that the clerk may not be able to calculate the correct cost to bill the patient as they may not know what assistive device was being issued and each assistive device has its own price based on its specification. This may lead to irregular prices being charged posing a problem among paying patients. The other aspect that needs to be considered is that, should a person require an artificial limb which is generally extremely costly, the person is expected to pay and they may not be able to.

They would not be considered to fit the Free Health Care criteria as disability had to exist after maximum correction of the impairment which is then controversial.

# 4.11 THE FREE HEALTH CARE POLICY FOR PEOPLE WITH DISABILITIES AT THE HOSPITAL LEVEL 2003 $^{33}$

# 4.11.1 Brief Aim of the Policy

The President of South Africa announced the policy of Free Health Care for indigent people with disabilities on the 14<sup>th</sup> of February 2003 in his State of the Nation address, and it was then to be implemented on the 1<sup>st</sup> of July 2003 in all provinces. The free health services include "all inpatient and outpatient hospital services such as diagnosis and treatment, specialised services, rehabilitation and provision of assistive devices."<sup>33:4</sup>

The Free Health Care Policy intends to improve the health status and quality of life of indigent people with disabilities, as well as to achieve greater equity – in terms of health status, independence, and social participation. Originally it was intended only to apply once the person had reached their maximum functional level, however in some provinces it has been modified to apply to the newly injured as well. The policy is to allow people with disabilities to access health care for any ailment once they are stable in terms of their impairments and activity limitations.

#### 4.11.2 Problem Formation (Context)

Refer to the Background sections 1.3.4 and 1.3.7 for the international and national legislative framework and policies setting the backdrop to this policy. The setting in South Africa since 1994 has been of redistributive justice not just towards those affected by apartheid but equality for all, in particular for people with disabilities.

Table 11 below reflects the international and national legislation, conventions, charters and policies (in chronological order) which makes specific mention of the financial relief that needs to be provided to increase access to health services. Although some articles may not specifically mention people with disabilities, the concept applies to all, for example, all that are unemployed, as poverty and disability tend to co-exist and many people with disabilities may not be employed for various reasons.

YEAR	NAME	SPECIFIC MENTION OF FREE HEALTH SERVICES
1961	European Social Charter <sup>14</sup>	Article 13: any person who is without adequate resources and who is unable to secure such resources be granted adequate assistance and the care necessary in the case of sickness.
1969	Declaration on Social Progress and Development <sup>17</sup>	Article 19 notes that "free health servicesare the means to achieve the goals".
1988	Convention concerning Employment Promotion and Protection against Unemployment <sup>21</sup>	Article 5 (4) (g): Provision of medical care to unemployed people and their dependants.
1990	Convention on the Rights of the Child (UNICEF) 22	Article 23 (3) whenever possible, the child with disabilities should be provided health care services free of charge.
2006	UN Convention on the Rights of People with Disabilities <sup>8</sup>	Article 25: "Provide persons with disabilitiesstandard of free or affordable health care and programmes."

Table 11: Legislation and Policies that Advocate for Free Health Care Services

Moreover, the World Programme of Action Concerning Disabled Persons, the South African Constitution's Bill of Rights, Integrated National Disability Strategy as well as the Disability Rights Charter of South Africa all mention that health and rehabilitation shall be affordable to all people with disabilities.

The situation in South Africa is still of poverty and unemployment due to lack of adequate basic education and skills, which is, to a large extent, a historical legacy from the apartheid era. Thus the policy of Free Health Care is seen as a form of poverty relief and social security. Thus principles of equality are being applied.

Other policies that were implemented before the Free Health Care Policy include the Primary Health Care Policy, the National Rehabilitation Policy and the Guidelines for the Provision of Assistive Devices. The Primary Health Care Policy provides for free services at the community level including the rehabilitation package. The National Rehabilitation Policy talks about "affordability" of the provision of assistive devices and also mentions that there should be a list of basic assistive devices, which should be issued free of charge or at a nominal fee. It is also mentioned in this policy that the needs of those who cannot afford to pay for services should be considered. The Guidelines for the Provision of Assistive Devices also refers to assistive devices being part of the package of the services offered free of charge to children under six and people with disabilities qualifying for free health care.

#### 4.11.3 Actors

Mention has also been made to the Provincial Rehabilitation Programme managers in the foreword of the Free Health Care Policy document, as they were the ones who helped to develop the policy.

No mention has been made about who else participated except for "civil society organisations"<sup>33</sup> – it is assumed that the Disabled Peoples Organisations and Non Governmental Organisations working with people with disabilities had raised their concerns as well which has influenced government to come up with this policy.

# 4.11.4 Process of Policy Formulation and Adoption (source are interviews and policy documents)

# a) How the Policy Came About

From the policy document, it has been reflected that this Free Health Care Policy for people with disabilities follows the introduction of Free Health Care for pregnant women and for children under 6 years old after realising what impact this had on the health status of children, mothers and their babies. The National Government also had to improve on its service provision to people with disabilities especially in light of the prohuman rights stances taken by Disabled People's Organisations (DPOs) and activists and because it makes sense as a poverty alleviation mechanism. It is not known whether the policy was developed based on any specific research evidence, as this was not alluded to in the policy documentation.

From the interviews, it was mentioned that the Free Health Care Policy was decided on at a political level. Policy formulation followed thereafter. It was unclear whether people with disabilities were involved in the policy formulation. Again, comparing this flow of policy formulation in Figure 12 to the ideal in Figure 5 above, only 2 steps were taken as opposed to the ideal 7 steps.

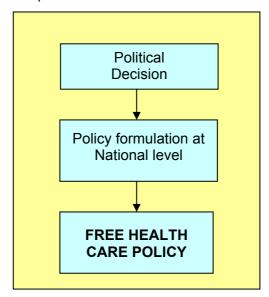


Figure 12: Free Health Care Policy Formulation Method

#### b) Involvement of People with Disabilities

It is unclear from the policy the extent to which people with disabilities was involved in the formulation of this policy. In the forward, the Minister of Health acknowledges the people who were involved in developing this policy document from "both government and civil society organisations." However, it is not clear who exactly participated, but indication has been made that there has been participation by people with disabilities. This aspect could be investigated further through discussions with the disability sector but this is beyond the scope of this study.

# c) Monitoring and Evaluation

It is mentioned in the Free Health Care Policy that there should be ongoing monitoring and evaluation and that both national and provincial departments of health would be responsible for this, but no more details other than this has been set out (e.g. what indicators to use, etc.). The National Department of Health commissioned report on the Free Health Care implementation would shed some light on this but it has not been released as yet. It could have implications for the revision of the policy.

# 4.11.5 Policy Content

# a) Design

Free health care has been offered to children under six years of age as well as pregnant women and has had positive effects on their health status. The Free Health Care Policy similarly intends to have positive effects on the health statuses of people with disabilities. The policy is meant to cater for people with moderate to severe disabilities and there are criteria, which can be used to ensure that those with minimal or temporary disabilities are excluded. Yet these people with disabilities also have health needs.

# b) Whether Mentions People with Disabilities and Definitions of Disability Used

The definition for a person with disability used in the policy is "People with a moderate to severe functional or activity limitation and/ or psychosocial participation restriction, lasting for longer than one year, or a prognosis that the disability will last longer than one year. The activity/ functional limitation or participation restriction needs to exist after maximum correction or control of impairment (WHO definition as adjusted)". 33:1

This definition is thus acceptable and in line with the current trends in defining disability as it looks at the functional limitation and participation restriction aspects of disability. It however, makes no mention of environmental factors, in order not to complicate matters as discussed previously. It is postulated that if environmental factors are taken fully into account, it would broaden the targeted population beyond what is affordable by the government.

The Assessment Tool and Training Manual for the Free Health Care Policy clearly defines in broad outlines the extent of a moderate and severe disability. It has categorised disability into one of the following sub-groups:

- Moving (transfers)
- · Moving around
- Self care
- Communication
- Seeing
- Hearing
- Mental-psychiatric diagnosis
- Intellectual disability

Furthermore these activity restrictions are to be looked at in the broader context – as in how it affects the individual's involvement in the major life areas of living, learning, socialising and working/occupation. Any individual scoring moderate or severe in one or more of the above-mentioned categories would qualify for free health care. Hence the tool is quite sensitive to any activity limitation and participation restriction. The tool has adopted the International Classification of Functioning, Disability and Health (ICF) categories but is not extended to environment factors, which affect the health status of people with disabilities. The tool is also relatively easy to administer – setting out good parameters for assessment. However, questionnaire respondents and interviewees do not think the eligibility section is clear enough and their responses also alluded to a lack of clear guidelines.

The tool and policy has made use of the International Classification of Functioning, Disability and Health's conceptual terms<sup>2</sup> and has taken disability to mean an activity limitation, which affects the individual's involvement in major life areas.

Furthermore it has also incorporated automatic qualification criteria of the following:

- "Persons with a chronic, irreversible psychiatric diagnosis, or dementia, irrespective of the fluctuation in mental health status"
- "Frail older persons, according to [Department of Social Development's] DQ 98
   [Dependency Questionnaire of 1998] classification"
- "Long term, state-subsidised, institutionalised patients, excluding patients in residential care not complying with criteria (of permanent disability, of a moderate or severe nature, and those persons with confirmed chronic irreversible psychiatric diagnosis or dementia)." 33:2

These were put in to aid easy classification as it would not be then necessary to do the full assessment of these individuals.

Specific mention is made to the exclusion of those persons who do not have functional difficulties and who have communicable and non-communicable diseases such as Diabetes Mellitus, Epilepsy, Human Immunodeficiency Virus (HIV), or Tuberculosis (TB). These people do not have moderate to severe functional limitation or participation restrictions merely because of having these illnesses.

It is also mentioned that persons who have to wait more than six months for maximum correction, should also score as a person with disabilities. This is important as a facilitating factor – i.e. not being excluded because of a lack of services available to get maximum correction/control.

It is also mentioned that persons with temporary disabilities will be excluded. There is a transient phase for some participation restrictions; for example, a person who has bilateral plaster casts on his/her lower limbs will be wheelchair-dependent and hence will have participation restriction. But this is only temporary as once plasters are off and the person has been rehabilitated, the person will no longer be "disabled".

#### c) Health Promotion, Early Identification and Prevention of Disability

By offering free health services, people with disabilities can access <u>all</u> health services but the onus is on the people with disabilities to access the services. This can lead to prevention of secondary disabilities. As mentioned previously, transport to the services is not mentioned and this is an issue which will intensify if an integrated strategy is not devised which links accessible public transport to health services, as transport impacts access to services. See discussion (Chapter 5) for further deliberations.

#### d) Sensitivity to the General and Specific Needs of People with Disabilities

Poverty and disability are strongly linked. The Free Health Care Policy allows indigent people with disabilities to be at an advantaged position in order to get free (hence very affordable) and appropriate care. The only hidden cost is the cost of transport. Thus this policy is sensitive to the needs of people with disabilities but does not take into account the transportation that is needed in order to access the services. As it is a policy about hospital services, transport is usually required for the person to access the service, unlike primary health care services

The policy is sensitive to the health care needs of indigent people with disabilities; however, but fails to formulate clear guidelines for responsibilities falling under other government departments, such as transport, to ensure accessibility of hospital based services.

# e) Integration of People with Disabilities

The policy hopes to achieve better integration of people with disabilities through their raised health status. Furthermore, the policy states that "this programme can and should facilitate and enhance intersectoral collaboration".<sup>33:1</sup>

The policy also states that the "free services refer to personal medical services only and not non-personal and intersectoral services". However if this entire policy (and disability services) could be co-ordinated with other government line functions as a package, this would be more effective as a policy. It is of no point just improving in one aspect only. Health is not the only answer. There needs to be more inter-sectoral collaboration.

#### 4.11.6 Accessibility of Services

# a) General Provisions Made for People with Disabilities

The Free Health Care Policy is making services economically accessible to people with disabilities but the bottom line is that the people still need to make their own way to the hospital. It is known that clinic services are already free due to Primary Health Care Policy but the rehabilitation services are not offered at every clinic.

Hence some people will have to travel to hospitals for rehabilitation services. There are many less hospitals than there are clinics, hence some people with disabilities may have to travel far in order to access appropriate services. People staying close to hospitals will have better access to services than those who have additional transport costs involved. This highlights the need for this policy to work together with other ones around transport, and other broader poverty alleviation measures.

#### b) Barrier Free Access

People with disabilities are being offered free medical and rehabilitation hospital services but it is assumed that these hospitals are already fully physically accessible. No mention is made that the hospitals should be made accessible to cater for people with disabilities in this policy. Furthermore no mention is made on training staff members on how to deal with people with disabilities. The policy assumes that people with disabilities will encounter no negative attitudes and that there will be someone at the hospital who can interpret Sign Language. It is thus left up to Provincial Rehabilitation Programme Managers and those who are interpreting this policy to realize these shortcomings and to make arrangements for these. The policy should in fact make mention of the need for it to work together with all these other aspects.

# c) Communication and Information Materials

Both the President (February 2003) and the Minister of Health (May 2003) communicated this policy to the Nation. Posters and training manuals were sent out to provinces via the Provincial Rehabilitation Programme Managers. Posters and training manuals were in English only. The posters were given to Provincial Rehabilitation Programme Managers to distribute and it was up to them to do the marketing too. There was a press release<sup>47</sup> on the 1<sup>st</sup> July 2003 about Free Health Care. From the interview with National Department Representative, it was also found that it was widely communicated via South African Broadcasting Corporation (SABC) radios and community radio stations and the Disabled Peoples Organisations (DPOs) were informed via their national and provincial structures.

# d) Training of Health Workers

From the interviews it became apparent that it was up to the Provincial Rehabilitation Programme Managers to ensure the "roll – out" of the policy.

User friendly, training manuals and copies of the policy were provided from the National Department of Health. It was also up to these managers to ensure that not only rehabilitation staff but others involved, actually understood the policy. Chief Executive Officers (CEOs) of hospitals and relevant (reclassification) clerks had to be made aware of the policy as well as the processes to follow to ensure smooth implementation. This information was communicated via workshops and departmental circulars.

As for special training needed, no mention was made in the policy document about training health workers to communicate in Sign Language in order to make the services more accessible.

#### e) Infrastructure to Services and or Placement of Services

Free Health Services are offered at hospitals and this will increase the number of points that people with disabilities can access.

#### f) Cost Involved for Services

Hospital based health care services are free, should the person qualify.

# 4.11.7 Equity Impact

# a) Equalisation of Opportunities to Access Affordable and Appropriate Care

As mentioned previously by making the services free, this should allow people with disabilities to access services as and when required hence allowing equalisation of opportunities in ensuring good health.

#### b) Distribution of Benefits and Burdens

By accessing health services to try and manage impairments, people with disabilities will be offered greater equity in health status, independence and social participation. This in turn will minimise external stresses and vulnerability. It is also mentioned that the service should be seen in the broader context of social security and poverty relief, spreading the risk and subsidizing the poor.

#### c) Utilisation Patterns

As for 4.11.7 a), by having free services, utilisation of services is encouraged.

# d) Decision making and Decision Makers

Decision making in this policy document is limited to the bureaucrats and those implementing the policy. Therapists have to do the assessment and if the person qualifies, this will be communicated to the administration clerk who in turn will reclassify the patient as a non-paying user.

#### e) What is the Situation of the Poorest, Relative to other Population Groups?

By making the services free, the poorest are advantaged because they do not have to pay for services whereas others do. However, the transport to services has not been taken into account and this can be extremely costly. So even though people with disabilities may be advantaged by free services, they are still disadvantaged by the cost of transport to get there.

#### 4.11.8 Policy Implementation

Refer to Appendix 10 for the summarised results of the facilitators and barriers of the Free Health Care Policy, which was based on interview transcripts and questionnaires.

# a) Facilitators to Policy Implementation:

- Attitudes: From the findings of the questionnaires, it seems that the implementation of the Free Health Care Policy was aided by the attitudes of stakeholders viz: "support from [provincial] top management", the "...buying—in of Hospital management", the "enthusiasm of rehabilitation staff" and people with disabilities. The policy also "created more awareness about disability" and this was a desirable consequence. There was also economic will which facilitated policy implementation as "most ... clients are indigent; they already qualify for free service".
- Access to and Knowledge of Policy: Another important factor for the success in
  the implementation of the policy was the availability of the "printed guidelines with
  user friendly forms". This was mentioned a number of times by the few
  respondents.
- Resources-Technology: One province mentioned that they had also formulated a database for reporting purposes.

### b) Barriers to policy implementation:

- Attitudes: The fact that "managers [were] not willing to implement" and that there was "resistance to change", are not good signs for successful policy implementation. One probable reason for this resistance is a loss of revenue generation. It was also mentioned that "therapists use it when it's for their liking" suggesting that the policy is not applied uniformly and that therapists were selective whom they informed about the policy and who they chose to assess for eligibility for the benefit. This attitudinal barrier should be investigated further as it is not professional. Another response was that the "Database is combined with ICF lengthy process [and] therapists [are] not keen to complete it as it is time—consuming". One of the provinces (not identified for the sake of anonymity), has a database that it keeps to register all people with disabilities who qualify for Free Health Care as a control measure and for research purposes. However, it was pointed out that this measure was not working and that statistics obtained would be inaccurate and could negatively influence continued implementation of the policy.
- Process and product design: This theme was the most reported on thus indicating problems with the content and policy design. One respondent felt that the Free Health Care Policy did not offer "...clear guidelines" and that "each district has their own view". This sentiment was echoed as another respondent felt that a "lack of clear guidelines...create[s] different interpretation[s]". Respondents had problems with the "definition of disability" and had either "differences in understanding of qualifying criteria" or had "poor understanding about the criteria" and felt that this was due to "poor training". Some areas of concern included a "problem with criteria in that those using prosthetics and hearing aids would have to pay for their devices, as it was only if after maximal correction the person still had moderate to severe disability that they could be reclassified. However these assistive devices are extremely costly so people would go without it." So some people with disabilities were no better off despite the policy. And the fact that "people on [disability grants] were not automatically entitled for Free Health Care province[s] had to take steps to ensure that they were" as this did not make sense for them not to qualify for Free Health Care if they already qualified for a disability grant. There also appeared to be "different provincial approach[es] in the implementation" resulting in the non-uniformity of implementation across provinces. Another respondent also felt that "[a lack of a] monitoring and report back system" was a barrier to the implementation.

One of the other anomalies that occurred with this policy was that it was "not gazetted" so this posed problems for provinces who were legally then not required to implement it. This may have been used as an excuse as the policy resulted in losses of revenue for provinces.

- Resources-financial: The Free Health Care Policy "created huge unrealistic expectations of clients" as they expected to get lots of assistive devices etc. but there was still "poor resource allocation" and "funding" so provinces could only provide what they could afford.
- Economic will: It was found that some "Institutions [are] reluctant to reclassify newly injured patients" and "...other hospitals feels that free health services affect their revenue collection" as "hospital[s are] expected to meet certain target about fees collection". This posed a barrier despite the impact the policy was going to make on the lives of people with disabilities. It is unknown whether the policy was well researched before, because it would seem that most administrators seem to think that their province will be losing out on a lot of revenue. It is the researcher's impression that there is a bigger proportion of people with disabilities, who cannot afford the services versus those who can, and for those who cannot, the fees are already being waivered, hence there is possibly not much loss of revenue. Had some financial research been done beforehand, this might have appeased administrators' minds. It is also known that it is sometimes problematic obtaining financial information on patient fees accrued based on their financial classification.
- Access to and knowledge of Policy: It was widely reported that the involvement of other stakeholders complicated the implementation as administration clerks, nursing and other medical personnel also had to be made aware of the policy and the "Lack of information [at the level of] people with disabilities and clerical staff at admissions" hindered policy implementation. There was also "limited knowledge of policy especially among admin people, followed by nursing and medical personnel" and the training of and "co-ordination of multiple stakeholders- finance and admin clerks also complicated matters". The therapy staff in particular had to be well trained in the policy as they were the first gatekeepers, but the "no proper knowledge by new therapists" meant that therapy staff had to be constantly retrained due to the "...high staff turnover". What also caused difficulties was that "Disabled people [were] not fully aware of policy" and these were the main people who should know about this policy so that they could go to hospitals and ask for an assessment to be considered for this social assistance benefit.

#### 4.12. POLICY ANALYSIS

It was found that policy analysis became easier to do with the devised framework and that it helped the analyst pick out the salient points of the policy in terms of access and equity. Once the user is comfortable with the framework, policy analysis can be done rather rapidly and recommendations can be made (as was done in the relevant sections). Furthermore, as mentioned under benefits of policy analysis in 2.1 in the Literature Review, this policy analysis can be used retrospectively and prospectively.<sup>37</sup> In this case, it was used retrospectively, but having this framework will assist policy makers formulate their policies based on the framework. In addition, the researcher's proposed ideal flow of policy development depicted in Figure 5 can be an additional tool to consider for policy makers.

A consideration when doing policy analysis is that there is a potential influence of the "analysts' own values and perspective over the analysis and even the decisions made", <sup>37:367</sup> thus it is subjective to some extent. It must also be accepted that policies are formulated and implemented within specific historical contexts and outcomes are dependent on time and place. <sup>37:367</sup> Furthermore, policy analysis must consider the actors, the state of their relationships between the actors and the factors driving them in the particular context and the analyst may be aware of some dynamics in the relationship whereas others may not be. From this study, it has become clear that the researcher was at an advantage having worked as and with provincial rehabilitation managers. The researcher has utilised some of this knowledge to add value to this dissertation.

There are potential challenges for policy analysis. <sup>37:366</sup> Two of these include:

- "All policy is decided for political reasons" this may mean that the logical sequencing of policy formulation is not followed and this may mean that stakeholders were not always consulted. This has been reflected in this study with the Free Health Care Policy as an example.
- "Access to information is difficult and can be delicate" <sup>37:366</sup> this has been experienced by the researcher. It was postulated that this could be a reason for the poor responses from the Provincial Rehabilitation Managers.

# 4.13 STAKEHOLDERS ROLES

The policy analysis showed the differences in the formulation of policies and this confirms that policy formulation is a dynamic process<sup>37</sup> that does not necessarily follow a set recipe. It has also demonstrated that different actors or stakeholders have varying amounts of influence on policy formulation. Ideally, one would expect everyone to strive for a rights - based approach to services, but this is not the case.

Some stakeholders have to do more lobbying than others, in order to bring about equalisation of opportunities for people with disabilities. For example, therapists were the ones who initiated the Provision of Assistive Devices Guidelines as well as that of the National Rehabilitation Policy, whereas, ideally people with disabilities should have been the ones who initiated this. People with disabilities themselves need to be empowered enough to be the drivers of policy development and monitoring to ensure inclusion of the needs of people with disabilities. It has been shown in the results that the monitoring and evaluation is poor for all policies and people with disabilities are not involved at all in the monitoring of policy implementation.

#### 4.14 COMPARISON OF POLICY ANALYSIS FOR ALL FOUR POLICIES

Using the devised policy analysis framework was beneficial as it entailed reading through the policy with the view to answering specific questions, thereby focusing the analyst's thoughts and highlighting aspects of access and equity as well as that of the gaps.

#### 4.14.1 Brief Aim of the Analysed Policies

As most of the policies were drafted in more or less the same time periods, that is between 2000 (the National Rehabilitation Policy and Primary Health Care policies) and 2003 (the Free Health Care Policy and the Assistive Devices Guidelines), the aim of these policies were similar in that they all attempted to bring about equitable and accessible health care services whether it be through guidelines or affordable (free) health services.

#### 4.14.2 Problem Formation (Context)

Again the context of the policies and guidelines are similar as they were devised within three years of each other. Refer to 1.3.4 and 1.3.7 for the detailed context internationally and locally.

#### 4.14.3 Actors

Some policies had more stakeholders involved than others. Three of the policies/guidelines are specifically for people with disabilities hence it would be expected that people with disabilities would be involved in the policy formulation and monitoring and evaluation of these. However, this did not prove to be the case: only the National Rehabilitation Policy and the Standardisation of the Provision of Assistive Devices Guidelines made definite mention of Disabled People's Organisations involvement. As for the Free Health Care Policy, mention is made of "civil society organisations" but it is unclear whether Disabled People's Organisations were actually involved.

The Primary Health Care Policy did not mention that they had involvement of people with disabilities despite the Rehabilitation and Community Based Rehabilitation Programmes being included in the Package.

# 4.14.4 Process of Policy Formulation and Adoption

# a) How the Policy Came About

- Information gained from the interviews confirms that policy formulation is a dynamic process and does not necessarily follow a set recipe. Each policy was initiated from a different stakeholder:
- For the Assistive Devices Guidelines and National Rehabilitation Policy, the initiation was from the side of the Rehabilitation professionals who wanted a quideline.
- Service users and people with disabilities wanted to know what they could expect from rehabilitation services so that they could lobby for this. Therapists also wanted a guideline and together with Provincial Departments of Health and stakeholders drafted the National Rehabilitation Policy. For the National Rehabilitation Policy, the policy was drafted by provinces, criteria were devised, it was circulated, reformulated and final draft then went to the Ministerial Committee for approval.
- The Provision of Assistive Devices Guidelines were drafted by a task team called by the National Department of Health.
- The Free Health Care Policy was devised from a top down approach and as a result, lacks the necessary consultation process and provides less clear details compared to the National Rehabilitation Policy.
- The National Department of Health developed a strategy to bring about equity and redistribution of health services for all hence the Primary Health Care Policy was created. The policy was a National priority therefore it was drafted at a National level, and rehabilitation aspects were included into it; however it seems that neither rehabilitation staff nor Disabled Peoples Organisations were included in the formulation.

It would seem that comparing the policy process with the researcher's ideal seven step method, the steps were not followed through, and the policies undertook only some features of the "ideal" policy process. For two of the policies (that of the Primary Health Care and the Free Health Care policies), they were formulated from a top down approach and these were the two, which had minimal stakeholder involvement.

See Table 12 below, which compares the researcher's seven - step model to the policy processes the four analysed policies took.

STEP	DESCRIPTION	ANALYSED POLICY COMPLIANCE TO IDEAL STEP
1	Stakeholder/s identifies gap in equity realization based on international and national legislation and policies	All policies complied with this but only the stakeholders that identified this gap were different
2	Group builds up support from other stakeholders (to include people with disabilities)	Two policies did not have involvement of people with disabilities – these were the Free Health Care Policy, and the Primary Health Care Policy
3	Collaborates with all other stakeholders to draft up policy together with evaluation criteria (people with disabilities to be included)	Evaluation criteria (indicators for progress and success of policy implementation)were not drawn up. Only the National Rehabilitation Policy had a comprehensive Monitoring and Evaluation Section.
4	Policy is formalised by going through the correct government channels	All policies went through the correct government channels except the Free Health Care Policy was never gazetted.
5	Policy is implemented within available resources	Most policies were implemented but there was a delay in the implementation of the Free Health Care Policy in two provinces because of the confusion with regards to qualification criteria and the non-gazetting of the policy.
6	Policy is fine tuned and monitored on ongoing basis by policy implementing and formulating bodies as well as Disabled Peoples Organisations/ people with disabilities	Monitoring of all policies is inconsistent and not all mechanisms are functional and effective. People with disabilities are not involved in the monitoring of any of the policies.
7	Impact of policy is measured regularly until has desired effect or is replaced by another	Impact of policies not evaluated except for the Free Health Care Policy, whose implementation was evaluated by an external company (but report is unavailable to the public). Implementation of policies monitored to a certain extent.

Table 12: Comparison of Policy Process of Analysed Policies versus Researcher's Proposed Ideal Policy Process Model

#### b) Involvement of People with Disabilities

It is obviously important that people with disabilities are involved in decision making and hence integrally part of the policy processes: from formulation to monitoring and evaluation. Based on the information given by the policy documents it would appear that for the Primary Health Care Policy and the Free Health Care Policy formulations, people with disabilities were not involved. In the latter, reference has been made to "civil society organisations" but it is unclear who these are. The National Rehabilitation Policy and the Provision of Assistive Devices Guidelines had Disabled People's Organisations involved in the policy formulation. However it is only the former policy that calls for the involvement of people with disabilities in the planning, implementing and monitoring of rehabilitation programmes but based on the information gained from the interviews, it would seem that this is not happening anyway. This policy analysis framework has therefore highlighted one of the major shortcomings of these policies.

# c) Monitoring and Evaluation

The National Rehabilitation Policy document has a specific section for monitoring and evaluation and gives broad guidelines, rationale, principles and strategies for such. For the Primary Health Care Policy the document's layout and design lends itself to easy monitoring and evaluation but this tool was not provided with the policy document. From the interviews, it was learned that there is a tool called the Clinic Supervisory Manual, which is currently being revised after input from clinicians.

The Provision of Assistive Devices Guidelines does not mention monitoring and evaluation at all. As for the Free Health Care Policy, monitoring and evaluation is mentioned but no details are given. The National Department of Health commissioned research on the implementation of the Free Health Care Policy in 2007. The report for this is unavailable. The findings of this report would be insightful.

# 4.14.5 Policy Content

#### a) Design

The design of the Primary Health Care Policy document is the most user-friendly in that it is like an instruction manual, and the layout of the document has clear sections for norms, standards on competences of skills, equipment, patient education, collaboration, etc. The National Rehabilitation Policy is also well structured and it has the section on monitoring and evaluation. The Provision of Assistive Devices Guidelines describes assistive devices in general and so is not specific. It is also not specific in terms of the monitoring and evaluation. The Free Health Care Policy comes with an instruction manual as well as the reclassification tool but some adaptation of the policy had to be done by provinces as it was not clear on what to do with newly disabled people.

It is recommended that policies should be clear, specific, comprehensive, have a clear layout, be user-friendly and it should include monitoring and evaluation in the policy. The other addition that would add value to the policy documents would be a section, which specifically mentions the type of relationship needed with people with disabilities (as in that they should be the "watchdogs") as well as a section dealing on accessibility of the services. Unfortunately, for now these issues need to be spelled out because not all bureaucrats and administrators are privy to these. Long term, policies should be mainstreamed but this is not possible at this stage.

It is postulated that this is because firstly people with disabilities are not empowered enough to demand that their rights be upheld; secondly there are attitudinal barriers as well as inadequate awareness of the human rights based approach to disability and thirdly; there is insufficient intersectoral collaboration occurring.

# b) Whether Mentions People with Disabilities and Definitions of Disability Used

In terms of the Primary Health Care Policy document and that for the Provision of Assistive Devices Guidelines, no definitions of disability are given. The National Rehabilitation Policy does give a definition for people with disabilities and for the Free Health Care Policy document; a specific definition for people with disabilities is given as they are the targeted population.

#### c) Health Promotion, Early Identification and Prevention of Disability

The Primary Health Care Policy has prevention as one of the cornerstones of its policy and has thus included prevention strategies in all its programmes. Early identification is also advocated for. Prevention of secondary complications of disability is also included in the policy document. The National Rehabilitation Policy also extensively mentions prevention of disability in its documentation.

In the Provision of Assistive Devices Guidelines, prevention of disability is not mentioned per se but an assistive device "prevents disability" in the sense that it compensates for a loss of function or functional limitation and thereby enhances the person with disability's prospects of employment, education and/or participation.

As for the Free Health Care Policy, people who do access this policy should have a resulting raised health status through increased access to health services. Secondary complications of disability are also prevented through this access. However in the cases of those not catered for by the policy that is people with mild disabilities, if prevention of further complications is not addressed, the mild disability may be aggravated into a more severe type of disability.

In summary, all documents call for disability prevention albeit in different forms.

#### d) Sensitivity to the General and Specific Needs of People with Disabilities

The Primary Health Care Policy is a general health policy but has Rehabilitation and Community Based Rehabilitation programmes in its package of services and these programmes are sensitive to the needs of people with disabilities.

The National Rehabilitation Policy describes services for rehabilitation and is thus sensitive to the needs of people with disabilities. These needs are also targeted in the Provision of Assistive Devices Guidelines. The Free Health Care Policy also targets people with disabilities with moderate and severe activity limitations to address their needs. Thus all policies are sensitive to needs of people with disabilities.

# e) Integration of People with Disabilities

The Primary Health Care Policy in its Community Based Rehabilitation programme advocates for involvement of people with disabilities in designing, implementing and monitoring of services. It also advocates for People with Disabilities being part of Community Based Rehabilitation Health forums, hospital boards and community health. The National Rehabilitation Policy also calls for mainstreaming and for people with disabilities to be integrated/ re-integrated into society. Assistive devices can assist in reintegration of people with disabilities. Likewise the Free Health Care Policy hopes to achieve better integration of people with disabilities through their raised health status. All policies analysed thus calls for mainstreaming of people with disabilities.

# 4.14.6 Accessibility of Services

# a) General Provisions Made for People with Disabilities

The Primary Health Care Policy intends to increase access to services through Community Based Rehabilitation which are services based in the communities people live in. In the same way, the National Rehabilitation Policy also increases access to services as the Community Based Rehabilitation approach is advocated for. However the Provision of Assistive Devices Guidelines does not mention accessibility of services. The Free Health Care Policy although not explicitly stated, does increase access to services where hospitals are. As mentioned earlier, it would seem that a section on accessibility would be required in all future documents to ensure that this important point is addressed.

#### b) Barrier Free Access

Again this section is not detailed in most of the documents. In the Primary Health Care Policy there is some mention of destignatisation for mental health service users. This document is also the only one which specifically mentions accessibility of clinics to wheelchairs and availability of wheelchair accessible toilets. The National Rehabilitation Policy acknowledges environmental factors.

The Provision of Assistive Devices Guidelines does indicate that "personal assistants, such as those for the blind, people with locomotor disability, and the Deaf (Sign Language Interpreters), shall be made available by institutions to assist the public to access health services." It would be recommended that disability sensitisation training given to all staff members in order to improve the quality of access offered. There should be an integration of Universal Access into all policies which would highlight all physical infrastructure needs for people with disabilities.

# c) Communication and information materials

None of the documents mention the need to provide information materials in an accessible format for people with visual, cognitive, physical or hearing impairments. And none of the policies and guidelines are available in accessible formats. The Free Health Care Policy, the Primary Health Care Policy and the Provision of Assistive Devices Guidelines are available on the internet so if a visually impaired person had access to JAWS they could possibly access the information. Internet availability of documents with the exception of the National Rehabilitation Policy thus does improve access to information.

For the Free Health Care Policy, posters and booklets were available. All documents were only available in English. The Provision of Assistive Devices Guidelines and National Rehabilitation Policy are only available in booklet form. The Primary Health Care Policy is only available on the internet.

However internet availability is not satisfactory. There are many people with disabilities who do not have internet access. Information needs to be disseminated far and wide and in accessible formats. The National Department of Health representative mentioned that these documents were given to National Disabled Peoples Organisations for distribution and the other form of communication was through the media. Information needs to reach people at the grass roots and media coverage (television, radio, newspapers) will help the Department disseminate this information.

#### d) Training of Health Workers

The Primary Health Care Policy document has standards for competence of clinic staff and in almost every section; training of health workers is mentioned except for specific training on disability sensitisation. Technical training is required in the Provision of Assistive Devices Guidelines.

All analysed policies required training of the relevant health workers but it is only the Free Health Care Policy, which required training of other non-clinical staff such as the Chief Executive Officers (CEOs) and administration clerks. Other special training, which is required, is Sign Language usage but no mention was made in any of the policy documents except for in the Provision of Assistive Devices Guidelines. The Uniform Patient Fee Schedule, which details the patient fee for assistive devices as well as for therapy services, is also another field that all stakeholders need training or education on. This fee system is dependent on the financial classification (income level) of the client.

#### e) Infrastructure to Services and or Placement of Services

Ideally services should be community based thereby making these more accessible. The Primary Health Care and National Rehabilitation Policies advocate for Community Based Rehabilitation (CBR) services, which would meet this expectation. The Provision of Assistive Devices Guidelines does not specifically mention placement of service apart from the mention of the items for Alternative and Augmentative Communication which is to be made available at a tertiary level. Free Health Services are offered at hospitals and this will increase the number of points that the people with disabilities can go to access services. On the other hand, there is no mention of transportation to the services, which is a major factor, which would impact on the accessibility of services. This is also later discussed in section 5.5.

# f) Cost Involved for Services

People who qualify for Free Health Care services do not pay for services. Similarly services provided by the Primary Health Care Policy are for free. The National Rehabilitation Policy talks about the "affordability" of rehabilitation services. The Provision of Assistive Devices Guidelines calls for payment for assistive devices according to the Uniform Patient Fee System. Children under six and people with disabilities qualifying under the Free Health Care Policy are also entitled to free assistive devices.

However it is not known whether this is being consistently applied. Furthermore, it is known that there is an inconsistency in the quality of services offered, in the types and number of assistive devices issued and this varies from province to province. For example: in the under - resourced provinces, access to motorised wheelchairs is more limited than in the well - resourced provinces.

An additional example may be that a person with a spinal cord injury may undergo intensive multi-disciplinary rehabilitation and receive a customised wheelchair, high specification wheelchair cushion, a transfer board, and wheelchair gloves from a well resourced province, whereas a person with the same condition may only receive a few therapy sessions and only a standard wheelchair from an under-resourced province. No matter what fee the client had to pay or not (if he/she qualified for Free Health Care), he/she would receive more services in the well - resourced province, and this would be more value for (no) money for that client.

These analysed policies thus can ensure some degree of accessibility to services and assistive devices as the services are either for free or a nominal amount is required (for assistive devices). By getting the assistive devices for free, this would also allow some equalisation of opportunities.

# 4.14.7 Equity Impact

#### a) Equalisation of Opportunities to Access Affordable and Appropriate

All four analysed documents offer equalisation of opportunities to access affordable health services through its affordability (see 4.14.6 f). In terms of the appropriate health care, free basic health services together with Community Based Rehabilitation and rehabilitation are provided. The National Rehabilitation Policy also enlists the Community Based Rehabilitation strategy and this is appropriate. Should the person with disability qualify for Free Health Care services, then the assistive device is free as well as other appropriate health services. It should be mentioned that some assistive devices are only provided at certain institutions, which would limit access.

#### b) Distribution of Benefits and Burdens

All four analysed documents provide health benefits, which are spread out, to the medically uninsured population, which constitute the majority of the population. The National Rehabilitation Policy clearly articulates these benefits to be that of "improve accessibility to all rehabilitation services", "equalisation of opportunities", "enhance human rights for persons with disabilities" and "addressing issues of poverty and disparate socio-economic circumstances."

Should a person obtain an assistive device, he/she will derive some benefit. By accessing health services to try and manage impairments, people with disabilities will be offered greater equity in health status, independence and social participation. This in turn will minimise external stresses and vulnerability. It is also mentioned that the service should be seen in the broader context of social security and poverty relief, spreading the risk and subsidizing the poor.

#### c) Utilisation Patterns

By making services appropriate, affordable and accessible (see 4.14.7 a), utilisation of services is encouraged. All four analysed documents should result in increased utilisation patterns.

# d) Decision making and Decision Makers

Community Based Rehabilitation advocates that people with disabilities and their families as well as their communities are the part of the team of decision makers. The Community Based Rehabilitation approach is advocated for in the Primary Health Care and National Rehabilitation Policies. However in terms of the Provision of Assistive Devices Guidelines, no specific mention is made of people with disabilities being involved in decision making.

# e) What is the Situation of the Poorest, Relative to other Population Groups?

As the Primary Health Care services are accessible and affordable, the poorest are able to have equal access to basic health services. Community Based Rehabilitation services would also ensure accessibility of services as these are to be brought to the community.

Only if the person qualifies for Free Health Care or is under six years of age, will the health services and or assistive device be provided for free. Should poor people with disabilitiesqualify for Free Health Care, they will have accessibility to health services which would place them on equal footing with their peers. However, the transport to services has not been taken into account and this can be extremely costly, so even though people with disabilities may be advantaged by free services, they are still disadvantaged by the cost of transport to get there.

#### **CHAPTER 5: DISCUSSION**

In this Chapter, the results presented in the preceding chapter will be discussed. Policy implementation in general is initially discussed and thereafter an in - depth discussion on each of the barriers and facilitators to policy implementation follows. The other end of the policy implementation is then presented, that is, from the viewpoint of the end - user. This will be based on two sources of information. The impact of inaccessible transport on service utilisation is then presented as it negatively influences access to services. Finally the chapter wraps up with some discussion on the way forward.

#### 5.1 IMPLEMENTATION OF POLICIES

Through this research, it has become clear that there are a wide range of international and regional conventions, policy statements and legislation specifying commitments to people with disabilities. Despite strong political commitment to address inequities and discrimination, a large gap still exists between policies and implementation. One of the gaps is that policies do not prescribe data collection hence there is insufficient data for planning, and measurement of services for vulnerable groups

Dube<sup>53</sup> notes the fact that there are capacity constraints at programmatic level that limit the effective implementation of any policy (not only health ones). Policy implementation issues are not addressed consistently, for various reasons, at different levels of government. These reasons include "limited conceptual understanding, poor championing, inadequate or inappropriate institutional arrangements, and a general lack of capacity."

Two other factors that have contributed to the poor implementation of legislation and policies are that the definition and nature of people with disabilities' participation have not been adequately reviewed and articulated, and that the policy requirements for disability mainstreaming are not linked to performance management, thereby undermining commitment to implementation. In addition, legislation and policies are not implemented, due to a lack of allocated fiscal resources and commitment.

Where successful implementation has occurred, it has largely been due to political support by the ministers and senior civil servants in charge of departments and/or the sustained commitment and ongoing advocacy by the disability sector, led by Disabled People South Africa (DPSA).

Dube<sup>53</sup> believes that problems associated with the lack of budgetary allocations, the ignorance of civil servants charged with the responsibility of implementing these policies and procedural bottlenecks, among other things, have been identified as some of the main causes of "policy evaporation" within the South African context. It has also been noted that policies are sent to provinces without funding and this limits implementation of these policies.

Most of the policies described were devised between the years 2000 and 2003. It is thus necessary to measure if the situation has changed since earlier studies such as the national baseline survey on disability of 1998<sup>1</sup>. A study conducted in 2006 by Saloojee et al.<sup>48</sup> in Gauteng, found that there were still unmet health, welfare and educational needs for children with disabilities. The study found that only 26% of children in need of rehabilitation received such services. Children with motor impairments were more likely to receive rehabilitation than those with intellectual impairment (44% vs 8%). Of the children requiring assistive devices, only 28% had been issued with these. This study highlights the gap in services.

Lack of money, limited awareness about available services, and bureaucratic obstacles were the main reasons offered by caregivers for the low utilisation of available services and resources. Three main reasons given by caregivers for not attending rehabilitation included "financial and transport difficulties, no improvement seen in child despite therapy and because they were unaware that child could benefit from therapy." One of the reasons offered by a caregiver for the low utilisation of rehabilitation services was: "I have arthritis and now I cannot carry my child for long distances". This highlights the consequences caring for a child with disabilities can have, as well as how the lack of a mobility aid (assistive device) and lack of accessible transport places a caregiver's health at risk.

Saloojee et al.<sup>48:235</sup> also found "little evidence of co-operation between the health, education and social development departments regarding disability. Consequently these services were fragmented and parents ill informed of the available resources."

Other viewpoints on Primary Health Care (PHC) include those critics who believe that a true PHC approach has not been implemented in South Africa and that the health care system still operates on a largely medical model that is more curative than preventative or promotive in orientation, without real community involvement<sup>58</sup>. The rural health networks that do exist are "mostly doctor driven and a team approach involving all stakeholders in health, including traditional leaders and healers is the rare exception rather than the norm." <sup>58:677</sup>

Implementation is essentially seen as a linear, top-down and centrally directed process, in which those responsible for implementation simply follow the policy instructions that percolate down to them. The theorists propose that actors such as local health managers and frontline health workers themselves directly influence the form that any policy takes, through their words and actions. Their views are, in turn, influenced by the culture of the organisation and society in which they work.<sup>49</sup>

#### 5.2 GENERAL DISCUSSION OF BARRIERS TO POLICY IMPLEMENTATION

It has been stated previously in the Introduction and Literature Review that people with disabilities need more health care services due to their impairments, but also experience greater levels of unmet need than people without any disabilities. It was also mentioned that legislation and policies need to be introduced to correct this, but it has been found that in many cases, legislation and policy that support people with disabilities are not implemented. Some reasons for this are:<sup>50</sup> lack of understanding on the part of mainstream infrastructure and development implementers about how to include a disability perspective in their work, lack of training and information on good practice, institutional discrimination and local cultural perceptions.

Having discussed each policy separately in the last section, it seemed necessary to discuss the barrier themes as a whole as many of these themes were cross - cutting across the policies. Facilitators to policy implementation should be applauded and maintained but it seems essential that some of the barriers be discussed in more depth so as to develop a better understanding of these and to foster a way forward.

#### 5.2.1 Attitudinal Barriers

Attitudinal barriers can be described as "the intolerance of the society in which we live towards people with disabilities which leaves them with a feeling of marginalisation and a sense that they have been sidelined from the broader society". Feelings of pity, shame and denial are commonplace along with superstitious beliefs that pervade many communities in South Africa. The attitudes of communities and families in which people with disabilities live, as well as of people with disabilities themselves, contribute to converting impairments into disabilities. An example of this could be a person with an impairment, such as a person with a head injury, not being accepted by his/her community who may physically or verbally abuse him/her. This, in turn, may cause him/ her to shy away from society and be afraid to attend recreational activities or go out. In this case, the attitudinal barriers significantly restrict the person's participation in society.

Attitudinal barriers were mentioned for three of the four analysed policies. This is similar to previous findings such as that of the National Baseline Disability study¹ which found that attitudinal barriers was a theme that cut across most of the participant life stories, irrespective of disability. All of the participants in the National Baseline Disability study spoke of suffering from discrimination and other people's ignorance and insensitivity. In another study,⁵¹ derogatory physician or provider attitudes was also stated as a barrier to women with disabilities accessing health services despite their medical insurance.

This study talks about the non - involvement of people with disabilities and also about the lack of service integration and intersectoral collaboration when it comes to addressing disability issues, as well as the non - prioritization of rehabilitation services (all mentioned as barriers in implementation of the Primary Health Care Policy). It is postulated that some "powers that be" do not see people with disabilities to be important people and that their needs are not just as important as other people who are "sick". But it could also be that some people choose to turn a blind eye as they do not understand people with disabilities or the concept of disability. To support this argument, it has also been mentioned previously that the Provision of Assistive Devices Guideline was never made into a policy because it was not seen as a priority and it had high funding requirements. This is in contrast to the HIV/AIDS programme which has definite policies and lots of funding attached. The irony is that many people with HIV/AIDS do tend to end up with a disability in the long term anyway.

In particular for the Free Health Care Policy, managers were not willing to implement the policy for reasons such as a loss of revenue generated, despite the fact that the reason for instigating the policy for eligible people, was to increase access to services – a basic human right.

#### 5.2.2 Environmental Access

Other studies<sup>51</sup> have reported a variety of barriers to access, such as physically inaccessible offices and lack of information in accessible formats (e.g., Braille, audiotape) for education materials and insufficient Sign Language interpreters. This study also mentioned the "lack of interpreters at entry points and no Brailled information leaflets/pamphlets" as being a barrier to people with disabilities from accessing health services.

In Malawi, health care clinics, hospitals and public transport were reported to be accessible<sup>45</sup> by the majority of those with disabilities (over two thirds). This is in contrast to the findings of this study and to the situation in South Africa. According to the National Primary Health Care Facilities Survey conducted in 2003 by Health Systems Trust (HST),<sup>52</sup>

the percentage of facilities with infrastructure which allows some extent of accessibility to the facility for a people with disabilities is depicted in Figure 13 below:

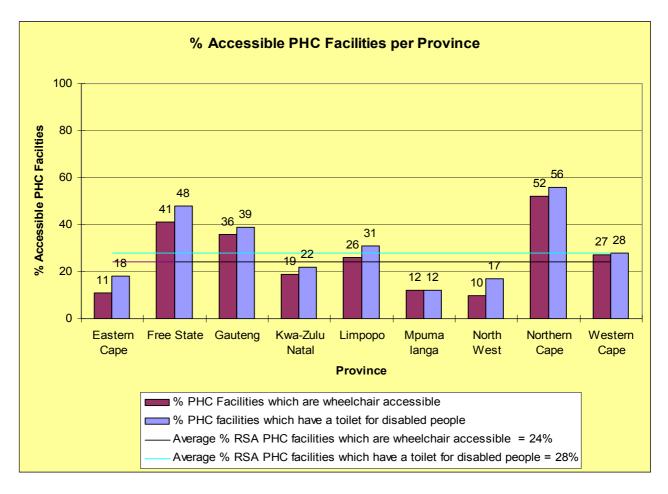


Figure 13: Level of Accessibility of Primary Health Care Facility per Province in South Africa 2003 According to Health Systems Trust Report<sup>52</sup>

The figure above reflects that in South Africa on average only 24% of facilities are wheelchair accessible and only 28% of Primary Health Care facilities have a (single) accessible toilet in their facilities. These figures are very low and indicate that overall, South African Primary Health Care facilities are inaccessible. It is obviously not possible to facilitate usage of health care facilities if there are physical barriers to access. The two criteria used in the Health Systems Trust study on Primary Health Care facilities looked at physical access for a mobility impaired person, and did not look at other environmental and attitudinal barriers.

This research study also concurs with the findings of the Health Systems Trust study. It was mentioned that in a relatively well resourced district and province, only 22% of Community Health Centres had accessible toilets, which means that people with disabilities are unable to access toilets in a manner that is dignified or respectable in most (78%) clinics. It was also mentioned that the ramps may be in place, but it does not necessarily mean that they have the right gradient and may not be safe to use without handrails.

This could mean that the ratio of one in four Primary Health Care facilities in South Africa that are so called "wheelchair accessible" could be, in actual fact, be a lot lower.

Universal Design<sup>6</sup> or the creation of barrier free environments is the way forward to promote access. Universal design is based on a very simple idea: all buildings, products and services should be designed in such a way that the number of potential users is optimised. The need for specialised design or adaptations must be minimized and one simple design that can meet the needs of people of all ages, sizes and abilities equally should be made prevalent. South Africa needs to move in this direction in order to make the services more accessible.

#### 5.2.3. Human Resources

#### a) Numbers of Rehabilitation Professionals

Dube<sup>53</sup> in his South African study of the legislation and policies concerning people with disabilities found that there are capacity constraints at programmatic level that limit the effective implementation of policy. This study also points to this. A lack of human resources was mentioned strongly for three of the four policies analysed.

The number of therapy staff is vital in order to ensure effective service implementation. The researcher however, could not find <u>current</u> available numbers of therapists in the public sector. A source<sup>54:42</sup> reflecting numbers of Clinical Psychology, Occupational Therapy, Physiotherapy and Speech Therapy and Audiology, "outputs" of tertiary educational institutions, was found which reflected the trend over a ten - year period. A graphical depiction of this is reflected below in Figure 14. There appears to be very slight growths in the numbers of professionals trained over the years, with the physiotherapy numbers increasing the most steadily over the years. The number of Speech Therapy and Audiology graduates, appears to be the most erratic. There needs to be consistency in the numbers of professionals trained so as to supply a steady stream\* of staff into the public sector so as to ensure service delivery.

One of the key recommendations of a study conducted by Wadee and Khan<sup>55</sup> is the need for a national database on health care providers. The researchers found that there are multiple data sets and currently it is difficult to make sense of data as there are too many 'unknowns'. The exodus of human resources from the public sector to the private sector is not quantified.

Through community service and possible attraction and retention through this strategy

There are also health professionals that have registered with the relevant councils (e.g. Health Professions Council South Africa) but either do not practice or have migrated hence the numbers available for South Africa are inaccurate.

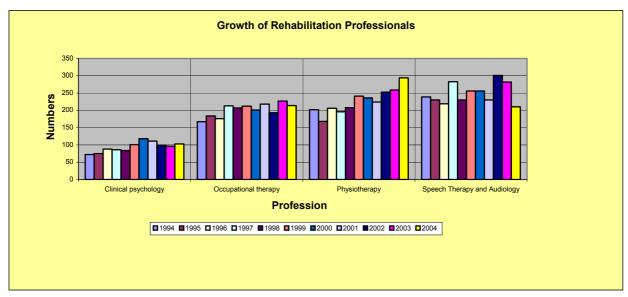


Figure 14: Growth in Human Resource Capital over a Ten - Year Period

Day and Gray<sup>56:217</sup> reported that the National Department of Health's Annual National Health Plan 2006/07 contains the following targets in relation to human resources: "fully mapped distribution of all staff and agreement on appropriate baseline level of staffing by discipline, for tertiary and level 2 services". This would require that the national Department provide "target minimum staff levels and activity thresholds by specialty and hospital type", thereafter each provincial Department would have to "map current and required staff against delivery points, levels of care and outreach services".

From the literature reviewed, a source of information contained in the National Rehabilitation Policy<sup>31</sup> was a table of the number of therapy staff per province. Figure 15, shows the graph that was drawn up using this information and depicts the grave situation in South Africa in 1997.

The current vacancy rate is not known, eleven years on. The information on the numbers of trained professions as depicted in Figure 14 could not be used as it cannot be assumed that all these graduates entered the public sector (despite community service programme).

The information depicted in Figure 15 shows the proportion of Medical Orthotists and Prosthetists, Occupational Therapists, Physiotherapists and Speech Therapists out of the total number of these professionals in South Africa in each province. This figure clearly shows that the majority of the categories of rehabilitation professionals were concentrated in one province, viz. Gauteng.

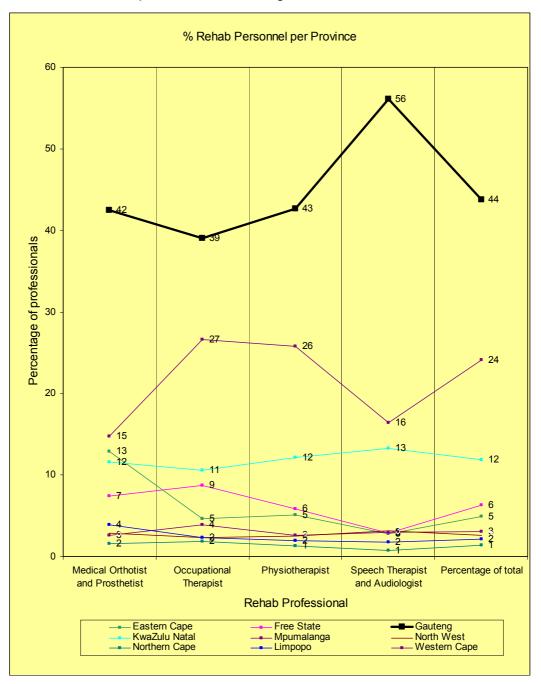


Figure 15: Therapy Professionals Vacancy Rate in South Africa in 1997 According to Data Provided in National Rehabilitation Policy.<sup>31</sup>

Thereafter the other biggest concentration of professionals was in the Western Cape followed by Kwa-Zulu Natal. Mpumalanga, Free State, Limpopo, Northern Cape and North West provinces only could account <u>for 5% or less</u> of each of the categories of the total health professionals in the country!

This is similar for Eastern Cape - the only exception being that of the Medical Orthotists and Prosthetists (MOPs) category which accounted for 12-13% of the total MOPs for the country. There is a huge gap in service provision across the provinces. An extreme example would be the 57 % of all speech therapists that are in Gauteng, whereas there was only 1% of this profession in Northern Cape!

# b) Workload of Rehabilitation Professionals

On the National District Health Information System, one of the indicators contained in the dataset is the doctor clinical workload; there does not appear to be an indicator for therapy staff.

The numbers of rehabilitation professionals needs to be brought into context. The number of professionals needs to be compared with the population group of people with disabilities. Using figures of people with disabilities from Census 2001<sup>7</sup>, each province's population of people with disabilities is compared with the number of health professionals (sum total of Physiotherapists, Occupational Therapists, Speech Therapists and Medical Orthotists and Prosthetists according to data provided in National Rehabilitation Policy). <sup>31</sup> The results are depicted graphically in Figure 16, which reflects the unequal distribution of health professionals. For example, the potential patient load of a rehabilitation professional in Gauteng is 106 patients and Western Cape 103 patients, whereas 1 rehabilitation professional in Limpopo, North West and Eastern Cape Provinces has a potential patient load of 1746, 1118 and 1034 patients respectively.

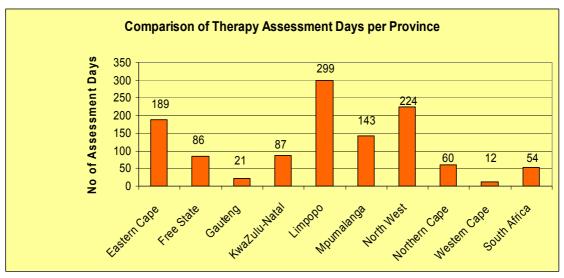


Figure 16: Potential Patient Workload per Rehabilitation Professional per Province 1997

To highlight what this means, if it was assumed that 1 professional takes 1 hour to assess a person with a disability, and could assess 7 patients a day, and this would mean that one professional in the Limpopo would take 299 working days to assess his/her patient load, whereas, the same professional in Western Cape would take only 12 working days to get through their patient load assessments. This scenario is based on the following assumptions: (i) that the population of people with disabilities is accurate; (ii) that the number of health professionals in 1996 as reported in the National Rehabilitation Policy is accurate; (iii) that a person with disability would require a service of either a Physiotherapist, Occupational Therapist, Speech Therapist or Medical Orthotist and Prosthetist and not more than one type of rehabilitation service.

It is noted that the source of information is outdated and attempts were made to access current information but this failed and this is beyond the scope of this study.

Nonetheless it shows the disparity in resources.

# c) Vacancy Rate of Rehabilitation Professionals and Reasons for this

The Health Department faces severe problems with respect to recruiting and retaining skilled personnel. Ntuli and Day conducted a study<sup>57</sup> in 2003, which reveals the high number of vacancies in health professional posts. See Figure 17 below.

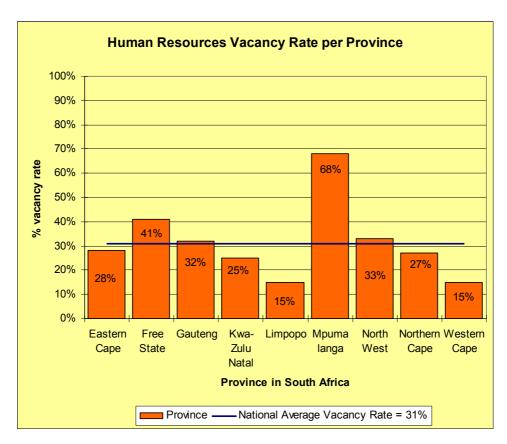


Figure 17: Health Personnel Vacancy Rate per Province According to Ntuli and Day (2003)<sup>57</sup>

The horizontal line represents the national average vacancy rate of 31 per cent. The vacancy rates in Mpumalanga, and to a lesser extent in the Free State province, are especially troubling. According to Ntuli and Day<sup>57</sup>, health personnel cite low levels of job satisfaction, poor working conditions, low salaries and despondency in the face of the HIV epidemic as underlying their dissatisfaction. The National Department of Health's Human Resource Plan for Health<sup>54:49</sup> also cites: "Lack of management and support, work overload, poor working conditions, lack of appropriate skills and emotional burnout are believed to be important factors among these, as are high crime rates and uncertainties about the future" as other reasons for the "brain drain". The factors which attract health professionals to other countries include: "better wages, easier working conditions and opportunities for professional advancement in foreign countries." 54:49
Without a stronger human resource pool, the dream of equitable access to high quality health care will not be realised.

Mpumalanga, Free State and Gauteng provinces show higher than average vacancy rates. The fact that Gauteng is in this list poses as a bit of a surprise as this province is an urbanised area and urbanised areas are generally more resourced than others.

### d) Retention Strategies

Limpopo province, according to the Ntuli and Day<sup>57</sup> study reflects a less than expected vacancy rate, which leads the researcher to ask the question: "What are they doing to attract and retain staff that is different to other provinces?" It is known that health professionals are given the rural allowance, which can be an incentive, and furthermore, they offer community service professionals the senior post immediately after completion of the community service year.

The last mentioned strategy is also employed by the Western Cape. It is known that this practice is not adopted in provinces such as Gauteng as a recruitment/ retention strategy. The reason for this is that this practice is not acceptable according to the DPSA (Department of Public Administration South Africa) regulations.

However it is clear that more health professionals need to be recruited and retained in the service to deliver a more accessible, equitable and quality health service. There is an "Inverse Care Law" bhich states that: "The availability of good medical care tends to vary inversely with the need for it in the population served." The burden of poverty and ill health in rural areas is made all more difficult by the operation of this law.

Measures taken by the National Department of Health to attract medical and therapy staff to rural areas includes the one year compulsory community service for doctors now extended to two years, as well as rural and scarce skills allowances. Community service has made a difference to the staffing in rural and public health hospitals and clinics and many areas rely solely on community service staff to render services. These staff, however, do not tend to stay on<sup>58</sup>. Community service, scarce skills and rural allowances may be a way of attracting staff but it does not necessarily mean that the professionals will stay on in the service. There is a shortage of experienced senior personnel.

There have been several initiatives<sup>58:677</sup> to attract medical staff to the rural areas and these have been the following:

- An electronic clinical support network for Rural practitioners Healthlink, a project
  of the Health Systems Trust runs an email discussion group called 'mailadoc'
  which makes it possible for rural practitioners to obtain answers to clinical
  problems from urban specialists as well as rural colleagues.
- An association to improve networking and support for rural practitioners the Rural Doctors' Association was formed in 1995 and is growing in membership and hosts a popular annual conference. The association has addressed a number of issues of importance to rural doctors and addresses rural health policy issues at a national level.
- The Southern African Academy of Family Practice/Primary Care supports rural doctors and numerous educational and community based projects in rural areas.
- Centres of Rural Health have been established at three different universities with dedicated academic posts and a number of decentralised campuses which expose students to rural health care early in their training.

These are the efforts made to attract doctors to rural clinics however it not known whether this is successful. This could be a possible strategy for retaining rehabilitation staff in rural areas and in the public sector generally.

#### e) Impact of Inadequate Human Resources on Policy Implementation

The lack of human resources especially therapists has an obvious impact on actual service delivery, but the other consequence of not having a stable staff base is that the policies (of the past) that need to be implemented are at risk of being ignored or forgotten. There is thus a need for ongoing training of therapists at all operational levels to ensure that the policies are implemented. Moreover, there is also sometimes a change in management structures and these new managers also need to be trained in these policies.

# f) Skills Mix Needed

Another challenge in terms of human resources is in terms of the skills mix.<sup>54</sup> State subsidies at tertiary educational facilities are biased towards postgraduate studies but this is in conflict to the emphasis on the training of mid-level workers necessary to implement Community Based Rehabilitation (CBR). There needs to be overall monitoring of this skills mix.

# g) Other Gaps with regards to Human Resource Component of Policy Implementation

A South African study conducted by Dayal<sup>59</sup> on the Human Resource component of the National Rehabilitation Policy found that the gap between policy and practice was due to four root causes:

- Rehabilitation professionals resisting to integrate with each other;
- A lack of a rehabilitation team identity;
- Capacity constraints at national, provincial and local levels and;
- Incoherent policies, norms and standards that guide human resource for rehabilitation professionals.

All these factors hindered the implementation of an integrated rehabilitation service.

Dayal<sup>59</sup> found that there was a lack of teamwork amongst rehabilitation professionals. Since professions within rehabilitation services are being managed separately, this led to uncoordinated service delivery, as well as a lack of a rehabilitation identity. Furthermore professional "soft issues" are also a barrier to integrated service delivery. From the management perspective, Dayal<sup>59</sup> found that there was firstly, a lack of leadership and guidance and secondly, there were confusing messages being relayed from higher structures.

To make recommendations to tackle the barrier of inadequate human resources is beyond the scope of this study. However, Dayal's study<sup>59</sup> makes the following recommendations for maximum integration of rehabilitation services and teamwork, which will ultimately benefit people with disabilities:

- Professional norms and standards as well as training curricula are to be reviewed so as to allow for role clarity and teamwork amongst rehabilitation professionals;
- There needs to be strategic human resources management for rehabilitation professions;
- There needs to be a separate rehabilitation professions plan within Human Resource Plan for Health especially with regard to recruitment and retention;
- A rehabilitation professions identity needs to be created and there should be role clarity and;
- The organisational structures will need to be reviewed so that they allow management of rehabilitation services as opposed to professions.

#### 5.2.4 Financial Resources

Health care budgets has been challenged by a number of trends: economic recession, the continued fight against AIDS, the prevalence of chronic lifestyle diseases with persisting communicable diseases, demoralised and scarce health staff and emerging drug resistance to some diseases (e.g. Tuberculosis).

It is understood that resources are finite, and that decisions need to be made to ensure that investments yield the greatest possible return - this is in terms of the egalitarian approach. Rights language refers to a 'right to health' and a 'right to health care', which, in the context of limited resources, can place managers and policy makers at a loss on what to prioritise and how to account to those that do not receive a service.

Financial resources to provide services are always a point of concern. Pauw and Mncube argue that despite the disability grant system being a good measure to fight poverty, the social assistance provisioning should not be increased. The reason given for this is because the resources are finite and within the already limited finances, money can only be re-allocated from other departments to the Department of Social Development. That would mean that already compromised departments such as Education and Health would be further disadvantaged and this would not make sense as both these departments could raise the health and poverty status of the population more proactively rather than dealing with the poverty alone, by handing out grants.

#### 5.3 GENERAL DISCUSSION ON FACILITATORS TO POLICY IMPLEMENTATION

#### 5.3.1 Attitudes

In terms of attitudinal facilitators to policy implementation, a positive staff attitude was conducive. It is known that attitude can influence the shape that services can take for example "creativity and innovation of health personnel" and their "enthusiasm" assisted in the implementation of the Provision of Assistive Devices Guidelines and the Free Health Care Policy. Furthermore intersectoral collaboration also facilitated the National Rehabilitation Policy and the Free Health Care Policy. Success stories are also something that will assist in improving the perceptions of service.

#### 5.3.2 Political Will

Political will was also a facilitating factor to implementation and respondents (interviews and questionnaires) listed this as a positive factor for the Primary Health Care, National Rehabilitation and Free Health Care Policies.

# 5.3.3 Process and Product Design

The process and product design was one of the three biggest categories that was reported on, and thus can be regarded as significant. Most of these policies provided guidelines for service provision and the layout and design of these documents were user-friendly and most respondents looked favourably on this aspect.

# 5.3.4 Resources

Having human resources helped implement services as reported most often by respondents. Having adequate financial resources also had a positive contributing factor on policy implementation of the Primary Health Care and Provision of Assistive Devices Guidelines. Other listed resources which impacted positively on the Primary Health Care Policy implementation included support systems such as the community structures, home based care programmes and a structured District Health System.

#### 5.3.5 Management Support and Organizational Structure

Management support and organisational structure played a role in the facilitation of policy implementation. It was stated that support from management structures such as head office, top management, district management as well as provincial managers assisted in policy implementation of Primary Health Care and Free Health Care.

Another aspect that was mentioned as being partly instrumental in the National Rehabilitation Policy and Free Health Care Policy implementation was the availability of the policies and assessment tools.

# 5.4 POLICIES AND SERVICES AS EXPERIENCED BY PEOPLE WITH DISABILITIES AT THE GROUND LEVEL

The positive policy environment in South Africa presents unique opportunities for people with disabilities to address issues such as poverty, access to assistive devices, access to public health services and providing free primary health care to people with disabilities affected by poverty. However, the researcher felt that it was appropriate to obtain some indications of how people with disabilities at the ground level view the services that the Department of Health are offering through these policies. One research paper by Saloojee et al.<sup>48</sup> and a piece by the QuadPara National Chairperson<sup>61</sup> were analysed to obtain this information as to their experiences with health services.

Shortcomings of the health department on the provision of rehabilitation services as well as assistive devices provision was mentioned throughout the text in the form of the finding of the national baseline disability survey which was conducted in 1998. Now in the new millennium and 10 years on from the study, it will be worthwhile to re-evaluate the service provision. In the interview with the National Department of Health representative, it was not clear whether another baseline disability survey would be conducted because Census 2011 was coming up and this may shed some light on service provision and it would thus be more cost-effective to wait for this.

The following excerpts were written by Mr Ari Seirlis, National Chairperson for the QuadPara Association of South Africa and posted on the Disability Mailing List<sup>61</sup> as the organisation's view of the current progress of the South African government and society towards meeting the needs of people with Disabilities. This letter was written in response to whether one should CELEBRATE the 2007 International Day of the Disabled Persons or not.

"On public transport: There is no public transport system in South Africa that will cater for people with mobility impairments. One has to understand that transport is the key to successful integration into mainstream society especially for people with mobility impairments, but of course it also allows old and frail people to continue operating in society, and allows women pushing prams to circulate, and it allows people who have broken their legs or sprained their ankles and are immobile for a short period of time to continue in their day-to-day routine. Access to transport is a human right; the government used October to highlight their Transport Month and yet not once engaged the disability sector on the needs in this period.

On **Access**: People with disabilities are still being recognised by their impairment instead of by their human rights. People with disabilities often do not have access to buildings, the physical environment and access to information and essential services.

On **Assistive Devices Provision**: The Department of Health has failed in the implementation of the assistive device policy, whereby everybody with impairment has the right to the assistive devices or mobility aids which are appropriate. Many provinces have not managed their budgets accordingly to be able to honour this.

On Environmental and Attitudinal Barriers: Does the solution lie in handing out wheelchairs to people who are mobility impaired? I don't think so, it is a holistic strategy which will help. You cannot give someone a wheelchair if the environment that they are operating in is inaccessible; they are just as handicapped, not by their disability, but by the environment (actually physically and by prevailing attitudes). The handing out of wheelchairs has often become so popular and political, no one has really bothered to measure how much freedom and mobility it actually gives the recipient. The tone of this is not to discourage people in giving away much-needed mobility; we will always need wheelchairs, we will always need assistive devices and care attendants, we will always need the support of civil society. In order to free and empower people with disabilities, we need to look not only at what tangible devices we need, but what environment we are operating in. Right now we are truly DISABLED by prevailing attitudes and the environment in this country. Our impairments are not disabling us.

On **Policies and Legislation for people with disabilities**: So often, people employ disability instead of employing skills, and thus a misplaced employee will never be loyal, will never perform, and will always be looked upon as a quota or figure, satisfying a piece of legislation which is resented by most, including people with disabilities. We praise them for encouraging legislation. But who is implementing this legislation? Who is monitoring its impact and outcome? Those benches in the House of Assembly and Council of Provinces are too warm. Our comrades in Parliament who truly understand the meaning of disability need to warm the spirits of our people on the ground and find a way, even challenging their own political parties to ensure tangible results from the human rights which we have. It is so sad ..."

It is thus clear from the study by Saloojee et al.<sup>48</sup> and the piece of Seirlis<sup>61</sup> that the end users of the services are still not satisfied with the provisions. In summary, they have mentioned the following challenges and barriers to services: financial and transport difficulties, unequal provision of services, access, provision of assistive devices, environmental and attitudinal barriers as well as the lack of effective monitoring of policies and legislation for people with disabilities.

# 5.5 TRANSPORT AS A BARRIER TO ACCESSING HEALTH SERVICES FROM THE ENDUSER'S POINT OF VIEW

As this study was taken from the provider's viewpoint as opposed to the end user's point of view, transport was not highlighted as being an issue, even though it is widely mentioned these days as a significant barrier. Accessibility and the cost of the transport are two major challenges for people with disabilities. "Mobility is one of the most crucial factors in the rehabilitation of [persons with disabilities]. It contributes to their life in dignity and to their standard of living". In South Africa a large percentage of the population uses taxis as public transport and it is known that almost all taxis are not accessible. Saloojee et al<sup>48</sup> found that regular visits to a hospital 30km away for rehabilitation therapy, consumed as much as 5% of the average family's monthly income for the transport costs for one return trip alone. Disability cannot remain in the realms of the Health and Social Development Departments: it requires an integrated approach and multiple co-ordination, just as the Integrated National Disability Strategy calls for, but this is not being done.

The UN Convention on the Rights of People With Disabilities<sup>8</sup> calls for governments to make public transport system accessible by "remodelling pedestrian routes in order to make them more accessible to [persons with disabilities], especially those utilising wheelchairs; priority parking for [persons with disabilities]; or providing incentives for employers and community organisations to provide transport. Other measures such as cash subsidies, improvement to existing public transport system, and specially adapted automobiles and the transfer of new technology in transport is also very important in ensuring the integration of persons with disabilities into mainstream society." This is something that still needs to be done.

#### 5.6 THE WAY FORWARD

It is clear that we have many policies, which do cater for, and bring about access of health services to people with disabilities. However in order for them to make a real difference in the life of a people with disabilities, policies need to be implemented. In order to ensure that they are implemented, there needs to be more emphasis on Monitoring and Evaluation of activities. This is embodied in article 33 of the UN Convention on the Rights of Persons with Disabilities<sup>8</sup> which advocates for national implementation and monitoring. The article calls for one or more centralised units in government to facilitate action in different sectors and at different levels. This researcher sees the Office on the Status of Disabled Persons (OSDP) in the President's Office as the vehicle for this. It is further mentioned that a framework, as well as the legal and administrative systems should be strengthened in order to promote, protect and monitor implementation. This should be done by the OSDP.

People with disabilities themselves need to be included in health professions and they need to be supported and developed to attain leadership roles so that they can make a difference. It is advocacy, however, that promotes an environment conducive to policy change. There is a need for effective advocacy to raise awareness to the continued lack of attention to enabling conditions. By enabling conditions, reference is made to all those factors which would ensure successful policy implementation, of which intersectoral collaboration would play a critical role. Furthermore the human rights issue of disability would also form the crux of the matter. Finally it is again advocated that people with disabilities need to monitor and evaluate policies – they as the end users have to be the referees.

Having discussed the results, what follows now is a chapter on recommendations based on the findings of this research.

#### **CHAPTER 6: RECOMMENDATIONS**

One of the objectives of this research was to pose recommendations. These recommendations can be used for further investigations.

#### 6.1 RECOMMENDATIONS FOR POLICY PROCESSES

- In view of the fact that there is a rapid and high rehabilitation staff turnover, there needs to be constant re-education on the official definition of disability as approved by South African Cabinet. This is so that all policy implementers have a common understanding of disability, as this will affect service delivery.
- The effectiveness of the various mechanisms, which allow people with disabilities to be involved in policies, needs to be strengthened. The following were identified 1) The Office on the Status of Disabled Persons; 2) National level stakeholder consultation;
   Networking and working relationships on a provincial level; 4) Local/ Provincial Disability Forums as well as; 5) Rehabilitation support groups which includes advocacy and awareness raising on policies.
- Policy implementation in general and the monitoring of this will thus need to be strengthened. The mechanism for policy implementation needs to be done consistently for each policy. In particular, there needs to be tangible indicators or targets for provincial departments to use in their data collection and reporting.
- People with disabilities themselves also need to be empowered enough to be the drivers of policy development and policy monitoring to ensure the inclusion of people with disabilities' needs. There should be a vehicle for this. It is recommended that this function rest with the Office on the Status of Disabled Persons, but this office will first need to be strengthened. Policies should not be developed in isolation departments should work in co-ordination. The onus does not rest with just one department to address disability. For example Department of Health's mandate is to provide health services for all users including people with disabilities; similarly Department of Transport needs to provide transport for all users including people with disabilities and this should be co-ordinated that the transport takes the end user to where service points are.

#### 6.2 RECOMMENDATIONS FOR POLICY ANALYSIS

- Uniform training on health policy analysis for National and Provincial Rehabilitation/ Disability Programme managers is recommended.
- Health policy analysis should be done during/whilst policies are being devised as well as during the planning phase for policy implementation in order to ensure that all aspects of the policy is interrogated and potential challenges avoided.
- The concept of Universal Access should be integrated into all policies related to disability.

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# 6.3 RECOMMENDATIONS ON ADDRESSING BARRIERS TO POLICY IMPLEMENTATION

- All stakeholders should be adequately involved in policy processes and should be fully
  aware of what is required from them. This will ensure that the policy is effectively
  implemented through intersectoral collaboration. The National Rehabilitation Policy and
  the Primary Health Care Policy both alluded to the Community Based Rehabilitation
  strategy, so there should have been adequate training offered for potential mid level
  workers, coupled with registration with the Health Professions Council. However, this was
  not the case and resulted in the poor implementation of these policies.
- Ongoing training on policies for people with disabilities is highly recommended to ensure that all staff including those at the grass roots is familiar with the available policies so as to ensure implementation.
- Policy implementation in general and the monitoring of this will need to be strengthened.
- Available monitoring tools needs to be strengthened. As the National HIS is used in all
  provinces, it can give snapshot pictures of implementation as well as analysis of trends. It
  would therefore seem strategic to include more indicators in the National HIS in order to
  monitor and evaluate policy implementation. Indicators from the Clinic Supervisors
  Manual could also be indicated on the information system.
- People with disabilities need to be involved with the monitoring of services and there
  needs to be a mechanism for this. This function could possibly rest with the Office on the
  Status of Disabled Persons (OSDP) but through the information gained in this study, it
  would seem that this office is not functioning as effectively as it should.
- In terms of transport, National and Provincial Departments of Public Works and Transport need to seriously look at addressing the accessibility of public transport. In order to fast track this process, penalties should be put in place and the possibility of providing transport subsidies investigated. This is necessary as people with disabilities are still being marginalized and government has not met their needs. Another possible suggestion would be that private transport companies could provide accessible rides like the "Dial-a-Ride" programme (which is successfully running in Cape Town) and then be subsidised by government.
- The suggestions put forward could be seen as a Transport Assistance Scheme very much like the Social Assistance Grant. There needs to be coordination of disability programmes between government departments such as Department of Health, Department of Social Development, Department of Public Works and Transport to improve disability services.
- As for attitudinal barriers, this is also non negotiable. There are various Acts in place, which makes discrimination illegal. This needs to be reinforced. Disability sensitisation should be rolled out through the Social Clusters in Government and the Office on the Status of Disabled Persons should ensure this by engaging with Disabled People Organisations, such as Disabled People South Africa, to roll out. Furthermore, there should be pro bono work offered by legal firms in order to take up constitutional rights such as discrimination of people with disabilities. This will ensure that everyone will start to realise that the rights of vulnerable groups should no longer be ignored. Mechanisms for this also include the South African Human Rights Commission and Equality courts as well as the Joint Monitoring Committee on Children, Women, Disabled People and the Elderly.
- Financial Resources are always a constraint in any department or programme. Creative ways of utilising already limited resources are needed. Furthermore, Private Public

Partnerships could possibly be a means to achieve this. Prioritisation of disability issues is obviously required. Value for money exercises should also be undertaken with the view of long - term sustainability (e.g. it is not feasible to provide cheap wheelchairs which will break down quickly and for which there are no spare parts available and which will lead to further health problems such as scoliosis). Instead, appropriate wheelchairs that can be adjusted to the user's requirements, should be provided which are easily maintained, durable and which does not pose a health problem.

- Human Resources studies have been done which have given reasons for the migration
  of health care professionals from the public sector. A task team or an action plan needs to
  be devised to address these shortcomings in order to reverse the process. This will take
  time.
- Accessibility facilities needs to be made physically accessible and future planned facilities should be designed using universal design as the basis. There needs to be a concerted effort to do this. If the legal cases increase regarding physical access to buildings, this will increase pressure on departments to make buildings accessible.

## 6.4 RECOMMENDATIONS ON STRENGTHENING FACILITATORS TO POLICY IMPLEMENTATION

- Support by top management All policies should be communicated to top management of provinces and they need to understand the principles and be supportive.
- Availability of training tools for policy implementation. Printing of tools (posters, pamphlets, assessment form) is a simple need but will go a long way to ensure implementation. The availability of these tools in all institutions is a way of communicating this to all stakeholders (e.g. staff working in the area, patients, visitors, other managers etc.). Budget for this should be strongly considered with future policies.

#### 6.5 RECOMMENDATIONS FOR FUTURE POLICIES IN TERMS OF CONTENT

- a. It is recommended that all policy documents should give definitions especially for disability. It would be helpful to the administrator and layperson if these are included and may be a form of awareness - raising on disability and will therefore increase understanding.
- b. All policies should address health promotion, early identification and disability prevention.
- c. All stakeholders should be involved, especially people with disabilities in line with the motto of Disabled People South Africa: "Nothing about us without us".
- d. In terms of Monitoring and Evaluation, it s recommended that all provinces should have a list of key indicators which would monitor policy implementation. Mechanisms that are used for monitoring and evaluation, such as the clinic supervisor's manual needs to include indicators for rehabilitation. There should be a minimum data set pertaining to disability and rehabilitation. This needs to be determined at a national and provincial level for research, policy implementation and budgetary purposes.

- e. Design of policy documents should be clear, specific, comprehensive and user friendly. All documents should be clearly laid out and the structure should lead to easy reading and comprehension, as all levels of stakeholders should be able to understand and interpret the content correctly. So what the person on the street reads in the document should be the same thing that the policy implementer understands.
- f. The needs of people with disabilities should be highlighted in all documents, as people with disabilities are a vulnerable group.
- g. All documents should encourage intersectoral collaboration and specify how this should be achieved.
- h. The general and specific health needs of people with disabilities should be taken into account
- i. There should be direct involvement of persons with disabilities in all aspects of policy processes from policy initiation, decision making, and monitoring and evaluation.
- j. Policies should mention that people with disabilities should be mainstreamed and provide some strategies for doing this.
- k. Documents should promote participation of people with disabilities in their integration or re-integration into society and this should be the ultimate goal of rehabilitation.
- Policies should acknowledge the role of the environmental factors. It would seem that a
  section on accessibility would be required in all future documents to ensure that this
  important point is addressed.
- m. Disability sensitisation training should be given to all staff members in order to improve the quality of access offered.
- n. Communication and information materials should be accessible to all end users. Media releases are very important in bringing the message across to the targeted audience. Furthermore user friendly, training manuals and copies of the policy should be made freely available and should be distributed to as many stakeholders as possible.
- o. In terms of infrastructure to services, there needs to be coordination with other departments such as Department of Transport. Lack of accessible and affordable transport is a major barrier to service utilisation. With regards to the placement of services, services should be placed in the community so that it is accessible to end users.
- p. Cost for services should be affordable or for free as it has been mentioned that people with disabilities are the "poorest of the poor" so that the cost of services will not be a barrier to accessing services.
- q. All policies should take heed of the benefits of the National Rehabilitation Policy:<sup>31:2</sup> "to improve accessibility to all rehabilitation services"; "right to have access to health care services"; "equalisation of opportunities"; "enhance human rights for persons with

disabilities" as well as; "addressing issues of poverty and disparate socio-economic circumstances."

## CHAPTER 7: LIMITATIONS OF THIS RESEARCH AND AREAS FOR FUTURE RESEARCH

#### 7.1. LIMITATIONS OF THIS RESEARCH

#### 7.1.1 LIMITATIONS ON THE SOURCES OF INFORMATION FOR THE STUDY

#### a) General Considerations

It has been previously stated that this research was based on findings gleaned from the four interviews with key informants, policy documents review and questionnaires to the Rehabilitation Programme Managers. However, this information was limited.

The information gained from the interviews with key informants was invaluable for this research; having done this thesis, it has become clear that there is a lot of information that is inaccessible to the public. There are still a lot of gaps in information and this dissertation presents what the researcher could find during the timeframe allocated. When writing the proposal, it was expected that there would be supporting documents available describing the policy development process. However, despite efforts to find such documents on the internet and from key stakeholders none were found.

#### b) Provincial Rehabilitation Programme Managers

There was a lack of responses to the questionnaires as only three provinces responded, and one province sent three replies, thus bringing the sample size to six. The information gained from the interviews was added to the responses of the questionnaires, in order to analyse more information. It is postulated that the following may have been reasons why officials did not return questionnaires:

- Programme managers have not been long in the post or are only acting in their position and hence are not confident enough to answer the questionnaire;
- Programme managers are afraid of what the researcher may think of their answers
  as the researcher has worked with them previously, thus may be afraid of
  providing "wrong" answers or;
- If seen in a pessimistic light, it is plausible that they show apathy towards research.

It is postulated that the one way to avoid this would have been physical interviews scheduled with them, which however would have resulted in increased cost implications. The other alternative would have been to conduct telephonic interviews.

Had all Provincial Rehabilitation Managers completed the questionnaire (interview checklist), this would have given results, which could reflect the picture for each province of South Africa.

This information could have been utilised to compare the situation in well resourced provinces versus under resourced provinces, and comparisons made for like-themes, for example comparing the human resource components of well resourced versus under resourced provinces and the effect this has had.

#### c) End - users as a Potential Source of Information

Another potential source of information for this study would have been interviews and or questionnaires as well as focus groups with the end users of the services (i.e. with people with disabilities). This research study was undertaken from the view point of the Department of Health and not from the end users.

While feedback from the end users would have been very beneficial, this would have extended the size and scope and hence time needed for this study.

#### 7.2 AREAS FOR FUTURE RESEARCH

- The researcher's proposed seven step model (Figure 5) for the method of policy formulation, implementation and monitoring of health policies to ensure inclusion of people with disabilities' needs, will need to be tested and validated for use in future policy processes.
- The devised framework should be further validated and then used to assess whether current and future health policies cater for the needs of people with disabilities. If not, action plans can be put in place in order to address this inequity.
- This research is merely a drop in the pond, as only four health policies were analysed. All
  the rest of the health policies (current and future) will need to be reviewed if one is to
  make inclusions and adaptations to these health policies so that they address access and
  equity adequately for people with disabilities. There thus needs to be more research into
  health policy analysis.
- The impact of the policies will need to be evaluated from the end-users point of view, in order to determine what impact the policies have had on the lives of people with disabilities. It would also be useful to understand the end users' involvement in policy development and implementation.

#### **CHAPTER 8: CONCLUSION**

In this research both internationally and national legislation in favour of people with disabilities was examined and found to be progressive and visionary. Governments have gone the full distance in terms of legal aspects to human rights to ensure that the interests of those with disabilities are provided for and protected by the law. However, legislation alone cannot improve our society or guarantee human rights; but it does provide an imperative framework.

A health policy analysis framework was developed to apply a disability lens in order to ascertain features of access and equity embedded in health policies. Four health policies namely Primary Health Care, Free Health Care, Provision of Assistive Devices and the National Rehabilitation Policy were analysed this policy analysis framework. Recommendations were made to improve policy design and content, specifically related to access and equity.

As part of the analysis, co-ordination and implementation challenges were analysed and discussed. Unfortunately, the implementation of policies was problematic. Barriers included: attitudes, environmental access, human and financial resources. Facilitators to policy implementation include: policy process and design, availability of human and financial resources, support systems, management support, organisational structures and finally positive attitudes that all impacted favourably on policy implementation.

Most policies did not have monitoring and evaluation guidelines that make implementation difficult to assess. Recommendations of this study includes: rigorous monitoring and evaluation, and more active involvement of people with disabilities in the monitoring of policies as well as all other processes of policy formulation. Furthermore intersectoral collaboration and disability coordination needs to be improved. People with disabilities need to engage with Departments proactively, while maintaining their independence and ability to advocate for change from outside the health system.

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## APPENDIX 1: INTERVIEW QUESTIONS FOR INFORMANTS AT NATIONAL, PROVINCIAL, HOSPITAL AND DISTRICT LEVELS

#### QUESTIONS TO ASK NATIONAL DEPARTMENT OF HEALTH REHABILITATION MANAGER

- 1. What definition of disability is National Government using?
- 2. How does this definition get filtered down to the provinces and programmes?
- 3. How does a policy for people with disabilities come about?
- 4. How do we ensure that people with disabilities are included in all policies?
- 5. How does a policy get decided on, drafted, passed and implemented?
- 6. What method is in place to ensure that the policy is implemented and done so properly?
- 7. What monitoring and evaluation mechanism is in place at a National and Provincial level in order to ensure implementation?
- 8. Is health policy analysis used? (What framework is being utilised?)
- 9. What are the barriers and facilitators to policy implementation for the following policies:
  - a. Free Health Care Policy for People with Disabilities at the Hospital Level
  - b. Standardisation of the Provision for Assistive Devices
  - c. National Rehabilitation Policy
  - d. Primary Health Care

#### QUESTIONS TO ASK PROVINCIAL DEPARTMENT OF HEALTH REHABILITATION MANAGER

- 1. What definition of disability are provinces using?
- 2. You have been there when they formulated Free Health Care Policy, National Rehabilitation Policy, and Primary Health Care- in your experience, how does a policy for people with disabilities come about? How does a policy get decided on, drafted, passed and implemented?
- 3. How do we ensure that people with disabilities were and are included in all policies?
- 4. You have implemented policies like the three mentioned above, what method is in place to ensure that the policy is implemented?
- 5. What monitoring and evaluation mechanism is in place at a Provincial level in order to ensure implementation?
- 6. What are the barriers and facilitators to policy implementation for the following policies:
  - a. Free Health Care Policy for People with Disabilities at the Hospital Level
  - b. Standardisation of the Provision for Assistive Devices
  - c. National Rehabilitation Policy
  - d. Primary Health Care

#### QUESTIONS TO ASK HOSPITAL REHABILITATION MANAGER

- 1. What definition of disability are hospital therapists using?
- 2. You have been there when they formulated Free Health Care Policy, National Rehab Policy, and Primary Health Care- in your experience, how does a policy for people with disabilities come about? How does a policy get decided on, drafted, passed and implemented?
- 3. How do we ensure that people with disabilities were and are included in all policies?
- 4. You have implemented policies like the Free Health Care Policy, National Rehab Policy and Standardisation for the Provision of Assistive Devices, what method is in place to ensure that the policy is implemented?
- 5. What monitoring and evaluation mechanism is in place at a Hospital level in order to ensure implementation?
- 6. What are the barriers/ facilitators to policy implementation for the following policies:
  - a. Free Health Care Policy for People with Disabilities at the Hospital Level
  - b. National Rehabilitation Policy
  - c. Standardisation of the Provision for Assistive Devices

#### QUESTIONS TO ASK DISTRICT REHABILITATION MANAGER

- 1. What definition of disability are the community rehabilitation services using?
- 2. How do we ensure that People with Disabilities were and are included in all policies?
- 3. You have implemented policies like the Primary Health Care Policy, National Rehab Policy and Standardisation for the Provision of Assistive Devices, what method is in place to ensure that the policy is implemented?
- 4. What monitoring and evaluation mechanism is in place at a District level in order to ensure implementation?
- 5. What are the barriers/ facilitators to policy implementation for the following policies:
  - a. Primary Health Care Policy
  - b. National Rehabilitation Policy
  - c. Standardisation of the Provision for Assistive Devices Guidelines

#### ADDENDING OUTSTIONNAIDE OFNIT TO DOOMNOLAL DELLA DILITATION DOOD ANNE

## APPENDIX 2: QUESTIONNAIRE SENT TO PROVINCIAL REHABILITATION PROGRAMME MANAGERS

## CURRENT SOUTH AFRICAN POLICIES IN ACCESS TO AND EQUITY IN HEALTH SERVICES FOR PEOPLE WITH ACTIVITY LIMITATIONS

#### **Dear Rehabilitation Programme Manager**

Thank you for participating in this study. This questionnaire will only take about 20 minutes to complete.

Simply <u>list barriers and factors which facilitated implementation of policies</u> with specific reference to people with disabilities in your province. Please feel free to write short explanatory notes and or additional comments.

#### Primary Health Care Policy 2000

1.					
2.					
3.					
4.					
5.					
Barriers to	Implementation	on of Policy			
1.	mpiomontati	on or oney			
2.					
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4.					
5.					
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- acilitating	abilitation Po		n of policy		
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acilitating 1. 2. 3. 4. 5.  Barriers to 1. 2.	Factors to Im	plementatio			

# Standardization of the Provision of Assistive Devices in South Africa-A Guide for Use in the Public Sector 2003 Facilitating Factors to Implementation of policy 1. 2.

5.	
Barriers to Implementation of Policy	
1.	
2.	
3.	
4.	
5.	

#### Free Health Care for People with Disabilities 2003

3. 4.

Additional comments:

Facilitating Factors to Implementation of policy	
1.	
2.	
3.	
4.	
5.	

Barriers to Implementation of Policy
1.
2.
3.
4.
5.


Thank you for your participation.

#### APPENDIX 3: INFORMED CONSENT FORM AND INFORMATION PAGE

#### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

#### TITLE OF THE RESEARCH PROJECT:

Current South African Policies in Access to and Equity in Health Services for People with Activity Limitations

REFERENCE NUMBER: N08/02/052

PRINCIPAL INVESTIGATOR: Françoise B. Law

ADDRESS: P.O. Box 330

Banbury 2164

**CONTACT NUMBER:** 012 354 6131 / 082 477 2048

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study investigator any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

#### What is this research study all about?

You will receive a structured questionnaire and/ or will be interviewed as to your views in the facilitating factors and barriers to implementation of Current South African Policies in Access to and Equity in Health Services for People with Disabilities. Interviews will take no longer than 1 hour. Completion of questionnaires should take no longer than 25 minutes to complete.

- This questionnaire and/ or interview session is all that is required of you.
- The entire study will run over 3 months and other national and provincial rehabilitation programme managers like you, as well as managers on a district level will be interviewed.
- Your answers will be recorded digitally and on paper and the results of the questionnaire will be analysed by the investigator.

#### Why have you been invited to participate?

> Since you are dealing with the implementation of health policies relating to people with disabilities, your viewpoints will be greatly beneficial for the purposes of this study

#### What will your responsibilities be?

➤ To explain as clearly as possible, based on your experiences, the facilitating factors and barriers to implementation of current South African Health Policies with regards to people with disabilities.

#### Will you benefit from taking part in this research?

By participating in the study, you are helping the researcher gain more insight into the policies as well as helping identify barriers and facilitating factors to policy implementation. This information can be possibly used at a national level for assistance with implementation plans of future policies.

#### Are there in risks involved in your taking part in this research?

There are no physical risks to you. If you do not want to answer some of the questions asked, you may skip answering that question

#### If you do not agree to take part, what alternatives do you have?

- ➤ If you choose to take part in the study, you are doing this at your own free will. You, as the participant can change your mind about yourself taking part at any time, during the study.
- > If you do not wish to take part, your decision will be respected and there will be no consequences

#### Who will have access to your medical records?

N/a

## What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

➤ N/a

#### Will you be paid to take part in this study and are there any costs involved?

> No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

#### Is there any thing else that you should know or do?

- ➤ No
- ➤ You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed.
- > You will receive a copy of this information and consent form for your own records.

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By signing below, I	agree to take part in a research study
entitled "Current South African Policies in Acces	ss to and Equity in Health Services for People with
Activity Limitations"	

#### I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests.

Signed at (place)	on ( <i>date</i> )	2008.
Signature of participant	Signature of witness	

#### **Declaration by investigator**

I, Françoise Bernadette Law declare	that:
I encouraged him/her to ask of	this document toquestions and took adequate time to answer them. adequately understands all aspects of the research, as
Signed at ( <i>place</i> )	on ( <i>date</i> ) 2008.
Signature of investigator	Signature of witness

#### **APPENDIX 4: PILOTED FRAMEWORKS Version 1**

#### 1. POLICY NAME:

#### 2. BRIEF AIM OF POLICY:

#### 3. CONTEXT:

To verify, define and detail the problem. To give a description of the situation and stakeholders. Policy contexts to be considered include historical, political, economic and socio-cultural contexts.

#### 4. ACTORS:

Potential actors may include: all levels of bureaucrats, medical and allied health professionals, policy elites and managers, advisors, experts, donors, financial institutions.

#### 5. CONTENT

- Does the policy lead to the prevention of disability? Or further disability of the already disabled?
- What evaluation criteria and definitions of disability are being used? Does it specifically
  mention people with disabilities or is there a general mention of all people?
- What does the policy offer in terms of accessibility of services to people with disabilities –
   what provisions are made for people with disabilities?
- What or how does the policy allow for the equalisation of opportunities for people with disabilities to access affordable and appropriate care?
- Is the policy sensitive to the general and specific health care needs of people with disabilities? Does it also make provisions for the following:
  - Barrier free access
  - Communication
  - Training of health workers
  - How does the policy integrate people with disabilities?

#### 6. PROCESS

How did the policy come about?

Did people with disabilities participate in process?

- 7. DISTINGUISH BETWEEN POLICY ALTERNATIVES
- 8. ESTABLISH EVALUATION CRITERIA AND MEASURES TO EVALUATE POLICY
- 9. IDENTIFY ALTERNATIVE POLICIES
- 10. EVALUATION OF VARIOUS POLICY ALTERNATIVES
- 11. MONITOR AND EVALUATE THE IMPLEMENTED CRITERIA
- **12. BARRIERS AND FACILITATORS TO IMPLEMENTATION** as described by National Department of Health and Provincial Rehabilitation Programme Managers.

#### Factors to be included:

- Attitudinal
- Environmental access- buildings, transport, information
- Resources-technology, finances, institutions
- Process and product design
- Political and economic will
- Other

Steps 7-11 were removed as those components are for prospective policy analysis and the purpose of this research is for retrospective policy analysis.

#### **PILOTED FRAMEWORKS Version 2**

#### 1. CONTEXT

1.1. Context; to verify, define and detail the problem: description of situation and stakeholders. Policy contexts to be considered include historical, political, economic and socio-cultural/economic contexts and practices of decision-making.

#### 2. ACTORS

2.1. Who were the stakeholders and what was their influence on the policy

#### 3. CONTENT – what is included in the actual policy on what should happen

- 3.1. DESIGN: What factors explain the nature of the design?
- 3.2. What DEFINITIONS of disability are being used? Does it specifically mention people with disabilities or is there a general mention of all people?
- 3.3. Does the policy encourage HEALTH PROMOTION, EARLY IDENTIFICATION and lead to the PREVENTION OF DISABILITY? Or further disability of people already disabled?
- 3.4. Is the policy SENSITIVE TO THE GENERAL AND SPECIFIC HEALTH CARE NEEDS of PEOPLE WITH DISABILITIES?
- 3.5. How does the POLICY INTEGRATE PEOPLE WITH DISABILITIES?

#### 4. PROCESS – what in fact does happen

- 4.1. How did the POLICY COME ABOUT? The particular processes used in initiating and implementing the schemes
- 4.2. Did people with disabilities PARTICIPATE in process? The relative inputs of technicians, service providers and community members in design and implementation;
- 4.3. The speed and manner of implementation.

#### 4.4. IMPLEMENTATION:

How and why does the process of implementation influence design? Does the implementation process influence the equity impact? How? How do patterns of decision making influence impact?

#### 5. ACCESSIBILITY OF SERVICES What does the policy offer in terms of

What provisions are made for people with disabilities? Does it also make provisions for the following:

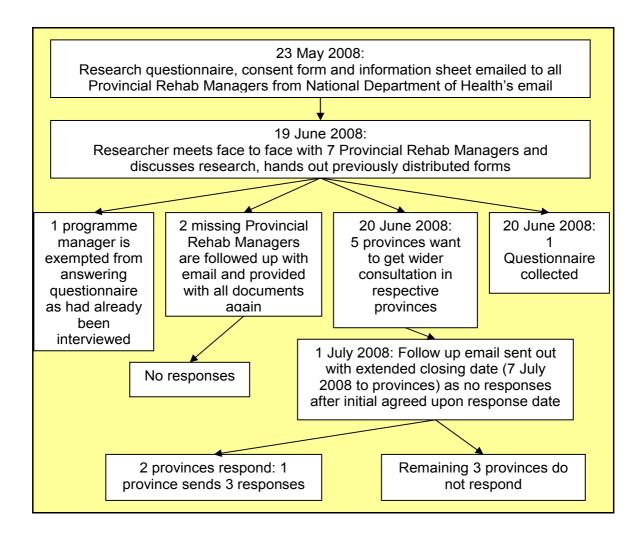
- 5.1. Barrier free access (physical access to facilities, services are community based, fee structures etc)
- 5.2. Communication and information materials
- 5.3. Training of health workers
- 5.4. Is there any mention of INFRASTRUCTURE transportation in particular to the service, or the placement of the service (so that it is accessible)
- 5.5. Is there a COST involved for the service?

#### 6. EQUITY IMPACT:

- 6.1. What or how does the policy allow for the equalisation of opportunities for people with disabilities to access affordable and appropriate care?
- 6.2. What distribution of benefits & burdens?
- 6.3. What utilisation patterns?
- 6.4. How are decisions made and who makes them?
- 6.5. What is the situation of the poorest relative to other population groups?

It was decided to remove the implementation section out of the policy analysis framework and to discuss this separately.

## APPENDIX 5: STEPS TAKEN TO ELICIT RESPONSES FROM PROVINCIAL REHABILITATION PROGRAMME MANAGERS



## APPENDIX 6: APPROVAL LETTERS FROM COMMITTEE FOR HUMAN RESEARCH

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REHABILITATSIE STUDI



UNIVERSITEIT-STELLENBOSCH-UNIVERSITY jou kennisvennoot. your knowledge partner

11 March 2008

Ms FB Law Tahwana Rehabilitation Centre Dept of Health Gauteng

Deat Ms Law

RESEARCH PROJECT :

"CURRENT SOUTH AFRICAN POLICIES IN ACCESS TO AND EQUALITY IN HEALTH SERVICES FOR PROPLE WITH ACTIVITY LIMITATIONS"

PROJECT NUMBER : NO8/02/052 It is a pleasure to inform you that the Committee for Human Research has approved the above-mentioned it is a presente to intorin you may the communes for rivolved, for a period of one year from this project on 5 March 2008, including the sthical aspects involved, for a period of one year from this

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in all further correspondence.

Please note that a progress report (obtainable on the website of our Division) should be submitted riense note that a progress report (obtainable on the website of our Division) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

This Committee adheres to the following guidelines in the evaluation and monitoring of research protocols:

- Declaration of Helsinki
- Guidelines on Ethics of the SA Medical Research Council
- International Guidelines: Council for International Organisations of Medical Sciences (CIOMS)
- · Guidelines for Good Practice in the conduct of Clinical Trials in Human Participants in South Africa of the Department of Health, RSA
- Applicable RSA logislation

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FAUL DO

The Committee is accredited with the Office for Human Research Protections (OHRP) of the Federal Department of Health and Human Services, U.S.A., under the registration code IRB00005239.

Yours faithfully

Jule

FRANKLIN WEBER RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG) Tel: +27 21 938 9657 / E-maij: fweb@sun.go.za

Head of Department: Ms G MJi

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#### UNIVERSITEIT-STELLENBOSCH-UNIVERSITY jou kennisvennooi - your knowledge pariner

12 August 2008

Ms F Law Twshane Rehabilitation Centre Department of Health Gauteng

Dear Ms Law

RESEARCH PROJECT

: "CURRENT SOUTH AFRICAN POLICIES IN ACCESS TO AND EQUALITY IN HEALTH SERVICES FOR PEOPLE WITH ACTIVITY LIMITATIONS"

PROJECT NUMBER : N08/02/052

Your letter dated 7 August 2008 refers.

The Chairperson of the Committee for Human research approved the title change of the project to: Developing a Policy Analysis Framework to Establish Level of Access and Equity Embedded in South African health Policies for People with Disabilities in accordance with the authority given to him by the Committee.

This approval will be submitted to the Committee for ratification.

Kind reg

pp Prof Par de Albiers

Chairperson: Committee for Human Research RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)

Tel: +27 21 938 9207 / E-mail: mertnude@sum.ac.za

Fakelteit Gesondheidswetenthappe - Faculty of Mantch Sciences

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## APPENDIX 7: PRIMARY HEALTH CARE POLICY FACILITATORS AND BARRIERS TO IMPLEMENTATION

FACILITATOR DESCRIPTION	THEMES	BARRIER DESCRIPTION
"Community involvement & participation"		"Therapists decide on what the clients need and what they must get-no community /family/client role involvement in decision making"
"Success stories of Primary Health Care – builds up support"	Attitudes	"Societal (employers and community members) attitudinal barriers makes re-integration difficult" "Poor integration of programmes"
	Environmental physical access	"Lack of service integration- work in silos"  "Physical access for people with disabilities into and around clinics. May have ramps but gradient is too steeps, or may not have handrails. Only two out of nine Community Health Centres where people with disabilities go for therapy in the district have accessible toilets!"
"Resource allocation"	Resources in general	"Inadequate safety and security"  "Staffing, equipment, space shortages at clinics even if itinerant staff is available"  "Inadequate equipment"  "Insufficient working space for therapy – both individual and group treatments. Space is sometimes sacrificed to other more prioritised projects such as Anti Retro Viral clinics). And in planning for clinics, rehab staff not always consulted, hence space is poorly designed"  "Lack of access to faxes, telephones, computers and internet makes communication difficult, and unable to access information"  "Inadequate transport"  "Access to transport –no dedicated transport so unable to do many home visits"  "Outreach services are limited by transport shortages"
"Community service therapists improved staffing substantially"		"Lack of resources generally – personnel and transport"  "Have specialists not generalists at the clinics"  "Human resource"  "Salary levels for Specialised Auxiliary Services
"Student training exposure- demystifies community rehab and attracts some staff"	Resources: human resources	Officer" [therapy assistant]  "As services are run by Community Service Therapists there is a lack of continuity of services"  "Recruiting and retaining staff- Not enough exposure of community rehab to students hence they do not know what it is about and do not want to work there"
"Some community service therapists placed at districts are attracted to the services and are retained"	103041063	"Brain drain again"  "Human resources (esp. therapy assistants)"  "Limitation on staff attending to clients as no posts in clinics"  "Rotating therapy staff – clinic nurses do not have opportunity to build relationships with therapists"  "Lack of Community Rehabilitation Workers training – cannot form support groups /self help groups"  "No training institution for Specialised Auxiliary Services Officer" [therapy assistant]

FACILITATOR DESCRIPTION	THEMES	BARRIER DESCRIPTION
"Dedicated budget for Assistive Devices"	Resources:	"Budgetary constraints"
	financial	"Funding"
"Sufficient Budget"		"No money"
"Community based structures"	Resources:	
"Strong Home Based Care Programme"	support	
"Structured District Health System"	systems	
"Available norms and standards"		"No clear guidelines"
"Policy serves as a guideline as comes		"Management issues not discussed beforehand: no
with Norms and Standards so gives clear		standards /clarity on issues such as acceptable
directions"		patient caseload"
"Development of guidelines"		
"Use as a baseline for serve	Process and	
implementation"	product	
"Uses as motivating tool"	design	"Poor definition of the role of disability and rehab in
"Serve as a guidelines for service		Primary Health Care"
planning"		
"The district Primary Health Care		
Managers are aware that we are part of		
the Primary Health Care services"	D - 11411211	
"Political will"	Political will	
"International interest"	International influence	
"Appointment of provincial & district		"Reporting and Management structures in the
rehab Managers"		District"
"Decentralised management"		"Poor referral systems"
	Management /	"Nursing managers who do not understand
"Ability to lobby for budget and receptive	organisational	rehabilitation – expect programme to run like
attitude from district management"	structure	Tuberculosis programme etc"
"Support from Head Office"		"Institutional arrangement"
"Support from management in the		"Reporting lines (therapists to nursing manager who
district"		doesn't understand rehab)"
"Departmental referral system"		,
,		"Each district has their own view"
	Access to and	"Training needed"
	Access to and	"No internet to access policy"
	knowledge of policy	"Policies not displayed"
	policy	"Policy not known at times"
		"Unavailability of policy"
	Purchasing of	"Lengthy and inefficient Procurement processes,
	assistive	and non-prioritisation of rehabilitation items- delay
	devices	when ordering assistive devices."
	Mindset	"Mindset barrier – two schools of thought – those
		that think that therapists should be exclusively at the
		institutional level and those that think that therapists
		can be at the community level."
	National indicators	"Non inclusion in the national data"
	Involvement	" Development of guidelines"
	of	"Rehabilitation staff not involved in the formulation
	stakeholders	of the policy"
	Prioritisation	"Rehabilitation staff [is] expected to assist with other
	of	prioritised programmes despite the rehab staff being
	rehabilitation	so limited and unable to offer full rehabilitation
	services	services themselves."

## APPENDIX 8: NATIONAL REHABILITATION POLICY FACILITATORS AND BARRIERS TO IMPLEMENTATION

FACILITATOR DESCRIPTION	THEMES	BARRIER DESCRIPTION
"Intersectoral collaboration between all departments"	Attitudes	"Disability is cross-cutting issue and the success of rehab services is dependent on other services and departments"
		"No working relations between departments makes intersectoral collaboration impossible"
"Basic Sign Language training for first line workers"	Environmental access	"Our services are inaccessible for Deaf and blind people- lack of interpreters at entry points and no brailed information leaflets/pamphlets"
	Resources: financial	"No money to stock/ order"  "Lack of budget for key services e.g. provision of assistive devices"
		"Does not enjoy appropriate budget allocation"
"Some posts allocation at local areas"	Resources: Human Resources	"High turnover of staff"  "Recruitment and retention of staff especially of specialist therapists"
		"Scarcity of personnel"
		"Staffing, space and equipment shortages" "Lack of Community Rehabilitation Workers training"
"Enabling policy – used for advocacy, to lobby for resources, changes in behaviour etc."		"No people with disabilities involvement/participation in planning, implementing and monitoring of rehab. Programme"
"Only framework available on disability and rehab services"		"No clear guidelines"
"Serve as a guidelines for service planning"	Process and	"Each district has their own view"
"Comprehensive document on rehabilitation -advocacy tool" "Framework document, not instruction	product design	
manual"  "Provides guidelines for implementation"  "Uses as motivating tool for Community  Based Rehabilitation"  "Some monitoring tools for the services"		"Non inclusion in the national data"
"Some monitoring tools for the services" "Focus on disability as a human rights		
issue" "Congruent with the Integrated National Disability Strategy" "Provincial policy"	Political will	
"Policy always available"	Access to and knowledge of Policy	"Shortage of documents" "Limited knowledge of Community Based Rehabilitation approach" "No provincial rehab policies in place"

## APPENDIX 9: STANDARDISATION OF THE PROVISION OF ASSISTIVE DEVICES FACILITATORS AND BARRIERS TO IMPLEMENTATION

FACILITATOR DESCRIPTION	THEMES	BARRIER DESCRIPTION
"The province is in the process of appointing people with disabilities for repair workshops in the institutions"  "The province is supplying the repair parts for recycling"  "Creativity and innovation of health personnel"  "Loan system for those who need them temporarily ( uses recycled items)"  "Therapists' attitudes and commitment to policy"  "Facilitate equitable way of providing	Attitudes	"Some therapists use discretion but finalising
assistive devices"  "Outlines generic criteria"  "Provides provinces with a standard tool"  "Provincial Wheelchair Policy"  "Use as monitoring tool"  "User friendly"	Process and product design	policy for [province Y] use due to the Free Health issue"
"Sufficient budget"  "Additional funding or resources from National Department of Health and donations"  "The province has introduced database for assistive devices that will help them to draw a report to motivate for the budget"	Resources: Financial	"Due to shortage, the therapists do not have time to log in the clients in the database, the province struggle to get prove to motivate for a better budget"  "Funding-demand exceeds budget available"  "No/ minimal budget at district & institution level — not life saving"  "Only issue the basic assistive devices not what is appropriate for especially motorised chairs and mattresses — to try and cover a bigger number"  "Free Health problems"  "Funding"  "Lack of budget for assistive devices"
	Resources: Human Resources  Access to and	"High staff turnover- retrain"  "There is no dedicated working space(workshop) and personnel for repairs in some of the institutions"  "Scarcity of personnel- newly trained graduates work alone so they are compelled to issue assistive devices"  "No clear guidelines"
" Assistive device supplier contracts offers a variety of devices and simplifies ordering"	knowledge of Policy  Purchasing of Assistive	"Each district has their own view"  "Inefficient and lengthy procurement processes results in waiting lists for assistive devices despite having adequate budget- procurement process
	Devices Involvement of other stakeholders	can take as long as six months" "Billing system by admin classification of patients"
	Management structure	"Lack of monitoring mechanisms at all levels" "No monitoring and report back system"

### APPENDIX 10: FREE HEALTH CARE POLICY FOR PEOPLE WITH DISABILITIES ON THE HOSPITAL LEVEL FACILITATORS AND BARRIERS TO IMPLEMENTATION

Support from toy management	HOSPITAL LEVEL FACILITATORS AND BARRIERS TO IMPLEMENTATION				
"Resistance to change" "Therapists use it when its for the pititing" "Therapists use it when its for the it liking" "Therapists use it when its for their liking" "Database is combined with ICF- lengthy process therapists not keen to complete it as it is time – consuming"  Attitudes  At	FACILITATOR DESCRIPTION	THEMES	BARRIER DESCRIPTION		
"Resistance to change" "Interpolation at Collaborations-information to the people with disabilities" Created more awareness about disabilities " The people with disabilities" Attitudes  A	"Support from top management"		"Managers not willing to implement"		
"Therepists use it when its for the itking" Therepists use it when its for their liking" The people with disabilities"  The agreat need, so was implemented.  "Staff supportive to a certain extent"  "Toestes access to health services"  The supportive to a certain extent."  "Most of our clients are indigent, they already qualify for free service"  "Political will:  "Revenue collection- other hospitals feels that free health services after their revenue collection."  "Province X] is very rural with high percentage of indigent clients thus we have developed our policy with some changes to the National policy."  Process and product design  Process in understanding of qualifying criteria."  "Poor understanding about the criteria."  "Poor understanding about the criteria."  "Province M law the open on Disability Grants not automatically entitled for Free Health Care-province had to take steps to ensure that they were."  "Created Automatically entitled for Free Health Care-province had to lake steps to ensure that they were."  "Created New University that they could be reclassified. However these assistive devices are extremely costly so people would go without it."  "Problem with the criteria-people on Disability Grants not automatically entitled for Free Health Care-province had to take steps to ensure that they were."  "Created New University that they could be reclassified. However these assistive devices are extremely costly so people would go without it."  "Problem with the criteria-people on Disability Grants not aut			"Resistance to change"		
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#### **APPENDIX 11: SUMMARY OF POLICY ANALYSIS**

ANAL VOIC	DDIMADY HEALTH CADE	NATIONAL	ACCICTIVE DEVICES	EDEE HEALTH CADE
ANALYSIS	PRIMARY HEALTH CARE	NATIONAL REHABILITATION	ASSISTIVE DEVICES	FREE HEALTH CARE
AIM OF POLICY	Accessible and equitable health care services	Formal policy guideline for rehabilitation in order to achieve equitable services	Equitable and appropriate provision of assistive devices plus maintenance of assistive devices	To improve the health status and quality of life of indigent PWD
ACTORS	<ul> <li>National &amp; provincial health departments</li> <li>Other government departments</li> <li>NGOs</li> <li>Universities,</li> <li>Private hospitals</li> <li>Professional bodies</li> <li>Labour organisations</li> <li>SALGA.</li> <li>No mention of people with disabilities</li> </ul>	<ul> <li>Other government departments</li> <li>Office on the Status of Disabled People</li> <li>Provincial health departments</li> <li>Professional bodies and associations</li> <li>NGOs for people with disabilities</li> <li>Disabled People's Organisations</li> <li>Private sector</li> </ul>	<ul> <li>Disabled People's         Organisations</li> <li>Disability Action         Research Team</li> <li>Disabled People         South Africa</li> <li>Provincial Health         Department         (Limpopo)</li> </ul>	Provincial Programme managers. No mention about who else participated except for "civil society organisations"
PROCESS INITIATION	National Department of Health	Rehabilitation professionals & people with disabilities (service users)	Rehabilitation professionals	Politicians
PARTICIPATI ON OF PWD* IN PROCESS	People with disabilities not involved	Involved and mentioned that PWD should participate in planning, implementing and monitoring. people with disabilities should be involved in decision making	Disabled People's Organisations were involved in policy formulation	No involvement of people with disabilities but reference to "civil society organisations"
MONITORING & EVALUATION	No specific section or targets/ indicators. Have tool for measuring Primary Health Care = Clinic Supervisor's Manual (interviewee information)	Specific section for monitoring and evaluation . Broad guidelines. Rationale, principles and strategies given	No details	Mentioned but no details. Implementation report commissioned but not available
POLICY DESIGN	User friendly. Clear layout. "Instruction manual"	Strategic document. Implementation of INDS	Assistive devices described in general	Follows principle of Free Health Care for children under 6 years of age
DEFINITION OF DIS- ABILITY	No definition given	WHO definition broad definition	No definition given	Amended WHO definition specific definition
PREVENTION OF DISABILITY	Prevention is one of the cornerstones of this policy- it is mentioned in every section	Extensively mentioned	No mention but an assistive device "prevents disability" as enhances prospects of employment, education and or participation	Prevents further complications of disability
SENSTIVITY TO SPECIFIC NEEDS OF PEOPLE WITH DISABILITIES	General health policy caters for general health needs. Has Rehabilitation and Community Based Rehabilitation programmes in package of services	People with disabilities are focus of policy-sensitive to their needs. Disabled People Organisations were involved in policy formulation	Targeting people with disabilities specifically their assistive devices needs	Targets people with disabilities with moderate and severe activity limitations

ANALYSIS	PRIMARY HEALTH CARE	NATIONAL REHABILITATION	ASSISTIVE DEVICES	FREE HEALTH CARE
INTEGRATIO N OF PEOPLE WITH DISABILITIES	People with disabilities to be involved in designing, implementing and monitoring. People with Disabilities to be part of Community Based Rehabilitation Health forums, hospital boards and community health	Calls for mainstreaming and people with disabilities to be integrated/ reintegrated into society	Assistive Devices can assist in re-integration of people with disabilities	Hopes to achieve better integration of people with disabilities through their raised health status.
ACCESSIBILI TY OF SERVICES TO PWD*	Increases access to services through Community Based Rehabilitation	Increases access to services through Community Based Rehabilitation	Not much mention	Does increase access to services where hospitals are
BARRIER FREE ACCESS	Some mention of destigmatisation for mental health service users. Mention on accessibility of clinics to wheelchairs and availability of wheelchair accessible toilets	Acknowledges environmental factors	No mention about the physical accessibility of facilities providing the assistive devices. "Personal assistants, such as those for the blind, people with locomotor disability, and the deaf (Sign Language Interpreters), shall be made available by institutions to assist the public to access health services. "	No mention is made that the hospitals should be made accessible to cater for people with disabilities in this policy. Furthermore no mention is made on training staff members on how to deal with people with disabilities.
COMMUNICA TION AND INFO	No specific mention of accessible format	Specific mention of communication and strategies for this is not mentioned	No specific mention of accessible format. Policy available on National Department of Health website	Posters and pamphlets available. Policy available on National Department of Health website
TRAINING OF HEALTH WORKERS	Has standards for competence of clinic staff. Patients Rights Charter applies to all patients	In almost every section, training of health workers is mentioned	"Assessment and prescription for assistive devices shall only be done by appropriately trained rehabilitation providers" and "newly trained graduates should be specifically trained in the issuing of assistive devices" Furthermore "training/rehabilitation should be done by an appropriately trained rehabilitation provider."	Provincial Rehabilitation Programme Managers to ensure the roll out of the policy. User friendly, training manuals and copies of the policy provided. CEOs of hospitals and relevant (reclassification) clerks had to be made aware of the policy as well as the processes to follow to ensure smooth implementation. As for special training needed – no mention was made about training health workers to communicate in sign language in order to make the services more accessible.

ANALYSIS	PRIMARY HEALTH CARE	NATIONAL REHABILITATION	ASSISTIVE DEVICES	FREE HEALTH CARE
PLACEMENT OF SERVICES	Accessible as in community based. Also advocates for Community Based Rehabilitation services	No mention of transportation to the service. NRP advocates for Community Based Rehabilitation making services more accessible to users.	No specific mention is made about the placement of services. It is only mentioned that items for Alternative and Augmentative Communication be made available at a tertiary level. No list of what level assistive devices should be provided at so subject to interpretation	Free Health Services are offered at hospitals and this will increase the number of points that the people with disabilities can go to.
COST OF SERVICES	Free	"Affordability" of rehabilitation services is mentioned	Payment for assistive devices according to Uniform Patient Fee System. Included in children under six and disabled people qualifying for free health care	Services free, should the person qualify.
AFFORD- ABLE & APPRO- PRIATE CARE	Free basic health services	Seven objectives of National Rehabilitation Policy lead to improved accessibility and equity	Should the person with disability qualify for Free Health Care services, then the assistive device is for free. Some assistive devices are only provided at certain institutions thereby limiting access.	The services free and this should allow people with disabilities to access services as and when required hence allows equalisation of opportunities in ensuring good health.
DISTRI- BUTION OF BENEFITS AND BURDENS	Health benefits spread out to medically uninsured population who constitute majority of population	"To improve accessibility to all rehabilitation services"  "Right to have access to health care services"  "Equalisation of opportunities"  "Enhance human rights for persons with disabilities"  "Addressing issues of poverty and disparate socio-economic circumstances."	Should a person get an assistive device, he/she will derive some benefit.	By accessing health services to try and manage impairments, people with disabilities will be offered greater equity in health status, independence and social participation.  This in turn will minimise external stresses and vulnerability. It is also mentioned that the service should be seen in the broader context of social security and poverty relief, spreading the risk and subsidizing the poor.
UTILISATION PATTERNS	As services are made more accessible and affordable, utilisation of services is encouraged	By making services appropriate, affordable and accessible, utilisation of services is encouraged. Intersectoral collaboration encourages the usage of services other than that of Department of Health	Utilisation patterns will remain unchanged with the implementation of this guideline. This guideline is rather general and it does not specifically mention what assistive devices people with disabilities are entitled to, hence service users cannot lobby for them.	By having free services, utilisation of services is encouraged.

ANALYSIS	PRIMARY HEALTH CARE	NATIONAL REHABILITATION	ASSISTIVE DEVICES	FREE HEALTH CARE
DECISION MAKING AND DECISION MAKERS	Community Based Rehabilitation places decision making in the hands of people with disabilities	Community Based Rehabilitation advocates that people with disabilities and their families as well as their communities are the decision makers.	No specific mention is made of people with disabilities being involved in decision making. In terms of budgeting, the guideline refers to those who are directly involved with the issuing of the devices should be involved in the budgeting of the assistive devices	Decision-making in this policy document is limited to the bureaucrats and those implementing the policy. Therapists have to do the assessment and if the person qualifies, this will be communicated to the administration clerk who in turn will reclassify the patient.
SITUATION OF POOREST RELATIVE TO OTHERS	As the Primary Health Care services are accessible and affordable, the poorest are able to have equal access to basic health services	Community Based Rehabilitation services would ensure accessibility and the affordability of services.	Only if the person qualifies for Free Health Care or is under six years of age, will the assistive device be provided for free. Others who receive assistive devices are expected to pay a fee.	By making the services free, the poorest are advantaged because they do not have to pay for services whereas others do. However, the transport to services has not been taken into account and this can be extremely costly, so even though people with disabilities may be advantaged by free services, they are still disadvantaged by the exorbitant cost of transport to get there.

<sup>\*</sup>PWD has been used as an acronym for people with disabilities