

Access to healthcare for persons with disabilities in Eswatini

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DECLARATION OF ORIGINALITY

I hereby declare that this thesis is my own original work and that it has never been previously in its entirety or in part been submitted for any other qualification at any other institution of higher learning. All sources that I have used, made reference to or quoted have been indicated and acknowledged.



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ABSTRACT

Achieving the right of access to healthcare for persons with disabilities is a challenge in Eswatini as a result of various barriers, such as availability of services, acceptability in healthcare facilities, financial and geographical accessibility. As a means of facilitating access to healthcare for persons with disabilities, Eswatini ratified the United Nations Convention of the Rights of Persons with Disabilities and subsequently developed the National Disability Policy Reform documents.

The study therefore employed a case study research design utilising multiple data sources to establish the extent to which the National Disability Policy Reforms had addressed access to healthcare for persons with disabilities. The study aimed to establish how the manner in which these reforms were developed and implemented influenced access to healthcare for persons with disabilities in Eswatini. Data Source 1 encompassed a review of the National Disability Policy Reform documents. Data Source 2 included in-depth interviews with key informants (n=7) who were involved in the development and implementation of the National Disability Reform documents. Data Source 3 included focus groups with persons with disabilities (n=5), caregivers of persons with disabilities (n=6) and healthcare professionals (n=7). Additional electronic questionnaires were conducted with healthcare professionals (n=7) as part of Data Source 3. All data were analysed using a framework approach, specifically the Integrated Disability Policy Analysis Framework.

Findings of the study indicated that the National Disability Policy Reform documents had adequately addressed the availability of services and acceptability of persons with disabilities within healthcare facilities. The National Disability Policy Reform documents however neglected to consider the significant role of financial and geographical accessibility on influencing access to healthcare. Findings also revealed that while the development of the National Disability Policy Reform documents was a collaborative effort between different stakeholders, the processes of implementation of these documents was not entirely clear. As a result, the promises of the National Disability Policy Reform documents were not translating into actions as persons with disabilities lacked knowledge on the existence of the National Disability Policy Reform

documents. Persons with disabilities were also not aware of their rights to healthcare, and they still experienced challenges when they had to access healthcare.

A policy brief was developed to communicate the findings of the study to policy makers. Access to healthcare guidelines with pictorial support were developed to conscientise persons with disabilities, caregivers of persons with disabilities and healthcare professionals about the rights to access for persons with disabilities.

Keywords: access to healthcare, disability policy, human rights, Integrated Disability Policy Analysis Framework; persons with disabilities; policy analysis

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I CAN DO ALL THINGS THROUGH CHRIST WHO STRENGTHENS ME

Philippians 4:13

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DEDICATION

This study is dedicated to all persons with disabilities and their families. I hope for a day where your rights will be fully realised.

TABLE OF CONTENTS

DECLARATION OF ORIGINALITY	ii
ABSTRACT	iii
ACKNOWLEDGEMENTS.....	v
DEDICATION.....	vii
LIST OF TABLES	xv
LIST OF FIGURES.....	xvii
CHAPTER 1: ORIENTATION.....	1
1.1 INTRODUCTION.....	1
1.2 BACKGROUND AND PROBLEM STATEMENT	1
1.3 RESEARCH PARADIGM AND RESEACHER POSITIONALITY	4
1.4 DEFINITION OF TERMS	6
1.5 AFRICAN TERMS USED IN THE STUDY.....	9
1.6 LIST OF ABBREVIATIONS AND ACRONYMS	10
1.7 CHAPTER OUTLINE	10
1.8 CONCLUSION	13
CHAPTER 2: LITERATURE REVIEW.....	14
2.1 INTRODUCTION	14
2.2 UNPACKING DISABILITY	14
2.2.1 Models of Disability	15
2.2.2 Disability and Poverty	21
2.2.3 Cultural Aspects of Disability	23
2.2.4 Disability in Eswatini	25
2.2.5 Third Party Disability	27
2.3 THE HUMAN RIGHTS OF PERSONS WITH DISABILITIES	28
2.3.1 International Legislature Pertaining to Disability Rights	28
2.3.2 Eswatini Legislature Pertaining to Disability Rights	32

2.3.3 Implementation of Disability Policy and Legislature	36
2.3.4 Policy Analysis and Legislature	38
2.4 ACCESS TO HEALTHCARE	40
2.4.1 Experiences of Persons with Disabilities when they access healthcare ...	43
2.4.2 Barriers to Accessing Healthcare.....	46
2.5 THE HEALTHCARE SYSTEM IN ESWATINI	51
2.6 CONCLUSION.....	52
CHAPTER 3: RESEARCH METHODOLOGY	54
3.1 INTRODUCTION	54
3.1.1 Study aims.....	56
3.1.2 Main Aim.....	56
3.1.3 Sub-aims.....	56
3.2 RESEARCH DESIGN	56
3.3 STUDY SETTING	59
3.4 RESEARCH FIELDWORKER	63
3.5 INDEPENDENT OBSERVER	65
3.7 ETHICAL CONSIDERATIONS	66
3.8 TRUSTWORTHINESS CONSIDERATIONS	67
3.9 THE INTEGRATED DISABILITY POLICY ANALYSIS FRAMEWORK	70
3.9.1 The Walt and Gilson Health Policy Analysis Framework	71
3.9.2 The Peters et al. (2008) Access to Healthcare in Developing Countries Framework.....	72
3.10 CONCLUSION.....	73
CHAPTER 4: DATA SOURCE 1: DOCUMENT ANALYSIS.....	75
4.1 INTRODUCTION	75
4.2 AN OVERVIEW OF THE DOCUMENT ANALYSIS PROCEDURES	75
4.3 AIM OF DATA SOURCE 1	75
4.4 DOCUMENT SELECTION.....	76

4.5 DEVELOPING OF THE CODE BOOK	78
4.6 DOCUMENT ANALYSIS	81
4.7 RESULTS FROM THE DOCUMENT ANALYSIS.....	81
4.8 DISCUSSION	87
4.8.1 Actors	87
4.8.2 Context	87
4.8.3 Content	88
4.8.3 Processes	93
4.9 IMPLICATIONS FOR DATA SOURCE 2.....	94
4.10 CONCLUSION.....	94
<i>CHAPTER 5: DATA SOURCE 2: IN-DEPTH INTERVIEWS WITH KEY INFORMANTS</i>	<i>96</i>
5.1 INTRODUCTION	96
5.2 AIMS OF DATA SOURCE 2.....	96
5. 3 PARTICIPANTS OF DATA SOURCE 2	97
5.3.1 Participant Selection Criteria.....	98
5.3.2 Description of the Participants	99
5.3.3 Participant Recruitment.....	101
5.4 SETTING FOR IN-DEPTH INTERVIEWS.....	101
5.5 MATERIAL AND EQUIPMENT	102
5.5.1 Information Letters and Consent Forms	102
5.5.2 Biographical Questionnaire	102
5.5.3 Interview Script	104
5.5.4 Recording Equipment	106
5.6 METHODS	107
5.6.1 Pilot Study.....	107
5.6.2 Data Collection	108
5.6.3 Data Analysis.....	109
5.7 FINDINGS FROM IN-DEPTH INTERVIEWS	110
5.7.1 Actors	110

5.7.2 Context	112
5.7.3 Content	114
5.7.4 Processes	116
5.8 DISCUSSION OF THE RESULTS FROM DATA SOURCE 2	118
5.8.1 Context	118
5.8.2 Content	120
5.8.3 Processes	124
5.9 IMPLICATIONS FOR DATA SOURCE 3.....	124
5.10 CONCLUSION.....	125
CHAPTER 6: DATA SOURCE 3: FOCUS GROUPS	126
6.1 INTRODUCTION	126
6.2 AIMS OF DATA SOURCE 3.....	126
6.3 PARTICIPANTS OF DATA SOURCE 3	127
6.3.1 Selection criteria for participants.....	127
6.3.2 Participant Recruitment.....	129
6.3.3 Participant Description	132
6.4 SETTING FOR FOCUS GROUPS.....	137
6.5 MATERIALS AND EQUIPMENT	137
6.5.1 Information Letter and Consent Forms	137
6.5.2 Biographical Questionnaire.....	138
6.5.3 Focus Group Script.....	140
6.5.4 Recording Equipment	142
6.5.5. Procedural Checklist.....	142
6.6. DATA COLLECTION.....	142
6.6.1 Focus Groups	142
6.6.2 Electronic questionnaire	144
6.7 DATA ANALYSIS.....	144
6.8 FINDINGS FROM DATA SOURCE 3	146
6.8.1 Reports by Persons with Disabilities on the Actors.....	146
6.8.2 Reports by Persons with Disabilities on the Context.....	146

6.8.3 Reports by Persons with Disabilities on the Access	147
6.8.4 Reports by Persons with Disabilities on the Processes	150
6.8.5 Reports by Caregivers of Persons with Disabilities on the Actors.....	152
6.8.6 Reports by Caregivers of Persons with Disabilities on the Context	152
6.8.7 Reports by Caregivers of Persons with Disabilities on the Experiences of Persons with Disabilities when Accessing Healthcare Services	153
6.8.8 Reports by Caregivers of Persons with Disabilities on the Processes	156
6.8.9 Reports by Healthcare Professionals on the Actors.....	157
6.8.10 Reports by Healthcare Professionals on the Context	158
6.8.11 Reports by Healthcare Professionals on the Experiences of Persons with Disabilities when Accessing Healthcare Services.....	159
6.8.12 Reports by Healthcare Professionals on the Processes of the National Disability Policy Reform documents.....	163
6.9 DISCUSSION OF THE FINDINGS FROM DATA SOURCE 3	164
6.9.1 Actors	164
6.9.2 Context	164
6.9.3 Content	165
6.9.4 Processes	171
6.10 IMPLICATIONS FOR CHAPTER 7	172
6.11 CONCLUSION.....	173
 CHAPTER 7: DEVELOPMENT OF PRACTICAL INTERVENTIONS TO FACILITATE ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES	
.....	174
7.1 INTRODUCTION	174
7.2 OVERVIEW OF THE RESEARCH AIM	175
7.3 THE INTEGRATED DISABILITY POLICY ANALYSIS FRAMEWORK	175
7.3.1 The Relevance of Employing the Integrated Disability Policy Analysis Framework.....	177
7.4 THE DEVELOPMENT OF THE POLICY BRIEF	179
7.4.1 The Relevance of Developing a Policy Brief	180
7.5 THE ACCESS TO HEALTHCARE GUIDELINES	190

7.5.1 Process Followed During the Development of the Access to Healthcare Guidelines.....	191
7.6 CONSIDERATIONS WHEN CONDUCTING RESEARCH WITH KEY STAKEHOLDERS	194
7.6.1 Policy Stakeholders	194
7.6.2 Healthcare Professionals.....	196
7.6.3 Persons with Disabilities	197
7.7 CONCLUSION.....	199
CHAPTER 8: CONCLUSION AND RECOMMENDATIONS.....	200
8.1 INTRODUCTION	200
8.2 SUMMARY OF THE FINDINGS	200
8.2.1 Data Source 1: Document Analysis	200
8.2.2 Data Source 2: Key Informants Interviews.....	201
8.2.3 Data Source 3: Focus Groups	203
8.3 IMPLICATIONS OF STUDY FINDINGS FOR PRACTICE	205
8.4 EVALUATION OF THE STUDY	206
8.4.1 Strengths	206
8.4.2 Weaknesses	208
8.5 RECOMMENDATIONS FOR FUTURE RESEARCH	209
8.6 CONCLUSION.....	211
REFERENCES.....	212
APPENDICES.....	251
APPENDIX A: Ethics Approval University of Pretoria	251
APPENDIX B: Permission from Swaziland Health Ethics Committee	252
.....	253
APPENDIX C: Permission from the Federation for Disability Organisations	254
.....	254
APPENDIX D: Permission from Superintendent of the public tertiary state hospital.....	255

APPENDIX E: Poster Presentation of the Study.....	257
APPENDIX F: Biographical Questionnaire for Key Informants	258
APPENDIX G: Key Informant Interview Script in English	259
APPENDIX H: Informed Consent Letter for Key Informant and Focus Group Participants	261
APPENDIX I1: Biographical Questionnaire for Participants.....	264
APPENDIX I2: Biographical Questionnaire for Participants in SiSwati.....	266
APPENDIX J: Information Letter for Focus Group Participants	268
APPENDIX K: Focus Group Script	270
APPENDIX L: Procedural Checklist.....	271
APPENDIX M: Questionnaire for online questions with healthcare professional.....	272
APPENDIX N: Access to healthcare guidelines in SiSwati.....	274
APPENDIX O: Code Book.....	275

LIST OF TABLES

Table 1: Summary of the Models of Disability	16
Table 2: Strategies Used to Increase Trustworthiness	68
Table 3: Operational Definitions of Concepts used In the Integrated Disability Policy Analysis Framework	79
Table 4: Provisions of the National Disability Policy Reform Documents for Access to Healthcare for Persons with Disabilities	82
Table 5: Criteria for the Selection of Key Informants for Data Source 2	99
Table 6: Biographical Information of Key Informants (n=7)	100
Table 7: Development of the Biographical Questionnaires for Key Informants	103
Table 8: Development of the Interview Script	105
Table 9: Actors Involved in the National Disability Policy of Swaziland and their Respective Roles and Responsibilities.....	111
Table 10: Themes on the Context of the National Disability Policy Reforms Derived from Data Source 2	112
Table 11: Themes and Sub-themes Related to Content as Reported by Key Informants	114
Table 12: Processes of the National Disability Policy Reforms as Reported by Key Informants	116
Table 13: Selection Criteria for Participants for Data Source 3	128
Table 14: Description of the Participants in the Persons with Disabilities Focus Group	132
Table 15: Description of Participants in the Caregivers of Persons with Disabilities Focus Group	134
Table 16: Description of Participants in the Healthcare Professionals Focus Group	135
Table 17: Description of Healthcare Professionals Participants who Completed the Electronic Questionnaire	136
Table 18: Development of the Biographical Questionnaire for Persons with Disabilities; Caregivers of Persons with Disabilities and Healthcare Professionals respectively	138
Table 19: Questions Included in the Focus Group Script with Theoretical Justification	141

Table 20: Context of the National Disability Policy Reform Documents as Reported by Persons with Disabilities	146
Table 21: Self-report Experiences of Persons with Disabilities when Accessing Healthcare Services	147
Table 22: Processes Followed in the Development and Implementation of the National Disability Policy Reform documents as Reported by Persons with Disabilities	150
Table 23: Themes Depicting the Context of the National Policy Reform Documents as Reported by Caregivers of Persons with Disabilities	152
Table 24: Experiences of Persons with Disabilities when They Access Healthcare Services as Reported by Caregivers of Persons with Disabilities	153
Table 25: The Processes of the National Disability Policy Reforms as Reported by Caregivers of Persons with Disabilities	157
Table 26: Actors of the National Disability Policy Reforms Documents as reported by Healthcare Professionals	157
Table 27: Context of the National Disability Reform documents as Reported by Healthcare professionals.....	158
Table 28: Experiences of persons with disabilities when they access healthcare services as reported by healthcare professionals	159
Table 29: Processes of the National Disability Policy Reforms as Reported by Healthcare Professionals	163
Table 30: Access to healthcare for persons with disabilities in Eswatini-A Policy Brief for Policy Makers.....	181

LIST OF FIGURES

Figure 1: The Walt and Gilson (1994) Policy Analysis Triangle Framework for Policy Analysis.....	39
Figure 2: Schematic Representation of the Methodology Chapters for all Three Data Sources of the Study.....	55
Figure 3: Schematic Representation of the Case Study Research Design	59
Figure 4: A Map of the Kingdom of Eswatini showing Mbabane’s specific location..	61
Figure 5: The Integrated Disability Policy Analysis Framework combining the frameworks of Walt and Gilson Policy (1994) and Peters et al. (2008).	70
Figure 6: Data Collection Steps followed in Data Source 3	143
Figure 7: Four steps followed during the development of the Access to Healthcare Guidelines	192
Figure 8: Access to Healthcare guidelines	193

CHAPTER 1: ORIENTATION

1.1 INTRODUCTION

Chapter 1 outlines the research problem addressed in the study and draws attention to the significance and relevance of the study. The chapter then affords a definition of the most important and frequently used terms. This is followed by a list of abbreviations, acronyms and African words used across the thesis. The chapter concludes with an overview of the eight chapters of the thesis.

1.2 BACKGROUND AND PROBLEM STATEMENT

The World Health Organisation declared that access to basic healthcare is a basic human right (World Health Organisation, 1946). In its Sustainable Developmental goal number 3, the United Nations highlighted the importance of health and well-being, by attributing Goal 3 to this specific human right (United Nations General Assembly, 2015). Due to their specific impairment, concomitant health conditions and lifestyle ramifications, persons with disabilities need healthcare more often than their counterparts without disabilities (World Health Organisation, 2011). However, persons with disabilities tend to experience more challenges when attempting to access healthcare than their peers without disabilities. This situation is further aggravated in low and middle income countries (LMICs), such as the Kingdom of Eswatini (formerly Swaziland), where the majority of the population experience preventable and manageable health challenges because they are poor. Persons with disabilities account for 16.8% of Eswatini's population and form a significant part of the country's poor majority (Central Statistics Office of Swaziland, 2010).

Eswatini's healthcare system consists of both traditional and western concepts of medicine and it is common practice for patients to explore the traditional route before accessing Western medicine (Fleminger, 2009). Western medicine options consist of both public and private healthcare. Public healthcare is structured according to

different levels of care namely: community healthcare, primary healthcare, regional healthcare and national referral hospitals (Magagula, 2017). The public healthcare is funded by the government and caters for the majority of the population, while private healthcare is covered by medical aid and those who can afford to pay for healthcare through their pockets (Magagula, 2017).

The United Nation's Convention on the Rights of Persons with Disabilities (CRPD) is a universal, legally binding standard that aims to ensure that the rights and dignity of persons with disabilities are guaranteed everywhere in the world (United Nations, 2006). The guiding principles of the CRPD include respect for inherent dignity; individual autonomy (including the freedom to make one's own choices and independence of people); non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; respect for the evolving capacities of children with disabilities, and respect for the right of children with disabilities to preserve their identities (United Nations, 2006).

Article 25 of the CRPD specifically mandates signatory states to recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (United Nations, 2006). It further requires that signatory states should ensure that all appropriate measures are taken to guarantee gender sensitive access to healthcare services for persons with disabilities, including their health-related rehabilitation (United Nations, 2006).

Article 26 of the CRPD further obligates member states to organise, strengthen and extend comprehensive habilitation and rehabilitation programmes, particularly in areas of health, employment, education, and social services (United Nations, 2006). These programmes should include early childhood intervention services and be based on the multidisciplinary assessment of individuals' needs and strengths. Programmes should

support participation and inclusion of persons with disabilities in their respective communities to ensure that services are available in as close proximity as possible to their home in order to combat additional challenges, such as transport costs. This guideline pertains to both urban and rural contexts (United Nations, 2006).

Eswatini ratified the CRPD on the 24th September 2012, as well as the optional protocol (Deputy Prime Minister's Office, 2013). Following the ratification, the National Disability Policy Reforms were developed. These policy reforms include the National Disability Policy of Swaziland in 2013; the National Disability Bill of Rights in 2014 and the National Disability Plan of Action in 2015. The National Disability Policy Reforms were developed with the intention of promoting, protecting and ensuring full enjoyment of all human rights and fundamental freedoms by persons with disabilities in Eswatini (Deputy Prime Minister's Office, 2013; 2014; 2015). Prior to the existence of these policy reforms, there were no comprehensive laws and policies that regulated and addressed persons with disabilities' access to equal opportunities in Eswatini, including access to healthcare (Deputy Prime Minister's Office, 2013; Mavundla, 2015).

Regardless of the enactment of the National Disability Policy Reforms and the ratification of the CRPD, persons with disabilities in Eswatini continue to experience challenges when accessing healthcare. International research reports highlight challenges that cut across four domains when persons with disabilities attempt to access healthcare, such as the availability of services; the acceptability of persons with disabilities in healthcare facilities; the geographical accessibility of services and the financial accessibility of services. In Eswatini, these challenges may be exacerbated by a disjoint between the provisions of the National Disability Policy Reforms and the actual experiences of persons with disabilities at the grassroots level. As a result, questions arise on why this disjoint possibly occurs, where it may occur, what the consequences of the disjoint could be, specifically on persons with disabilities when accessing healthcare services in Eswatini and how these could potentially be addressed from the perspective of different stakeholders, such as policy makers, persons with disabilities, their caregivers and healthcare professionals.

Therefore, the study aimed to establish the extent to which the National Disability Policy Reforms had addressed access to healthcare for persons with disabilities and the manner in which the development and implementation of the National Disability Policy Reform documents influenced access to healthcare for persons with disabilities. To achieve the above aim, a qualitative case study research design utilising multiple data sources, namely a policy analysis, key informant interviews and focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals, was conducted. All data obtained were analysed using a framework approach specifically applying the pre-determined themes of the Integrated Disability Policy Analysis Framework.

1.3 RESEARCH PARADIGM AND RESEARCHER POSITIONALITY

Presenting the positionality of a researcher (who the researcher is in relation to the study) in any qualitative enquiry particularly relative to the data is imperative for the integrity of a qualitative study (Pitard, 2017). Our positionality can be deduced from our philosophical beliefs which are shaped and influenced by what we know (ontology) and how we know it (epistemology) (Pitard, 2017).

The philosophical beliefs (Creswell, 2014) are therefore the researcher's views of what constitutes the truth and knowledge (Chilisa & Kawulich, 2012). These views represent our thinking, beliefs, and assumptions about society and ourselves, and they also frame how we view the world around us, which ultimately guides us in how we solve problems (Schwandt, 2001). Particular paradigms are typically associated with specific methodologies that lead researchers to ask specific questions and to use appropriate approaches to systematic inquiry (Chilisa & Kawulich, 2012).

The current study is underpinned by the constructivist philosophical worldview, which is typically associated with qualitative methodologies (Chilisa, 2011). The researcher is of the view that knowledge is generated as a result of a collaboration between the researcher and the research participants. The researcher believes in reporting on

participant's experiences and the interpretations that the participants attach to those experiences, while being aware and acknowledging the role that their context contributes to shaping these.

The constructivist worldview was therefore selected as an ideal philosophy for this study as it allowed the researcher to focus on understanding the provisions of the National Disability Policy Reform documents and their role in facilitating access to healthcare for persons with disabilities through the lens of these documents themselves, the policy developers and implementers within the context of Eswatini.

The constructivist philosophical worldview also values the opinions of key informants (in this case persons with disabilities, caregivers of persons with disabilities and healthcare professionals in Eswatini), as possessing knowledge on disability, disability rights and National Disability Policy Reform documents. Participants' experience on access to healthcare was acquired through their experience of living with a disability and accessing healthcare services as persons with disabilities in Eswatini, caring for persons with disabilities (caregivers of persons with disabilities), treating persons with disabilities (healthcare professionals) in healthcare facilities and for some of them, their involvement in the disability policy reforms as either actors or end users. The study furthermore, made significant the voice of persons with disabilities in an attempt to get an understanding of their perspectives on the National Disability Policy Reform documents themselves, and about their perceptions on the effectiveness of these disability policy reform documents in facilitating access to healthcare. Involving persons with disabilities was of utmost importance because they are often not personally involved in research that pertains to them, yet they have much to contribute as they are experts on disability (Williams & Moore, 2011). The constructivism worldview therefore highlights the importance of their knowledge and contribution as participants in this research study. The voices of persons with disabilities are often silenced in research pertaining to them because researchers are unfamiliar with ways that persons with disabilities access information and perform activities of daily living. As a result, researchers lack knowledge of how to design research in accessible

formats for persons with disabilities, based on these stakeholders' needs and experiences (Williams & Moore, 2011).

1.4 DEFINITION OF TERMS

This section presents the definition and description of crucial terms that are used across the thesis. These terms are presented in alphabetical order.

Access to Healthcare for Persons with Disabilities

Access to healthcare can be defined as a multidimensional process that includes quality of care, geographical accessibility, and availability of the right type of care for those who need it, financial accessibility and acceptability of services (Peters et al. 2008). In the current study, access to healthcare, specifically for persons with disabilities in Eswatini, is defined as the availability of affordable, comprehensive quality healthcare and rehabilitation services which are responsive to the physical, communication, sensory, cognitive, social, cultural and contextual needs of persons with disabilities within their geographical reach. This resonates well with the definition proposed by Peters et al. (2008).

Access to Healthcare Guidelines

In this study, access to healthcare guidelines refers to systematically developed concise statements accompanied by pictorial support to conscientise persons with disabilities, caregivers of persons with disabilities and healthcare professionals on the rights to healthcare for persons with disabilities in Eswatini. These guidelines are also intended to offer practical instructions on how healthcare facilities could provide reasonable accommodation for persons with disabilities (World Health Organisation, 2011).

Assistive Devices

In the study, the definition of the World Global Disability Action Plan of 2014-2021 (World Health Organisation, 2014) is used to define assistive devices. In line with this definition, an assistive device refers to any device or system that allows individuals with disability to perform tasks they would otherwise be unable to do, or to increase the ease and safety with which tasks can be performed. Examples of assistive devices include mobility aids such as wheelchairs and walkers, hearing aids, cognitive aids such as posters and checklists, communication devices, white canes, prosthetics, tools such as automatic page turners, book holders, and adapted pencil grips and adaptive switches and utensils, amongst others (World Health Organisation, 2014).

Caregivers of Persons with Disabilities

Caregivers of persons with disabilities refer to individuals who perform the majority (atleast 6 hours a day) of caregiving roles and responsibilities for persons with disabilities on a daily basis (Posner, 2016). In this study, these persons typically include informal caregivers, who are family members of persons with disabilities who care for them as an ethical obligation in the spirit of ubuntu (Williams & Crooks, 2008).

Disability

The definition of disability as stipulated in the CRPD's is employed in the study (United Nations, 2006) which regards disability as an evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. This definition is applicable to the study because it reflects the attitudinal and environmental challenges that influence the access to healthcare for persons with disabilities in Eswatini. This definition is situated within the human rights model of disability and focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centre stage in all decisions affecting him/her and, most importantly, locates the main "problem" outside the person and in society (Quinn & Degener, 2002).

Healthcare

This study applied the western definition of healthcare, which according to the World Health Organisation (1948) is a provision for an optimal state of physical, mental, and social well-being.

Healthcare Professionals

The study applied the World Health Organisation (2013) definition of a healthcare professional. According to this definition, healthcare professionals are trained individuals who maintain the healthcare of human beings through diagnosing, treating, preventing illnesses, injuries and other physical, sensory and cognitive impairments in accordance with the needs of the populations that they serve (World Health Organisation, 2013). Healthcare professionals' practice in different contexts, for example, in public or private settings. In this study, healthcare professionals are typically hired by the government and they practice in government healthcare facilities.

National Disability Policy Reform Documents

National Disability Policy Reform documents refer to the changes that were made by Eswatini after the ratification of the CRPD in 2012, in order to address the rights of persons with disabilities to alleviate the challenges experienced by persons with disabilities when accessing different services, such as healthcare, education, and employment. These are in the form of legislature documents developed and implemented by the government of Eswatini, namely, the National Disability Policy of Eswatini, the National Disability Bill of Rights and the National Disability Plan of Action.

Policy Brief

In this study, a policy brief refers to a document developed by the researcher to communicate the findings of the study to policy makers in a concise manner. In this study, the policy brief was based on the analysis of the National Disability Policy Reforms documents and the perceived experiences of persons with disabilities,

caregivers of persons with disabilities and healthcare professionals, using the Integrated Policy Analysis Framework.

1.5 AFRICAN TERMS USED IN THE STUDY

emaSwati

This is a term used to refer to the people of Eswatini

Incwala

Incwala is the Swati festival of first fruits and traditional prayer of the nation (Khumalo, 2013).

Kombi

A kombi is a term used in Eswatini to describe a 15-seater public transport mini-bus commonly used by commuters.

Tinkhundla (Inkhundla singular) centres

This is a term used in Eswatini to describe the different constituencies in different geographical areas of the country (Motsamai, 2012).

Tokoloshe

Tokoloshe (Tikoloshi in SiSwati) is an African term used to define a certain creature that may manifest in different forms. This creature is said to have the ability to bring a bad omen, mainly causing trouble for other people. The Tokoloshe is believed to bring about bad luck, illnesses and even death (Niehaus, 1995).

Ubuntu

Ubuntu is a Nguni term that is commonly used in the African region. Ubuntu is a humanist philosophy that dictates how we, as human beings, should be towards ourselves, but most importantly how we should treat others in our communities. The essence of Ubuntu is that “I am because you are” therefore a person is a person because of the support of other people (Mabovula, 2011).

Umuthi

Umuthi (Umutsi in SiSwati) is a term that is used to describe medicine used for either healing purposes or for evil purposes as defined by Nene (2014).

1.6 LIST OF ABBREVIATIONS AND ACRONYMS

CANGO:	Co-ordinating Assembly of Non-Governmental Organisations
CRPD:	Convention on the Rights of Persons with Disabilities
FODSWA:	Federation of Organisations of the Disabled in Swaziland
HIV/ AIDS:	Acquired Immune Deficiency Syndrome /Human Immunodeficiency Virus
LMIC:	Low and Middle Income Countries
MOH:	Ministry of Health
MSc:	Master of Science
TB:	Tuberculosis

1.7 CHAPTER OUTLINE

This thesis is presented in eight chapters. Chapter 1 presents the background and rationale for the study, the terms and African words mentioned in the thesis, as well as a list of abbreviations and acronyms. Chapter 1 concludes with an overview of the various chapters of the thesis.

Chapter 2 synthesises and critically presents literature pertaining to access to healthcare for persons with disabilities under the following sections: their right to access healthcare and their experiences of accessing healthcare services internationally, across Africa, and in Eswatini specifically. Next, the concept of disability is defined through discussing the models of disability, the link between disability and poverty is described, the causes of disability are highlighted and, disability specific to the Eswatini context is explained, as well as third party disability. Thereafter, human and disability legislation is discussed as has been enacted to facilitate the protection of disability rights internationally, in Africa, and in Eswatini. The implementation and analysis of legislature pertaining to disability as well as the current state of access to healthcare for persons with disabilities in Eswatini is then addressed. The chapter concludes with the different models of access to healthcare, the barriers that persons with disabilities still experience when they access healthcare as well as the structure, distribution and functioning of the healthcare system in Eswatini.

The study employed a case study research methodology utilising three data sources. The methodology, results, and discussion of these three data sources are described in Chapters 3, 4, 5 and 6. Chapter 3 details the methodology used in the entire study. It commences by describing the main and sub-aims of the study, followed by the constructive research paradigm underpinning the study and the study setting. The research fieldworker and the independent observer are then described, as well as, the ethical considerations to which the study adhered. The strategies employed to ensure trustworthiness and the theoretical frameworks undergirding the study are then highlighted. This chapter also provides a schematic overview of the structures of Chapters 4, 5 and 6 in relation to Chapter 3.

Chapter 4 provides the methodology used during the document analysis of the National Disability Policy Reform documents. In particular, the chapter gives a description of the aims of the chapter, the steps followed during the selection of the documents, and during the development of the coding book, as well as the processes followed during the document analysis. Additional to the methodology followed during the document analysis, the chapter presents findings from the document analysis and

further affords an in-depth discussion of these findings. Chapter 4 concludes with implications of the document analysis findings for Chapter 5.

Chapter 5 shows the methodology used during the in-depth interviews with key informants. This is done according to the aims of the study, a description of the study participants, details on the setting of the in-depth interviews, an outline of the materials and types of equipment used and the steps followed during data collection and analysis. Next, an account of the findings of the study is presented followed by a detailed discussion of these findings in relation to current existing literature and findings from the previous chapter. A conclusion is drawn from the findings with implications for the next chapter.

Chapter 6 focuses on the methodology utilised during the focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals, as well as additional electronic questionnaires with healthcare facilities. The methodology is presented according to aims, participants, setting, materials, and methods. A report on the findings from these groups is also presented along with a detailed interpretation of the findings using literature sources. The findings are interpreted in relation to currently existing literature and also in relation and comparison to the previous data sources (documents review and key informant interviews). This chapter concludes with the implications for the development of interventions that are described and illustrated in Chapter 7.

Chapter 7 affords a reflective process of the researcher on the study while overtly demonstrating the practical implications and application of the research findings in the field of disability. In particular, the chapter explains the value of using the Integrated Disability Policy Analysis Framework when analysing the National Disability Policy Reform documents in LMICs, using Eswatini as a case study. It also describes the development of the access to healthcare guidelines for persons with disabilities in Eswatini and it proposes, through the developed policy brief, strategies that may be implemented by the Government of the Kingdom of Eswatini to improve the content

and implementation processes of the currently existing National Disability Policy Reform documents. Additionally, the chapter presents methodological and practical considerations when conducting research with policy makers, healthcare professionals and persons with disabilities.

Chapter 8 depicts an overall summary of the results as well as the clinical, policy and practice implications. A critical appraisal of the study follows, focusing on both the strengths and limitations of the current study. The chapter concludes with recommendations for further research.

1.8 CONCLUSION

Chapter 1 provided the justification for the study by emphasising the challenges that persons with disabilities still experience when accessing healthcare, regardless of the enactment of the National Disability Policy Reforms in Eswatini. This was followed by a definition of and explanations of the terms, abbreviations and acronyms commonly used across the study. The chapter concludes with an overview of the eight chapters of this thesis and a conclusion.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The chapter affords an overview of the relevant literature as it pertains to persons with disabilities, their rights to accessing healthcare and their experiences of accessing healthcare services by documenting international, LMIC and Eswatini trends. Chapter 2 begins by unpacking the concept of disability through discussing the models of disability, the link between disability and poverty, the causes of disability, disability specific to the Eswatini context, as well as third party disability. The human and disability legislation that has been enacted to facilitate the protection of disability rights from a global, African and Eswatini perspective is discussed next, and it alludes to the implementation and analysis of these legislatures. The current state of access to healthcare for persons with disabilities in Eswatini is discussed and it deliberates on the experiences of persons with disabilities, the models of access to healthcare and some of the barriers that are still experienced by persons with disabilities when they access healthcare. The current structure, distribution and functioning of the healthcare system in Eswatini is discussed last. The chapter ends with a conclusion.

2.2 UNPACKING DISABILITY

There are currently a number of different theoretical approaches in the pursuit for defining and understanding disability, which impact directly on how disability is understood, including in the legislature domain. Variances in perceptions, various models and classification systems, and variations in understandings in different national and cultural contexts may all result in varying definitions of disability (Parnes, et al. 2009).

The rights of persons with disabilities, their access to healthcare, education, information, their employment opportunities and their socialisation are all determined through models of disability (Neille, 2013). Although the ideas underlying these approaches have differed, each approach has faced a variety of moral and political

issues in terms of how to best include and support persons with disabilities and have contributed to the contemporary understanding of the construct “disability” (World Health Organisation, 2011). The diverse existing models of disability may reflect the multidimensional character of disability and the different ideological and scientific positions toward it (Mitra, 2006).

2.2.1 Models of Disability

There has been a shift in how disability is viewed and explained, as is evident in the progression from the charity model of disability to the era of the human rights model of disability. The charity model of disability viewed persons with disabilities as being victims of circumstances and deserving pity (Griffo, 2014), which is a viewpoint that is incongruent to human rights as it encouraged dependency and thus disempowered persons with disabilities, resulting in the perpetuation of discrimination. Even though the medical model of disability subjugated the formulation of policy and practice for a while, its viewpoint was not one that facilitated and encouraged human rights for persons with disabilities. The way the medical model views persons with disabilities perpetuated stigmatisation of persons with disabilities, as it viewed persons with disabilities as lacking, as abnormal and as being in need of care, shelter and welfare (Degener, 2016b; Griffo, 2014). In an attempt to bridge the gaps that existed in the medical model, the social model came into being. The social model recognised the effects and impacts of environmental, societal and attitudinal barriers on the participation restrictions of persons with disabilities (Oliver, 1996). However, the social model neglected the impact of the impairment itself on the persons with disabilities (Retief & Letšosa, 2018). It failed to acknowledge the life situations of the persons with disabilities (Retief & Letšosa, 2018). The human rights model, on the other hand, acknowledges and considers such real-life situations and demands that they are considered when social justice theories are developed (Degener, 2016b). The human rights model is based on the CRPD and values the human dignity of persons with disabilities (Degener, 2016b).

Table 1: Summary of the Models of Disability

Model	Focus	Advantage	Disadvantage	Implications for the study
Charity Model (Shanimon & Rateesh, 2014)	<ul style="list-style-type: none"> Views the person with a disability as the “problem” and as dependent on the sympathy of others to provide assistance in a charity or welfare mode (Shanimon & Rateesh, 2014). 	<ul style="list-style-type: none"> Underlined in this model was the idea of justice that led to the establishment of charitable institutions which took in persons with disabilities as residents (Griffo, 2014). 	<ul style="list-style-type: none"> Overlaid with segregatory practices of social exclusion and institutionalisation, which marked those they took in with strong stigma and made them socially undesirable (Griffo, 2014). Power imbalance as persons with disabilities were seen as “weak” needing protection and not needing more than care and love. Persons with disabilities were seen as recipients of services. 	<ul style="list-style-type: none"> The current study will observe any current practices and beliefs that are in line with the principles of the charity model of disability.
Medical Model (World Health Organisation, 1980)	<ul style="list-style-type: none"> Views that disability was caused by disease or trauma. Views the solution for disability as intervention provided and controlled by healthcare professionals who are considered the experts (Degener, 2016b; Shanimon & Rateesh, 2014). Sees disability as a deviation from the normal health status (Degener, 2016b). Calls the ideological construction of disability through individualism and 	<ul style="list-style-type: none"> Has traditionally been given more scientific credibility (Smart & Smart, 2006), as this model defines disability in the language of medicine. 	<ul style="list-style-type: none"> Relegates persons with disabilities to medical rehabilitation establishments, many times for their whole lives with often pointless rehabilitative treatments (Griffo, 2014). Disempowers persons with disabilities and isolates them from the mainstream society, preventing them from accessing fundamental social, political and economic rights (Degener, 2016b). Legitimises segregated facilities for persons with disabilities, such as special schools, living institutions or sheltered 	<ul style="list-style-type: none"> It will be worth seeing how much impact the medical model of disability has on the accessibility of healthcare for persons with disabilities in Eswatini and how much it still affects decision making, especially because it is one model that has been influencing healthcare for a very long time.

<p>medicalisation, the politics of disablement (Oliver, 1990).</p> <ul style="list-style-type: none"> • Regards exclusion of persons with disabilities from society regarded as an individual problem and sees the reasons for exclusion are in the impairment (Degener, 2016b). 		<p>workshops by its assumption that persons with disabilities need to have shelter and welfare (Degener, 2016b).</p> <ul style="list-style-type: none"> • Led to the creation of mental health and guardianship laws that take an incapacity approach to disability by assuming that impairment can foreclose legal capacity (Degener, 2016a). These assumptions have a dangerous impact on human rights (Degener, 2016a) 	
<p>Social Model (Oliver, 1990)</p> <ul style="list-style-type: none"> • Views disability as a political issue, highlighting obstacles to effective participation in society (McClimens, 2003; Shakespeare, 2008). • Sees disability as all the aspects that impose restrictions on persons with disabilities; ranging from: <ul style="list-style-type: none"> ○ Individual prejudice to institutional discrimination; ○ Inaccessible public buildings; 	<ul style="list-style-type: none"> • Contributed in facilitating states to remove barriers hindering the participation of persons with disabilities and to their equality (Griffo, 2014). • Strongly influenced persons with disabilities and their organisations, strengthening their commitment to creating inclusive societies where everyone might live with equality of opportunity (Griffo, 2014). 	<ul style="list-style-type: none"> • Disregards other important elements of appraisal (Griffo, 2014). • Has the potential to deny the impact of disability on the individual as research into the experiences of persons with disabilities reflect that the nature of the impairment is often considered to be central in the structuring of experience (Shakespeare, 2008a). 	<ul style="list-style-type: none"> • It would be important to note if Eswatini's view of disability and disability issues shifted with the introduction of the social model and if the nation recognises the participation barriers and their impact on accessibility of services for persons with disabilities, with specific reference to accessibility to health.

- Unusable transport systems; and
- Segregated education
- With regards to the consequences of this failure to participate in society as they do not simply and randomly fall on individuals, but systematically upon persons with disabilities as a group who experience this failure to discrimination institutionalised throughout society (Oliver, 1996).

Human Rights Model
(Quinn & Degener 2002)

- Focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics.
- Places the individual at the centre stage in all decisions affecting them and, most importantly, locates the main "problem" outside the person and in
- Encompasses the values for disability policy that acknowledges the dignity of all persons, irrespective of disability.
- Comprehensive model as it includes both sets of human rights, civil and political, as well as economic, social and cultural rights.
- The human rights model of disability has not been brought into the human rights for persons with disabilities' debate yet (Degener, 2016b).
- Implementing the human rights model in some states will take a long time, especially in light of the slow progress in implementing the CRPD that some states are encountering.
- Considering that Eswatini has ratified the CRPD, it would be expected that the nation would be engaging in conversations involving the upholding of the human rights for persons with disabilities. It would be valuable to monitor the progress of implementation.

<p>society (Quinn & Degener, 2002).</p> <ul style="list-style-type: none"> Seeks to bring about a paradigm shift in disability policy that is based on a new understanding of persons with disabilities as right holders and human rights subjects (Degener, 2016b) 	<ul style="list-style-type: none"> Acknowledges life circumstances and demands them to be considered when social justice theories are developed. Offers room for minority and cultural identification and it offers a basis for assessment when the prevention policy can be claimed as human rights protection for persons with disabilities. Offers a roadmap for change for people living in poverty (Degener, 2016b). 	<ul style="list-style-type: none"> Persons with disabilities are not empowered in their rights and therefore placing them at the centre and expecting them to make decisions might pose as a challenge. Stakeholders themselves are not thoroughly trained and they have not fully understood the human rights issues of persons with disabilities. There is a mindset shift that needs to occur across different decision-making spheres including traditional and cultural domains in order for the human rights model to be implemented successfully. It is therefore important to develop knowledge transmission programmes which will assist in educating the nation on human rights for persons with disabilities. 	
<p>“Ubuntu” African Model of Disability (Berghs, 2017)</p> <ul style="list-style-type: none"> Views “Ubuntu” as an African humanist and ethical worldview that views disability as part of a common humanity and as a necessary part of what makes us humans. In an ubuntu model of disability, impairment 	<ul style="list-style-type: none"> Used as a tool for decolonising and setting African agendas on disability. African agendas on disability are necessary because they are informed by African histories and African’s understanding of what constitute disability (de Santos, 2015). 	<ul style="list-style-type: none"> Although debates are ongoing on the need for an African model , specifically “ubuntu”, the implementation of such a model may be hindered by the state politics for example, continued oppression and injustices towards disadvantaged groups including persons with disabilities as a result of colonial and post-colonial 	<ul style="list-style-type: none"> This model would be applicable in the context of Eswatini, especially in light of some of the negative perceptions of communities on disabilities. This model would be instrumental in driving the conscientisation of disability among communities in Eswatini.

becomes cognitive, sensory, mental, physical (inclusive of biological) and spiritual diversity that can have a multitude of shared meanings that society, as human collective, constantly (re) make together. Ubuntu can change over time and recognises difference of experiences of diversity of humanness (as positive or negative), which are part of our shared humanity (Berghs, 2017:).

- A model of ubuntu would facilitate the reinstatement of humanity and the fights against injustices amongst individuals and communities thus ensuring the well-being of persons with disabilities (Berghs, 2017) and is based on socio cultural and spiritual responses.
- Ubuntu locates disability politically within the wider environment and practices of sustainability, which are now important to the post-2105 agenda, CRPD and the (UN) Sustainable Development Goals linked to climate change (Berghs, 2017)

politics that is perpetuated by potential and continued political and economic gains for politicians (Berghs, 2017).

2.2.2 Disability and Poverty

Given that low socio-economic status is known to have a negative effect on health status, psychological well-being, food security and personal safety (Lustig & Strauser, 2007), poverty has in recent years, received a lot of attention. This is particularly evident given its position in the first of the eight United Nations Millennium Development Goals (2000) which aimed to eradicate extreme hunger and poverty and was further followed up by the Sustainable Developmental Goals which provides a blueprint to achieve a better and more sustainable future for all by addressing global challenges, such as poverty, inequality and justice (Kwon & Kim, 2014). The Sustainable Developmental Goals offer an improvement on the Millennium Developmental Goals as they address key systemic barriers to sustainable development, such as inequality, unsustainable consumption patterns, weak institutional capacity and environmental deprivation that the Millennium Developmental Goals neglected (United Nations, 2015) The Sustainable Developmental Goals have a bearing on disability as most of the goals address issues that are core to persons with disabilities. Poverty, food and security, access to healthcare, inclusive and equitable education, inequality and provision of justice all form part of the Sustainable Developmental Goals that directly affect persons with disabilities and need to be addressed by states in order to ensure the welfare of persons with disabilities.

Research has proven that poverty and reduced access to good quality healthcare services are interwoven (Wagstaff, 2002). Persons with disabilities in LMICs, such as Eswatini, have less access to healthcare services than those in high income countries. However, this phenomenon also exists within high income countries (Peters et al. 2008). In order to alleviate the barriers to access experienced by persons with disabilities, it is important to acknowledge the link between poverty, disability and ill health. For example, Eide and Jele (2011) argue that, together with unemployment and social isolation, poverty forms part of the key issues that contribute to the exclusion of persons with disabilities and is responsible for their cumulative disadvantage. Despite the acknowledgement of the relationship between poverty and

disability (Grut & Ingstad, 2006; Lustig & Strauser, 2007; Scullion, 2010; Yeo, 2005), little is known about the factors which maintain and perpetuate poverty.

Poverty plays a major role in the reduced access to healthcare services for persons with disabilities (Badu, Agyei-Baffour & Opoku 2016; Grut, Mji, Braathen & Ingstad, 2012; Kuwana, 2014; World Health Organisation, 2011). Despite the fact that the concepts of “poverty” and “disability” vary according to context (Whyte & Ingstad, 1995), the United Nations (2008) estimates that up to two thirds of persons with disabilities live in poor conditions, limiting them not only in terms of their socio-economic status but also in their access to basic services and human rights, and their ability to make independent choices (Loeb, Eide, Jelsma, ka Toni & Maart, 2008; Van Rooy et al., 2012).

Poverty is both a cause and a consequence of disability due in part to the mutually reinforcing nature of the two (Kuwana, 2014). Research has indicated that persons with disabilities are more likely to be poor and that poverty may accentuate the likelihood of getting a disability (Kuwana, 2014). Poverty could cause disabilities and can furthermore lead to secondary disabilities for those individuals who are already disabled, as a result of the poor living conditions, health endangering employment, malnutrition, poor access to health services and education opportunities, as discussed earlier (Braithwaite & Mont, 2009). Poor individuals, including persons with disabilities, are not able to generate any form of income to pay towards health services because they are mostly unemployed and this often affects their participation in health insurance and medical aid (Badu, et al. 2016). Poverty renders persons vulnerable to disability and disability impoverished individuals thereby creating less chances of breaking the poverty cycle. Individuals are not only disabled by a physical impairment but remain disabled by their living conditions (Barrat & Penn, 2009). Therefore, poverty and disability create a vicious cycle.

Poverty is strongly related to the social characteristics of the population, such as education and health standards, access to safe water and sanitation, and family size.

Orphans, the elderly and retired, destitute and street children, widowed women and persons with disabilities are considered the most vulnerable groups in Eswatini (Mabundza & Dlamini, 2018). For these groups, social protection schemes are crucial in order to safeguard their welfare (Ministry of Economic Planning and Development, 2007).

Persons with disabilities form a significant part of the poor majority of Eswatini, whose human rights have been violated for centuries due to past policies, programmes, strategies and attitudes (Eide & Jele, 2011). Conditions of persons with disabilities are exacerbated by their systematic exclusion from the mainstream old society and therefore, resulting in high rates of infection and affection of the above discussed issues (Eide & Jele, 2011).

In LMICs the price of accessing healthcare may be made expensive by the need for additional out of pocket considerations essential for healthcare (Hanass-Hancock, Nene, Deghaye & Pillay, 2018). In particular, there is a need for consideration for specialised transport to healthcare facilities, costs related to multiple trips to healthcare facilities and costs related to additional care and supports (Banks & Polack, 2013; Hanass-Hancock et al. 2018; Masuku, Mophosho & Tshabalala, 2018). Hanass-Hancock emphasises that these expenses depend on the type of disability.

2.2.3 Cultural Aspects of Disability

Ndlovu (2016) in a study where they describe African beliefs concerning persons with disabilities and its implications for theological education, posits that the African culture portrays disability in an “ambivalent” way. On one extreme, it portrays disability positivity. This is evident in the African principle of “ubuntu”. The gist of “ubuntu” is that “*umuntfu ungumuntfu ngebantfu*” meaning that “I am because you of other people” (Mabovula, 2011). In essence this principle posits that “we are our bothers’ keepers”. This principle advocates that all people must be treated with the utmost dignity and respect. As a matter of fact, there are some Swati proverbs that discourage the mistreatment of persons with disabilities (Ndlovu, 2016).

On the other hand, some African beliefs, cultures, religions and spiritual beliefs may perpetuate negative stereotypes about disability (Ndlovu, 2016). For example, in some African countries, the onset of disability was frequently attributed to evil spirits, witchcraft or disharmony among the ancestors (Legg & Penn, 2013; Mpofu, Peltzer & Bojuwoye 2011; Ross & Deverell, 2004). Alternatively, disability may be viewed as a punishment for a social transgression by the individual or family (Mpofu et al. 2011). Niehaus (1995) further submits that some people believe that there exists a *tokoloshe* who has the capability to make women give birth to babies with disabilities.

There are general myths in Eswatini that persons who have a disability are bewitched or inflicted by bad spirits and they are, as such, a result of a curse from the gods or a sign of bad omen (Shabalala, 2000; Thwala, Ntinda & Hlanze, 2015). Many continue to believe that being a person with a disability can bring bad luck (Shabalala, 2000; Thwala et al. 2015). As a result, many persons with disabilities are hidden in their homesteads and are not given opportunities to participate and contribute to society (Eide & Jele, 2011; Shabalala, 2000). There is thus wide evidence in Eswatini of culture disrespect for persons with disabilities (Thwala et al. 2015). It seems that in Eswatini, the consequences of deficiencies and disablement are particularly serious for women who are subjected to social, cultural and economic disadvantages that impede their access to healthcare, education, vocational training and employment (Joensuu & Roppanen, 2012).

These perceptions regarding the cause for disability, influence health seeking behaviour (Legg & Penn, 2013). The way the persons with disabilities and their families view disability and their belief system around disability will influence their management of disability (Grut et al. 2012). Stone-MacDonald and Butera (2012) point out that causality beliefs determine the ways in which both lay and professional people explain, treat and handle disability and consequently, how their explanatory models and beliefs develop. In many cases, historical, cultural beliefs and practices relating to disability influence when, how and for what reason people seek out treatment for illness and disability.

In South Africa, some families of persons with disabilities seek help from traditional healers, especially when they start feeling that the medical route is not helping (Grut et al. 2012; Nilsson, Johnson & Adolfsson, 2016). In many instances, traditional healers and Western healthcare practitioners are consulted concurrently. It is only after parents are convinced that the herbs are not working that they will resort to seeking Western practices (Barrat & Penn, 2009). The pluralistic health seeking patterns have an influence on the treatment outcomes of persons with disabilities.

Disability and spirituality are intertwined (Mweshi & Mpofu, 2001). In Africa, disability is also explained as caused by *umuthi*, and children with a disability are accepted as a religious blessing where the family will still pray and believe that the child with a disability will get better (Barrat & Penn, 2009). Families of persons with disabilities in African countries will go as far as taking the persons with disabilities to church to get better, before they are taken to healthcare professionals, such as physiotherapists, for rehabilitation (Barrat & Penn, 2009).

Barrat & Penn, (2009) conducted a study in Mpumalanga involving Swati participants, who share similar cultural beliefs with emaSwati from Eswatini. The study postulates that grandparents sometimes make decisions regarding raising their grandchildren and this may influence on decisions regarding healthcare. In particular, grandparents may make decisions about who to consult, and their decisions may be deemed more important than the decision of the parents, and typically grandparents were most likely to seek traditional medicine (Barrat & Penn, 2009).

2.2.4 Disability in Eswatini

Eswatini is a predominately rural country, with 75.8 % of the population living in rural areas in 2010 (Central Statistics Office, 2010). Eswatini has significantly poor access to improved water sources, sanitation and electricity (Braithwaite, Djima & Pickmans, 2013). Even though Eswatini is classified as a LMIC (World Bank, 2013), it is actually

more similar to low-income neighbouring countries, such as Mozambique, in that poverty is rife with the income distribution in Eswatini being extremely skewed.

Eswatini has a population of around one million people. The wealthiest 10 per cent of the population account for nearly half of the total consumption and there is an ever-widening gap between urban and rural development (Ministry of Economic Planning and Development, 2016). In the year 2012, almost 63% of the population of Eswatini was classified as poor and 29% as extremely poor (Braithwaite et al. 2013; Ministry of Economic Planning and Development, 2016). About 69% of the population live below the poverty line, and the worst situation being that 48% of the population cannot meet their food requirements i.e. they are considered to be living under extreme poverty (Ministry of Economic Planning and Development, 2007). Although agriculture is the dominant activity in Eswatini, more than 40% of households never have enough to eat. Insufficient incomes, lack of the means of subsistence and the poor conditions of their daily living combine to obstruct the underprivileged section of the population from attaining their human and economic potential (Ministry of Economic Planning and Development, 2007). An estimated 76% of the population in rural areas is poor whilst 50% of the urban population is poor.

The Central Statistics (2010) estimated a total of 171347 persons with disabilities in Eswatini, which accounts for about 16.8% of the country's population. A large majority (86%) of persons with disabilities in Eswatini live in rural areas (Ministry of Health and Social Welfare, 2000). Persons with disabilities form a significant part of the poor majority of Eswatini, whose human rights have been violated for centuries due to policies, programmes, strategies and attitudes (Eide & Jele, 2011).

In a study conducted by Eide and Jele (2011), the authors documented the living conditions among persons with disabilities in Eswatini. It emerged that persons with disabilities faced a critical problem which is inaccessibility to the outside world. Persons with disabilities in Eswatini struggle to access buildings, communications intended for the deaf, blind and persons with cognitive or communication disabilities, as well as services such as public transportation (Eide & Jele, 2011). These challenges were also echoed in South Africa (Fisher & Shang, 2013; Kritzing, 2011).

Schneider, Swartz & Braathan, 2014). There were evident gaps for persons with disabilities when accessing healthcare services and health information. In particular, in Eswatini, only one fifth of individuals with a disability who needed an assistive device, had and/or used one (Matter & Eide, 2018). The provision of assistive devices was also largely from non-governmental organisations and maintenance was mainly from the individual's family (Matter & Eide, 2018).

2.2.5 Third Party Disability

Third party disability is a term created to describe the “disability and functioning of family members due to the health conditions of their significant others (World Health Organisation, 2001; p. 251). The World Health Organisation (2001) acknowledges the impact that disability has on caregivers of persons with disabilities, as caring for another, whether voluntary or due to obligation, impacts on both the caregiver and the person being cared for (Owusu-Ansah, 2015). Turner and Findlay (2012) suggest that caregiving is a complex phenomenon that is bound to produce both psychological rewards as well as psychological distress.

In an Ugandan inquiry into the experiences of informal caregivers of the elderly who are also physically disabled, Owusu-Ansah (2015) reported the following psychological distresses experienced by caregivers: depression and loneliness, pain, frustration; psychological exhaustion and consumption by the role of providing care. In other countries, the psychological distresses amongst caregivers were reported to be further exacerbated in cases where there was a lack of support (Masuku et al. 2018; Owusu-Ansah, 2015).

In Korea, some caregivers of persons with disabilities have been known to be isolated from their communities for various reasons. One of these reasons being the fear of not accepting them and their children with disabilities into the communities (Azeem, et al. 2013). This isolation and loneliness contribute towards the development of anxiety

and depression (Azeem et.al, 2013). Dabrowska & Pitsula, (2010) echoes these findings on a study conducted in South Africa.

In some African countries, caregivers of persons with disabilities experience financial strain from taking care of their family members with disabilities (Dibakoane, 2017; Masuku et al. 2018). Due the obligations of their new role of caregiving, caregivers may stop working in order to care for the persons with disabilities full time (Dibakoane, 2017; Masuku et al. 2018). In South African study that explored the experiences of caregivers of persons with Aphasia, caregivers lamented that due to the need to sometimes to lift their family members with a stroke into for example wheelchairs, to the bath and when assisting them with physical home exercise, caregivers sometimes experienced physical strain (Masuku et al. 2018). Caregiver physical strain was also reported by caregivers of children with cerebral palsy in Zimbabwe (Dambi & Jelsma, 2014). In another South African study, psychological strain was reported by caregivers as a result of constant feelings of sadness, heartbreak and stress has also been reported (Dibakoane, 2017).

While the caregiving role could be challenging, for other caregivers, it does also present with psychological rewards (Manga, 2017). Research has documented that caregivers of persons with disabilities have experienced the caregiving role as fulfilling, especially if they are doing it voluntarily (Manga, 2017; Tang, 2009). Kleinman (2009) also positively described caregiving as an uplifting experience that opens up the caregiver to their own humanness and vulnerabilities.

2.3 THE HUMAN RIGHTS OF PERSONS WITH DISABILITIES

2.3.1 International Legislature Pertaining to Disability Rights

Globally, more than a billion persons are estimated to be living with a disability which translates to about 15 percent of the world's population (World Health Organisation, 2011). This group of individuals often lack access to the same opportunities as the

mainstream population. Persons with disabilities experience barriers in accessing services that many others have long taken for granted, such as access to health, education, employment, and transport, as well as information (Grut et al. 2012; Kuwana, 2014; Moodley & Ross, 2015). The barriers that infringe on the rights of persons with disabilities are further exacerbated in less advantaged communities (Moodley & Ross, 2015; van Rooy et al. 2012; Wagstaff, 2002).

In an attempt to protect persons with disabilities from discrimination, international bodies, such as the United Nations and African Union developed legislation to ensure that persons with disabilities are included in their respective societies and that they have access to all entities, including healthcare services. This acknowledgement of the rights of persons with disabilities and the advocacy for all services to be accessible for persons with disabilities dates as far back as 1948, with the enactment of the Universal Declaration of Human Rights. Article 25 of this Declaration refers specifically to accessibility of healthcare services for persons with disabilities (United Nations General Assembly, 1948). It states that everyone, irrespective of ability, has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care. It also states that everyone has the right to necessary social services and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond their control (United Nations General Assembly, 1948).

The rights to access to healthcare services for persons with disabilities were also echoed in the Declaration of the Rights on the Mentally Retarded (United Nations, 1971). As the term “mentally retarded” was later considered derogatory, this was changed to “intellectual disability” (www.federalregister.gov). Paragraph 2 of the declaration mentions that persons with cognitive disability have a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance to enable them to develop their ability and maximum potential.

Accessibility to healthcare services for persons with disabilities was also reiterated in paragraph 6 of the United Nations Declaration of the Rights of Disabled Persons (United Nations, 1975). The declaration specifically states that persons with disabilities

have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.

Africa as a continent has a long tradition of human rights, including rights for persons with disabilities. In accordance with these traditions of human rights, the African Union adopted the African Charter on Human and People's Rights as early as 1981 in Zambia (African Union, 1981). The Charter was entered into force in 1986 (African Union, 1981). The rights to healthcare services were amongst the specific human rights lobbied for in the Charter. The Charter also emphasises in Article 16 that every individual shall have the right to enjoy the best attainable state of physical and mental health (African Union, 1981).

Accessibility to services, including healthcare services for persons with disabilities, was further strengthened by the Standard Rules of Equalisation of Opportunities for Persons with Disabilities (United Nations General Assembly, 1993). This is evident in Rules 2 and 3 of the Standard: Rule 2 mentions that states should ensure the provision of effective medical care to persons with disabilities. Rule 3 mandates states to ensure that there is a provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

The most recent international convention, namely the CRPD, was developed in 2006 (United Nations, 2006) and ratified by Eswatini in 2012 (Mavundla, 2015). The CRPD is a universal, legally binding standard that aims to ensure that the rights and dignity of persons with disabilities are guaranteed everywhere in the world (United Nations, 2006). Parties to the convention are required to promote, protect and ensure the full enjoyment of human rights by persons with disabilities and to also ensure that they enjoy full equality under the law (United Nations, 2006). Article 25 of the CRPD (2006) mandates States to recognise that persons with disabilities have the right to the

enjoyment of the highest attainable standard of health without discrimination on the basis of disability. The declaration also mandates signatory states to take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation, for example, sterilisation and abortion services. The CRPD furthermore underscores that the same range, quality and standard of free or affordable healthcare programmes are provided to persons with disabilities, including in the area of sexual and reproductive health and in population-based public health programmes. For persons with disabilities, services should furthermore be positioned as close as possible to the persons with disabilities' own community, including in the rural areas, in order to address the notorious transport challenges faced all over the African continent (Russell et al. 2013).

The CRPD mandates that the quality of care that is provided to people without disabilities should be the same than those is provided to persons with disabilities. The services should be 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 healthcare. There should also not be any discrimination against persons with disabilities in the provision of health insurance and life insurance where such insurance is permitted by national law. Insurance should furthermore be provided in a fair and reasonable manner. It should be ensured that there is a prevention of discriminatory denial of healthcare, health services, food and fluids on the basis of disability (United Nations, 2006). It is therefore clear that, the CRPD (United Nations, 2006), just like the Universal Declaration of Human Rights and the African Charter on Human and People's Rights (African Union, 1981), affirms that all people, including persons with disabilities, have the same human rights.

The extent at which human rights approaches developed in Western contexts can be applied as they are in developing countries remains a point of debate (Broberg & Sano, 2018). While it is acknowledged that these human rights approaches may be relevant to LMIC context due some similarities in the vulnerabilities of persons with disabilities across contexts (Masuku, Johnson & Bornman, 2020), it is imperative to consider the different contextual, cultural and political factors in LMICs that may influence the implementation of these approaches (Broberg & Sano, 2018; Hussey, Maclachlan &

Mji, 2017). For example, it is important to be cognisant of the different political systems and power dynamics (Buse et al. 2005), the influence of traditional beliefs and practices on human rights, transitioning of some African states into democracy, the different interpretations of democracy and the imperative influence of social determinants (Bernadette et al. 2016).

2.3.2 Eswatini Legislature Pertaining to Disability Rights

Eswatini committed itself to the realisation of the human rights of persons with disabilities. Chapter 2, section 20 of the Constitution of Eswatini prohibits discrimination stating that *“for the avoidance of any doubt, a person shall not be discriminated against on the grounds of gender, race, colour, ethnic origin, tribe, birth, creed or religion, social or economic standing, political opinion, age or disability”* (Constitutions of the Kingdom of Swaziland, 2005, p.18).

In Chapter 3, section 30 of the Constitution of Eswatini, the country commits to respect and treat every citizen with human dignity. Even though the Constitution does not make specific reference to the rights to equal access to healthcare, the Constitution clearly states that the government of Eswatini and its society shall take appropriate measures to ensure that persons with disabilities realise their full mental and physical potential. The Constitution, furthermore, stipulates that the government of Eswatini shall enact laws for the protection of persons with disabilities so as to enable them to enjoy productive and fulfilling lives (Constitution of the Kingdom of Swaziland, 2005).

Issues of democracy and human rights continue to be a contentious subject in Eswatini. This is despite the constitutional guarantees and the country having ratified the CRPD which mandated the implementation of legislation that is directed towards upholding the rights of persons with disabilities in Eswatini (Mavundla, 2015). In response to the mandate of the CRPD, the Eswatini government adopted the National Disability Policy of Swaziland in 2013 (Mavundla, 2015: Deputy Prime Minister’s Office, 2013). The policy emanates from principles of the CRPD (United Nations, 2006) and other international conventions and declarations such as the UN Charter, the UN Standard Rules of Equalisation of Opportunities for persons with disabilities

and the Salamanca statement and framework for action on special needs education (United Nations General Assembly, 1993). Accessibility to healthcare for persons with disabilities is discussed in sections 4.9 and 4.10 of the National Disability Policy of Swaziland. The essence of the National Disability Policy of Swaziland pertaining to access to healthcare for persons with disabilities is the promise for comprehensive accessible information and integrated healthcare services provision for all persons with disabilities including children, adolescents and young people at all levels of healthcare service delivery. Furthermore, the National Disability Policy of Swaziland acknowledges that at the time of the adoption of the National Disability Policy of Swaziland, persons with disabilities in Eswatini did not have adequate access to healthcare services (Deputy Prime Minister's Office, 2013). The National Disability Policy of Swaziland therefore outlines strategies that are instigated to improve the accessibility of healthcare to persons with disabilities.

The adoption of the National Disability Policy of Swaziland has been followed by the drafting of the National Disability Bill of Rights of 2014, (Mavundla, 2015), which, to date, is still awaiting enactment. Section 4.9 of the National Disability Bill of Rights of 2014 promises the promotion of healthy lifestyles, prevention of diseases and disabilities, provision of care and rehabilitation for persons with disabilities. It further vows to provide adequate access to information and accessibility to services which will enable persons with disabilities to make informed decisions about their sexuality and reproductive health. The National Disability Bill of Rights also proposes the establishment of a National Committee for persons with disabilities. The Bill further covers registration of organisations of persons with disabilities, provision for the right to assistance in situations of risk and humanitarian emergencies (Deputy Prime Minister's Office, 2014; Mavundla, 2015).

Subsequent to the development of the National Disability Policy of Swaziland and the National Disability Bill of Rights of persons with disabilities in Eswatini, was the formulation of the National Disability Plan of Action 2015-2020 (Deputy Prime Minister's Office, 2015). The National Disability Plan of Action is, in essence, a plan of strategies and activities for the implementation of the National Disability Policy of Swaziland and legislation across all sectors of the Eswatini society (Deputy Prime

Minister's Office, 2015). It therefore serves as the guideline for the implementation of the National Disability Policy of Swaziland. The National Disability Plan of Action is structured across seven themes, namely, national co-ordination and mainstreaming mechanism for disability, advocacy and awareness raising, social protection, education and training, health, skills development and the labour market and Infrastructure and the environment. The theme of healthcare promises universal access to all public health interventions and the full spectrum of healthcare services on an equal basis with other members of society (Deputy Prime Minister's Office, 2015). The implementation timeframe for access to healthcare runs across five years. These guidelines are run by independent ministries and each ministry is expected to submit a progress report at the end of each year (Deputy Prime Minister's Office, 2015).

Even though Eswatini has ratified the CRPD and has adopted legislation such as the National Disability Policy and the National Disability Bill of Rights, of 2014, the country has however, not been reporting diligently under the international human rights instruments (Mavundla, 2015). The country's initial report under the CRPD which was due in October 2014, has not been submitted to date (mindbank.info/collection/type/crpd_country_reports/all). Reasons given for the non-compliance in reporting were that the country has not received an invitation from the treaty body to write and present the report and indicated the need for technical assistance and capacity building in the areas of treaty body reporting (Mavundla, 2015).

It is thus still difficult for both the citizens and institutions to engage effectively in the protection of the rights of persons with disabilities rights (Dlamini, 2013). There is currently no body that specifically monitors and implements the constitution. Consequently, regardless of the constitution having provided for the establishment of the Eswatini Commission of Human Rights and Public Administration, this commission has not been functional due to lack of funding (Mavundla, 2015). There has therefore been an outcry from the disability sector to say that Eswatini is slow in terms of implementing such legislation (Mavundla, 2015). This emphasises the need for persons with disabilities and other stakeholders to be empowered on issues pertaining

to disability and disability rights. This empowerment will equip them to better advocate for the rights of persons with disabilities, including their rights to access healthcare.

There currently exist a number of organisations for persons with disabilities in Eswatini and these organisations represent and advocate for the rights and welfare of persons with disabilities (Deputy Prime Minister's Office, 2015; Eide & Jele, 2011). The Co-ordinating Assembly of non-governmental organisations (CANGO) is the umbrella body for all non-governmental organisations in Eswatini (Mcobokazi & Jele, 2010). Thus, all non-governmental organisations, including those of persons with disabilities, report under this structure. Organisations for persons with disabilities include the Federation of Organisations of the Disabled in Eswatini (FODSWA) which is a human rights oriented co-ordinating body for organisations of persons with disabilities (Eide & Jele, 2011; Lang, 2008). FODSWA was formed in 1993 by organisations of persons with disabilities in Eswatini due to the lack of co-ordination of their activities (Mcobokazi & Jele, 2010). Other organisations that also rally behind human rights for persons with disabilities in Eswatini include Save the Children (an organisation which advocates for the promotion of all children's rights, including children with disabilities); Cheshire Homes of Eswatini (an organisation which focuses on the rehabilitation of persons with physical disabilities; St Joseph's Catholic Mission (an organisation which houses the Ekululameni Training Centre which is an initiative that provides vocational training to persons with disabilities over 18 years) and the organisations of persons with disabilities (which offers advocacy and development of work, aimed at empowering persons with disabilities) (Eide & Jele, 2011).

The organisations of persons with disabilities in Eswatini have been lobbying for the government to enact laws on the rights of persons with disabilities since the Eswatini Constitution of 2005 came into force (Eide & Jele, 2011; Mavundla, 2015). Organisations of persons with disabilities have also been instrumental in calling government to ratify the CRPD (Deputy Prime Minister's Office, 2013; 2015). Their efforts also forced government to look into disability law issues and as a result, the National Disability Policy of Swaziland (2013), the National Disability Bill of Rights (2014) and subsequently, the National Disability Plan of Action (2015) came into existence. Organisations of persons with disabilities in Eswatini have played participatory roles in collaboration with other stakeholders, such as the Deputy

Minister's Office, other line government ministries and the private sector in the process of drafting the disability policy reforms (Deputy Prime Minister's Office, 2013). The views and representations of all those who participated and contributed in any way were taken into consideration in the formulation of the policy. It is, however, still important to strengthen the collaborative work between organisations of persons with disabilities and the government as most of the laws and policies oblige or recommend strategies for implementation by government to address issues of persons with disabilities in Eswatini (Eide & Jele, 2011). Yet government seems to lack sufficient political will and resources when it comes to the monitoring and implementation of laws, policies and domestication of international instruments (Mavundla, 2015). Organisations of persons with disabilities are also lacking in terms of funding and technical skills, both of which are necessary for a robust activism on their part (Mavundla, 2015). There is, therefore, a need to train and empower disability people's organisations on disability rights and human rights programming.

2.3.3 Implementation of Disability Policy and Legislature

The implementation of public policies, including disability policies, depends on the practicality of the policy, the economic and political environment during which the policy is instigated, the effectiveness of the government organisations responsible for implementing the policies and how these policies are aligned to their directive (Tebele, 2016).

Different states have enacted disability policies and legislation which are aimed at integrating persons with disabilities in all activities and services that are enjoyed by the mainstream population and to protect the rights of persons with disabilities. In most African states, however, these policies have been unsuccessful due to evident gaps in the implementation process (Kolawole, Williams & Wasiu, 2018). Tebele (2016) argues that good quality written policies do not accomplish what they are intended for, if they are not implemented properly.

The challenges of disability policy implementation have been attributed to various factors, such as the lack of political commitment from state governments (Ajulor, 2018:

Kolawole et al. 2018). States are held accountable for challenges of policy implementation because they are the ones that are often held responsible to ensure that policies are implemented (Egonman, 2000). Difficulties with policy implementation have also been attributed to unrealistic goal setting, exclusion of the target recipients of the policy documents and the lack of consideration of policy environments (Ajulor, 2018). Challenges of policy implementation have also been credited to the lack of dedicated policy implementation funding from state governments (Brynard, 2010; Etiaba et al. 2015), and the lack of human resources with the necessary knowledge and skills on policy implementation and on disability (Brynard, 2010). The challenges in implementing policies result in the policies not achieving the desired outcome.

Eswatini, as a state, is no exception to the challenges of policy implementation as implementing legislatures in Eswatini is at a concerning slow pace (Eide & Jele, 2011). An example of the slow pace of policy implementation is the passing of the National Disability Bill of Rights as law in parliament, which to date, has not been done. Consequently, persons with disabilities in Eswatini continue to be marginalised, discriminated against and socially excluded from mainstream activities. Persons with disabilities have limited access to community services and to opportunities available to persons without disabilities, such as education, health, employment, public facilities, including buildings and transport (Eide & Jele, 2011: Mavundla, 2015). Consequently, persons with disabilities in Eswatini tend to be over-represented amongst the unemployed, the poor and the uneducated which has far-reaching consequences for them at individual, family and societal levels (Eide & Jele, 2011). The failure by the society to recognise disability as a human rights issue contributes to the devaluing and dehumanisation of persons with disabilities (Eide & Jele, 2011).

The devaluation of persons with disabilities and the challenges in policy implementation will continue existing until programmes that enable persons with disabilities to claim their human rights are implemented (Eide & Jele, 2011). Persons with disabilities are the experts in disability and their knowledge should be encouraged to lead the way. Persons with disabilities cannot work alone in their plight for their human rights to be realised, and they need the assistance of service providers,

government officials and the community at large as all these individuals have a significant contribution to make. All stakeholders need to work together with persons with disabilities in their struggle to establish a disability culture, which emphasises empowerment and pride (Lordan, 2000).

With the above in mind, it is important to note that Eswatini is building up a constitutional democracy with elements of traditional and modern governing. As a result, people in Eswatini have limited knowledge and experience of human rights. This is especially the case with poor and vulnerable population groups who often suffer when human rights implementation is not materialising (Joensuu & Roppanen, 2012).

2.3.4 Policy Analysis and Legislature

Policy analysis varies across different skills, methodologies and disciplines such as history, sociology, political science and legislative studies (Ditlopo, 2016). Hanekom (1987, p. 65) describes a policy analysis as *“an attempt to measure the costs and benefits of various policy alternatives or to evaluate the efficacy of existing policies; in other words to produce and transform information relevant to particular policies into a form that could be used to resolve problems pertaining to those policies”*. Weimer and Vining (1990, p. 1), on the other hand, define policy analysis simply as *“a client-oriented advice relevant to public decisions”*. Walt and Gilson (1994) postulate that policy analysis is necessary as a means of identifying and interpreting factors that could affect the efficiency of policy change.

Different authors proposed models and frameworks that can be effectively used for analysing public policies. Grindle and Thomas (1991), in their proposed model of policy implementation and analysis, contended that four aspects influence the ease with which policies can be accepted. The factors include the following: vested interests; levels required in order for policies to be appropriate; involvement of public participation and the resources required for implementation, as well as the length of time needed to show influence. The Walt and Gilson (1994) framework has been

widely applied in health policy research in LMICs (Gilson & Raphaely, 2008). Even though it has focused mostly on health policy analysis, the framework can be applied across disciplines. Walt and Gilson (1994) theorise that by using a simple model that integrates actors, context, content and processes, policy makers and researchers may better understand the process of policy improvement, enabling them to better plan for policy implementation. Walt and Gilson (1994) further suggest the use of this model in policies, both retrospectively and prospectively.

The four related concepts of the Walt and Gilson (1994) policy analysis framework are presented in Figure 1 and explained in more detail thereafter:

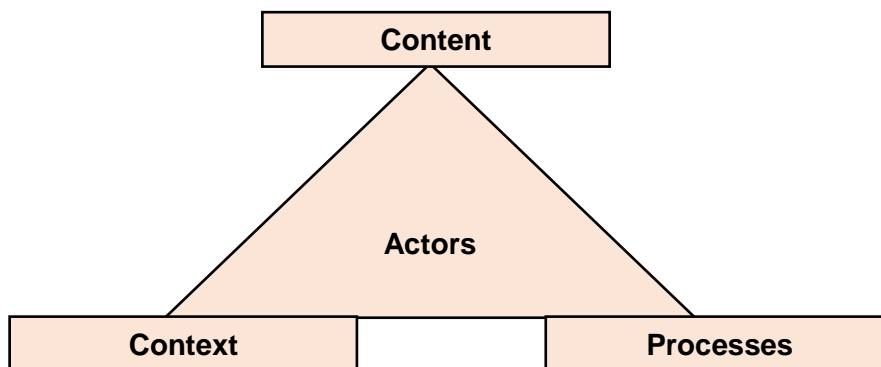


Figure 1: The Walt and Gilson (1994) Policy Analysis Triangle Framework for Policy Analysis

i. Actors

Actors refer to individuals, organisations, states or governments and the power that they possess in influencing the policy process at local, national, regional and international levels (Buse, Mays & Walt, 2005).

ii. Context

Context refers to systemic factors – political, economic and social, both national and international – which may have an effect on health policy (Buse et al. 2005). These factors can be further divided into:

- **Situational factors** (the specific conditions of a moment in history that influences the policy change intended) (Ditlopo, 2016; Leichter, 1979).
- **Structural factors** (the relatively unchanged circumstances of the society and the polity such as the structure of the economy and the political system) (Ditlopo, 2016; Leichter, 1979).
- **Cultural factors** (the values and commitments of society and groups) (Ditlopo, 2016; Leichter, 1979).
- **Exogenous factors** (the events and values outside of any one country or system) (Ditlopo, 2016; Leichter, 1979).

iii. Content

Content refers to the specific nature and design of reforms within the policy documents (Buse et al. 2005).

iv. Processes

Processes refers to the way in which policies are initiated, developed or formulated, negotiated, communicated, implemented and evaluated (Buse et al. 2005).

2.4 ACCESS TO HEALTHCARE

Although access to healthcare is frequently identified as a goal for healthcare policy, the specific meaning of access to healthcare often remains unclear (McIntyre, Thiede & Birch, 2009). Different researchers interpret access to healthcare differently

(McIntyre et al. 2009), resulting in different explanations of the concept of accessibility to health. For some authors, "access" refers to entry into, or use of, the healthcare system, while others characterise it only as the factors influencing entry (Penchasky & Thomas, 1981). For example, Penchasky and Thomas (1981) conceptualised accessibility to healthcare by using 5As, namely, *Availability, Accessibility, Acceptability, Affordability, and Accommodation*. Penchasky & Thomas (1981) submits that *availability* refers to the sufficiency of the supply of healthcare professionals, healthcare services and healthcare programmes; *accessibility* refers to the relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance and cost; *acceptability* refers to the relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider's attitudes about acceptable personal characteristics of clients and providers' attitudes about the preferred attributes of clients or their financing mechanisms; *affordability* refers to the relationship of costs of healthcare services and the consumers' income, particularly the ability of healthcare users to afford prices related to healthcare; and *accommodation* refers to the relationship between the manner in which the supply resources are organised to admit clients (including appointment systems, hours of operation, walk-in facilities, and telephone services) and the clients' ability to accommodate to these factors.

Recent authors have drawn from the 5As concept by Penchasky and Thomas (1981) and have used the model to develop their own models of accessibility to healthcare. For instance, Guillford et al. (2002) describes access to healthcare as the *services available* which refers to whether there is adequate supply of services and opportunities to obtain healthcare; *the utilisation of services and barriers to accessing these services*, which refers to the extent to which a population gains access also depends on financial, organisational and social or cultural barriers that limit the utilisation of services; *relevance and effectiveness*, which refers to ensuring that the available services are relevant and effective if the population is to gain access to satisfactory health outcomes. and *equity* which refers to the equity of access which may be measured in terms of the availability, utilisation or outcomes of services.

Peters, Garg, Bloom, Walker, Breiger and Rahman (2008) on the other hand define access to healthcare according to four pillars which are *availability* which refers to having the right type of care available to those who need it (such as hours of operation and waiting times that meet demands of those who would use care), as well as having the appropriate type of service providers and materials; *acceptability*, which refers to the match between how responsive healthcare service providers are to the social and cultural expectations of individual users and communities; *geographical accessibility* which refers to physical distance or travel time from service delivery point to the user's home; and *financial accessibility* which refers to the relationship between the price of services (in part affected by their costs) and the willingness and ability of users to pay for those services, as well as be protected from the economic consequences of health costs.

McIntyre, Theide and Birch (2009) delineates access to healthcare according to *availability* which refers to whether the appropriate healthcare providers or services are supplied in the right place and at the right time to meet the prevailing needs of the population; *affordability* which refers to "degree of fit" between the full costs to the individual of using the service and the individual's ability to pay in the context of the household budget and other demands on that budget; and *acceptability* which refers to fit between provider and patient attitudes towards and expectations of each other.

For several years, research on access to healthcare has been done widely within many countries utilising different methodological approaches and disciplines, but definitions vary significantly across populations depending on broad social, economic and cultural components (Cabieses & Bird, 2014). In order to guarantee the provisions of the disability policy of Eswatini and ensure access to healthcare for persons with disabilities, these should match the four pillars describing accessibility to healthcare as proposed by Peters et al. (2008), which are *Availability; Acceptability; Geographical Accessibility and Financial Accessibility*. The Peters et al.'s (2008) definition of accessibility is selected for the current study because even though it stems from the 5As definition by Penchasky and Thomas (1981), the definition makes specific reference to socialisation and culture as aspects that influence acceptability of

healthcare for persons with disabilities. These authors also make reference to financial and geographical accessibility separately when they discuss accessibility. Geographical accessibility is relevant in a study conducted in Eswatini because of the fact that 86% of the population of persons with disabilities reside in rural Eswatini (Eide & Jele, 2011), where roads are often undeveloped and the terrain presents difficulties (Vergust, Swartz, Mji, McLachlan & Mannan, 2015). Geography will therefore be a significant influence on the health seeking behaviours of persons with disabilities in Eswatini, especially those who reside in rural areas. Eswatini is also a country that is rich in culture (Fleminger, 2009) and whose cultural and traditional beliefs have a strong influence on the view of the society on disability and disability issues (Thwala et al. 2015). Culture and traditional beliefs could therefore have an impact on accessibility to healthcare.

2.4.1 Experiences of Persons with Disabilities when they access healthcare

Access to healthcare in its broadest sense (including availability, acceptability, geographical accessibility and financial accessibility) is more challenging in rural than in urban areas. This is particularly concerning in the current thesis, considering there is a higher prevalence of disability in rural areas compared with urban areas (World Health Organisation, 2011). Regardless of whether they reside in urban or rural contexts, persons with disabilities experience challenges when they attempt to access healthcare services (Sherry, 2014; World Health Organisation, 2011). These challenges are compounded in persons with disabilities who live in poor rural societies (Grut et al. 2012; van Rooy, 2012).

In LMICs, stigma towards persons with disabilities is often reflected through stereotypes which unfortunately has a negative effect on the mental (Trani, Ballard & Pena, 2016) and emotional well-being of persons with disabilities and also negatively influences their access to healthcare services (Shakespeare et al. 2018). Stigma can be defined as converging interrelated elements of labelling, stereotyping, separation, status loss, and discrimination in the context of social, economic and political power imbalances (Link & Phelan, 2001). Link and Phelan (2006) posit that stigma

encompasses four interlinked components. Firstly, the person is identified and labelled according to their human difference; secondly, the person is linked to undesirable characteristic; thirdly, the labelling separates “them” the stigmatised person from “us”, the so called normal population; fourthly, the stigmatised person experiences discrimination and loss of status and the exercise of power.

Stigma can be divided into public stigma, self-stigma, stigma by association and structural stigma (Pryor & Reeder, 2011; Trani et al. 2016). Public stigma is the prejudice and discrimination that is expressed and practised by the general public towards certain groups of people or individuals (Trani et al. 2016). Hence, it refers to the legitimisation and perpetuation of a stigmatised status by institutions and dominant ideologies (Pryor & Reeder, 2011). Self-stigma is defined as when persons with disability are aware of the stereotypes that are used to describe them, and then they agree with these stereotypes and apply these stereotypes to themselves (Corrigan, Larson & Rüscher, 2009). Finally, stigma by association is defined as negative attitudes directed towards friends and family members associated with stigmatised individuals or groups (Pryor & Reeder, 2011).

Internationally and in LMICs, persons with disabilities often experience stigmatisation and discrimination under the care of healthcare professionals working at healthcare facilities (Badu et al. 2016; Banks & Polack, 2014; Simpamba, Struthers & Mweshi, 2016). In particular, research has indicated that persons with disabilities are often not included in programmes that people without disabilities benefit from, such as programmes related to HIV/AIDS, or sexual and reproductive health (Shakespeare et al. 2018; Sherry, 2014). Shakespeare et al (2018) posit that healthcare professionals may perceive persons with disabilities as not being sexually active and as a result, may not include them in programmes related to sexual and reproductive health. Exclusion of persons with disabilities from sexual and reproductive health is intensified in women with disabilities (Rugoho & Maphosa 2017). For example, in Argentina women with disabilities reported challenges with obtaining contraceptives, voluntary sterilisation and with abortions after experiencing rape (Mollman, 2010). Healthcare facilities may also knowingly or unknowingly perpetuate disability stigma through

health promotion campaigns which use negative images of life with disability to encourage persons with disabilities to live healthy or safe lives and also use prenatal screening messages which may stigmatise life with disability.

Healthcare professionals have also been reported to present with negative attitudes towards persons with disabilities (Singongo, Mweshi & Rgoda, 2015). In particular, healthcare professionals have been reported to possess stereotypes, wrong perceptions about disability, and to also use abusive and discriminatory language when treating persons with disabilities (Badu et al. 2016; lezzoni, 2011). Visagie and Schneider (2014) postulate that healthcare professionals lacked stipulated standards of care for persons with disabilities in healthcare facilities, therefore the care that they provide to persons with disabilities, whether good or bad, is determined by the character of the specific healthcare professionals and their values and beliefs around persons with disabilities and disability.

Cultural beliefs define who people are, how they interact with the world and how they behave in certain situations and can be considered a combination of religious beliefs, socially accepted norms and traditions (Hanson, Lynch & Poulsen, 2013; Omu & Reynolds, 2012). Culture is reflected in all that individuals think and all that they do (Spencer-Oatey, 2012). These ways of being in the world give meaning and structure to each individual and each family.

As a result of the negative lens through which disability is viewed, caregivers of persons with disabilities, in particular children with cerebral palsy in Ndola Zambia, hide their children with disabilities as a way of protecting them from victimisation by a society that is unaccepting of persons with disabilities (Singongo et al. 2015). In so doing, they end up compromising access to healthcare for persons with disabilities, specifically their children (Groce & Kett, 2014; Thwala et al. 2015). Persons with disabilities are also hidden from communities because they are a source of shame and embarrassment to their families (Ndlovu, 2016). A study by Kassah, Kassah and Agbota (2012), which focused on the abuse of children with disabilities in Ghana,

confirmed the cultural belief that children with disabilities were cursed; this led to such severe stigmatisation that children were often hidden away by their parents or left at a river to die.

A South African study by Vergunst and colleagues (2015), further confirmed self-stigma as a reality that negatively influenced access to healthcare services. In the study by Vergunst and colleagues (2015), self-stigma was reported as emanating from persons with disabilities' experiencing the fear of meeting other people because they had a disability. One participant was quoted in the study as saying 'If I'm disabled, I'm not going to meet with other people' (Vergunst et al. 2015).

2.4.2 Barriers to Accessing Healthcare

Access to healthcare for persons with disabilities is challenging as a result of a number of barriers. These barriers will be discussed in more detail in this section.

2.4.2.1 Services and Staffing Barriers

Barriers to access healthcare services for persons with disabilities are also attributed to the shortage of healthcare professionals in healthcare facilities (Health Systems Trust, 2015; Joensuu & Roppanen, 2012; Maart & Jelsma, 2014). This shortage of healthcare professionals may be attributed to the lack of funding for healthcare professional posts (South African Presidential Health Summit Report, 2018). Joensuu and Roppanen (2012) further suggested that healthcare professionals in Eswatini are few in number in proportion to the population, mostly due to the brain drain to other African and international countries. The shortage of rehabilitation staff is not only a challenge that is specific to Eswatini, but other LMICs have a similar problem, as indicated in studies by Maart and Jelsma, (2014); Health Systems Trust, (2015); Shumba and Moodley, (2018); Visagie, Scheffler and Schneider (2013). People living in the rural areas have even fewer opportunities for medical services and healthcare professionals (Joensuu & Roppanen, 2012). In Eswatini, in particular, rehabilitation services such as physiotherapy, occupational therapy, speech and language therapy

and audiology are not easily available to persons with disabilities (Deputy Prime Minister's Office, 2015) as they are only offered in referral healthcare facilities which are situated in the main towns that are a distance from the residences of persons with disabilities (Deputy Prime Minister's Office, 2015). Rehabilitation is imperative for persons with disabilities as it contributes to their sense of autonomy, self-worth, social participation and improvement of quality of life (Mlenzana, Eide & Frantz, 2018).

In situations where persons with disabilities live closer to rehabilitation services, and can therefore access these services, literature suggests that due to their lack of knowledge and awareness on the availability of these services to them, persons with disabilities may not access them (Ali, King, Strydom & Hassiotis, 2013; Mactaggart et al. 2016; Saloojee, Phohole, Saloojee & Ijsselmuide, 2007). The lack of access to radio and television sets which are the common modes for communicating information, especially in rural Eswatini, along with the low literacy levels of persons with disabilities residing in rural areas are significant contributory factors to the information gaps on the existing services at their hospitals and clinics (Eide & Jele, 2011).

Healthcare facilities have also been unsuccessful in ensuring reasonable accommodation for persons with disabilities. Consequently, persons with disabilities endure long waiting periods between appointments and wait in queues during visits to healthcare facilities (Moodley & Ross, 2015; Vergust et al. 2015).

2.4.2.2 Distance to Healthcare Services

McLaren, Ardington, and Leibbrandt (2013) identified an association between the distance and the time that the vulnerable population has to travel to healthcare facilities and the use of healthcare services. The longer that it took persons with disabilities to travel to healthcare facilities, the less effort they made to access these services. Healthcare facilities are usually situated in long travel distances from homesteads of persons with disabilities, especially in rural areas (Vergunst, 2016). This then affects their travelling arrangements, ergo, translating into transportation

challenges. Transportation is one of the significant challenges that are experienced by persons with disabilities when they access healthcare services regardless of the type of a disability and the potential impact on transportation (Masuku et al. 2018; Mlenzana, Frantz, Rhoda & Eide 2013; Sherry, 2014; Vergunst, 2015, 2016).

Common transportation challenges that are highlighted in literature include that persons with disabilities have to travel long distances from sites that are barely accessible by motor vehicles, combined with expensive, unreliable public transport, making it very difficult for persons with disabilities to make regular follow-up visits to healthcare facilities (Barrat & Penn, 2013; Johnson, Nilsson & Adolfsson, 2015). Persons with disabilities often do not have their own private transport and it is expensive for them to hire private transport to get to healthcare facilities. Most of the available public transport does not have ramps which make it difficult for persons with disabilities in wheelchairs, or those who use walking aids and/or crutches. Public transport drivers are also not trained on how to engage with people with sensory disabilities such as those with significant hearing loss and visual disabilities (Badu, et al. 2016; Grut, et al. 2012; Kuwana, 2014; Moodley & Ross, 2015). In extreme situations, there will be areas where there is no public transport at all (Barrat & Penn, 2013) or persons with disabilities will have to wait for long hours for a public transport driver who is willing to accommodate persons with disabilities and their wheelchairs in their vehicle (Johnson et al. 2015).

Furthermore, the less developed the landscape is, the less likely it is for persons with disabilities to access healthcare services. People living in the hills and valleys are often not served by public transport (Vergust et al. 2015). The terrain is also an issue because persons with disabilities who use wheelchairs have to deal with mud, gravel, and uneven roads and find it taxing on their family and on themselves when they have to be pushed up a hill. In Eswatini, these factors may be more likely to be applicable as the majority of the country consists of areas that are classified as rural, with many hills and valleys. The design of the buildings in healthcare facilities (Vergust, 2015) and the referral pathways to other institutions, depending on service levels, can have

an influence on the access to services by persons with disabilities (Van Rooy, et al. 2012).

2.4.2.3 Access to Assistive Devices

Articles 2, 20 and 26 of the CRPD mandate that signatory states should promote the availability of assistive devices to persons with disabilities who need them (United Nations, 2006). This is further reiterated by the World Health Organisations' recommendation that assistive devices should be provided to persons with disabilities (World Health Organisation, 2011). However, only a small percentage (estimated to be between 5-10%) of all persons with disabilities who require assistive devices or assistive technology are provided access to these services (de Witte, Steel, Gupta, Delgado Ramose & Roentgen, 2018; World Health Organisation, 2001). In Eswatini specifically, the government has provided only 11.5% of assistive devices to persons with disabilities who required them, with private providers accounting for 32.7% of assistive devices (Matter & Eide, 2018). Moreover, these devices often favoured persons with physical disabilities (Matter & Eide, 2018) and not necessarily for example persons with communication challenges who may need augmentative and alternative communication devices. In the allocation of institutional budgets by respective healthcare facilities, rehabilitation services may not be prioritised and therefore may not be allocated a budget for goods or services (Shumba & Moodley, 2018). As a result of not having a budget allocation, coupled with a poor procurement process (Shumba & Moodley, 2018), rehabilitation healthcare professionals may struggle to provide and maintain assistive devices that are required by persons with disabilities. Owing to the fact that healthcare facilities are struggling to meet the demand of assistive devices required by persons with disabilities, their families then resort to alternative ways of acquiring assistive devices such as asking for donations from non-governmental organisations (de Witte et al. 2018). Generally, states entrust the maintenance of the assistive devices to persons with disabilities (Visagie et al. 2017).

Additional to the challenges with the allocation and maintenance of assistive devices is that some healthcare facilities have a shortage of medication and equipment which unfortunately hinders persons with disabilities from receiving the adequate standard of healthcare that is due to them (Vergunst et al. 2015; Visagie & Schneider, 2014).

2.4.2.4 Access to Health Information in easy language formats

Eide and Jele (2011) reported that more than half of the persons with disabilities in Eswatini had not received primary education, which implies that they present with low literacy levels. Neuhauser et al. (2013) posit that written health literacy information is usually presented on average at the sixth-grade level and that most materials and texts using written language might even be higher than the recommended sixth grade level. This finding from Neuhauser et al. (2013) indicates that persons with disabilities who have not attended school up to the sixth grade will be excluded from health literacy information. Healthcare professionals also tend to provide information using difficult medical terms not understood (Koch-Weser, DeJong & Rudd, 2009). The situation is further exacerbated by the fact that health information related to medication such as the frequency and the quantity of use is not adequately explained to persons with disabilities (Banks & Polack, 2014).

2.4.2.5 Communication Barriers

Persons with communication, visual and hearing impairments also continue to experience communication challenges, when they access healthcare services (Chaveiro, Porto, & Barbosa, 2009; Withers & Speight, 2017). The communication challenges are as a result of healthcare professionals more often not being trained in sign language and in communication strategies that will enable them to have conversations with specifically, persons with communication and hearing difficulties (Komaric, Bedford & van Driel, 2012; Kritzinger et al. 2014). Healthcare professionals often rely on interpreters when consulting with persons who are deaf, thereby compromising healthcare professionals to patient confidentiality. Persons who are deaf therefore run the risk of misunderstanding their diagnostic and therapeutic

aspects (Scheier, 2009) that could consequently reduce their access to preventative healthcare (Napier & Kidd, 2013; Munoz, Bradham, & Nelson, 2011). Deafness, in itself, is an invisible disability (Tye-Murray, Spry, Mauze' 2009). Social exclusion of these individuals is rife, as the deaf community is often ignored by the hearing community (Purcell, 2014). This places persons who are deaf at risk of marginalisation (Kuenburg, Fellingner & Fellingner, 2016).

2.5 THE HEALTHCARE SYSTEM IN ESWATINI

Eswatini's healthcare system is dual. It is made up of the traditional and Western concepts of medicine (Intellectual Disabilities Inception Report, 2006). The healthcare service based on the Western concept of medicine is considered to be formal and as such, benefits from government funding (Magagula, 2017). However, emaSwati utilise services of the traditional healthcare sector as their first choice (Intellectual Disabilities Inception Report, 2006) as about 80% of the population will visit a traditional healer before they visit a Western doctor (Fleminger, 2009).

By 1991, up to 85% of the population of Eswatini was reported to be already living within a radius of 8km from a healthcare facility, depicting that access to healthcare services had been increasing tremendously (Intellectual Disabilities Inception Report, 2006). Magagula (2017) postulates that Eswatini's healthcare system is based on a primary healthcare approach organised as four levels, namely, community based care which encompasses rural health motivators, faith based healthcare providers, volunteers and traditional practitioners, primary healthcare facilities which includes health centres, public health units, rural clinics and a network of outreach sites, five regional hospitals and three national referral hospitals. There is, however, evidence to suggest that the distribution of health resources tends to favour urban over rural based populations (Intellectual Disabilities Inception Report, 2006). Most of the regional and national referral hospitals which are most resourced in terms of human, physical and financial resources are situated in urban areas (Magagula, 2017).

There is currently a decline in the quality of healthcare services in Eswatini. This decline in the quality of healthcare services is due to many factors affecting the demand and supply of healthcare. The quality of healthcare services has been compromised by the increasing burden of disease in the face of limited financial and human resource capacity, limited medical supplies, shortage of equipment and inadequate infrastructure (Ministry of Economic Planning and Development, 2007; WHO, 2008). In 2014, non-communicable diseases accounted for 33% of all in-patients' admissions (Ministry of Health, 2014), while HIV and AIDS and Tuberculosis (TB) jointly accounted for about one third of all deaths in Eswatini (World Health Organisation, 2016).

The increase in patient loads, long queues, shortened consultation times by healthcare providers, combined with the complexity of many cases associated with HIV and AIDS, have all negatively influenced the quality of healthcare in Eswatini. The national capacity to effectively manage information, research and knowledge, requires strengthening (WHO, 2008). National healthcare information is not easily accessible to potential users due to un co-ordinated healthcare information systems. This leads to healthcare information about the country being either outdated or unavailable in national, regional and international databases (World Health Organisation, 2008).

2.6 CONCLUSION

This chapter provided a view of the pertinent issues that are related to access to healthcare for persons with disabilities. It is evident that globally, and on the African continent, as well as in Eswatini, laws and policy reforms mandate that access to healthcare is a human right for all. With these stipulations in laws and policy reforms, there has also been a shift globally from the way in which disability is supposed to be viewed and ultimately defined. This has been evident in how the models of disability have evolved from the charity model to the current human rights model. Despite these laws and policy reforms being in place, and the drive for a changing world view of disability, many individuals still experience challenges when they access healthcare

services. These challenges cut across the availability of services, the financial and geographical accessibility of services and the acceptability within societies, which influences their acceptance in healthcare facilities. Evidence suggest that there is a need to rethink the content and implementation strategies of the currently existing policy reforms at a national level and also to create an awareness of disability and the right of persons with disabilities to access basic health services.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

The chapter outlines and describes the research methodology used in this study. It commences with the main and sub-aims as they pertain to the different data sources. Next, the selection and justification of the constructivist research paradigm as the archetype that underpins this study is discussed. This is followed by a rationale for choosing the case study research design as the ideal research design for the study at hand. The preference for Mbabane in Eswatini as the study setting is subsequently explained. This is followed by a description of the research fieldworker, along with an explanation for her selection and her role in the study which is followed by a description of the independent observer. Next, ethical considerations with specific reference to ethics with persons with disabilities are described, followed by a description of the strategies used in the study to ensure trustworthiness of the data. Thereafter, the Integrated Disability Policy Analysis Framework which encompasses the Walt and Gilson Health Policy Analysis Framework (1994), enhanced with the Peters et al. (2008) Access to Healthcare Framework are discussed. The chapter closes off with a conclusion.

Figure 2 presents a schematic representation of how the data sources within the case study research methodology are used in this thesis, differentiating the various chapters, with an emphasis on Chapter 3, which is the current focus.



Figure 2: Schematic Representation of the Methodology Chapters for all Three Data Sources of the Study.

As previously mentioned, this case study research utilised multiple sources of data. Data sources are therefore discussed in Chapters 4, 5 and 6, respectively, with each data source highlighting its own specific methodology, results, discussion and implications for the next data source.

3.1.1 Study aims

The aims of the research are set out as the main aim, delineated into three sub-aims.

3.1.2 Main Aim

The purpose of this case study research study was to describe access to healthcare for persons with disability in Eswatini.

3.1.3 Sub-aims

The following three sub-aims were formulated to address the main aim of the study, namely:

- i. To describe the provisions regarding access to healthcare for persons with disabilities in Eswatini as guaranteed by the National Disability Policy Reforms.
- ii. To describe the design and implementation of the National Disability Policy Reforms by focusing on the actors, context and processes involved in order to understand possible influences on the provision and realisation of access to healthcare.
- iii. To describe the perceptions of stakeholders regarding the experience of persons with disabilities in accessing healthcare and the effectiveness of the National Disability Policy Reforms in facilitating access to healthcare for persons with disabilities in Eswatini.

3.2 RESEARCH DESIGN

A qualitative case study research design utilising multiple data sources was employed to address the main aim of the study (Creswell & Poth, 2018). The research design was deemed appropriate for the study because the researcher was interested in an in-depth and detailed understanding, description and analysis of access to healthcare

for persons with disabilities in Eswatini from the perspectives of all relevant stakeholders (Creswell & Poth, 2018). Case study research is considered a robust research method when an holistic, in-depth investigation is required (Zainal, 2007). It is specifically relevant for the current study because the researcher was exploring a case (persons with disabilities' access to healthcare) in a context (Eswatini) where limited research has been done on persons with disabilities with the aim of understanding the situation in its entirety (Kumar, 2012; McMillan & Schumacher, 2011).

A document analysis and in-depth interviews with key informants and focus groups with different stakeholder groups, namely, persons with disabilities, caregivers of persons with disabilities healthcare professionals (which also included additional electronic questionnaires) were utilised to understand the complexity of drafting, implementing and reviewing the National Disability Policy Reform documents to address access to healthcare for persons with disabilities in Eswatini. Consulting multiple sources was a significant means of providing different bases of evidence for the purposes of triangulating the data (Carter, Lukosius, Dicenso, Blythe & Neville, 2014). Through the use of qualitative methods, specifically different data sources, the researcher was able to go beyond the quantitative statistical results and understand the behavioural conditions from the participants' perspective (Zainal, 2007). The study was conducted in Eswatini as case studies require that the examination of the data should be conducted within the context of its use, in this case, Mbabane, the capital city of Eswatini (Lock & Seele, 2018).

Case study inquiry has however been criticised for its lack of rigour in its processes and sloppiness and bias in reporting of findings and conclusions (Yin, 2015). It has also come under scrutiny for its difficulty in the generalisation of results as it is often based on a small context-specific sample, is difficult to conduct and producing a large amount of documentation (Tsang, 2014). Even though the study is based on a single context, the fact that it is intensive as demonstrated through the use of multiple sources, mediates potential bias as qualitative intensive research provides in-depth descriptions with more precision (Yin, 2015). To further curb some of these criticisms,

the researcher was thorough in collecting and analysing data. The researcher was also detailed in reporting findings by being aware of potential bias, addressing that, and, if possible, disallowing it. While the researcher has been forthcoming about her interest and passion on the rights of persons with disabilities, all possible attempts have been made to not allow these personal factors related to the researcher to influence the reporting of findings. Trustworthiness strategies such as credibility, transferability, dependability and confirmability have been implemented across the different data sources and at different stages in the study to increase the rigour. The trustworthiness strategies are addressed in more detail in section 3.9 of this chapter.

The process of data collection, data organisation, analysis and data reporting of the different data sources yielded substantial amounts of data. This process was manageable because the study was organised according to the different data sources. For each data source, structure was applied to the collection, analysis of data and reporting of findings. A new data source was started only after the completion of the data source preceding it. The involvement of an experienced and trained research fieldworker in these processes also contributed to the process being manageable.

As the research was focused on a specific stakeholder group, namely, persons with disabilities, in a unique, but typically under-researched context (Eswatini), the generalisation of the findings was therefore not considered as a reasonable or relevant outcome of the study. Rather, the study was interested in describing and understanding the specific complexities and contextual conditions influencing access to healthcare for persons with disabilities in Eswatini with the aim of generating theory, informing policies and practices through the development of a policy brief and healthcare guidelines in an easy-to-read accessible format, as a relevant intervention. Persons with disabilities are a vulnerable heterogeneous group who are often not given the platform to express their views and practical knowledge in matters that pertain to them (Williams & Moore, 2011). Employing a case study research approach was therefore the ideal way of ensuring the social inclusion of persons with disabilities and their views within a human rights framework. Figure 3 depicts the specific processes that were followed in this case study research design.

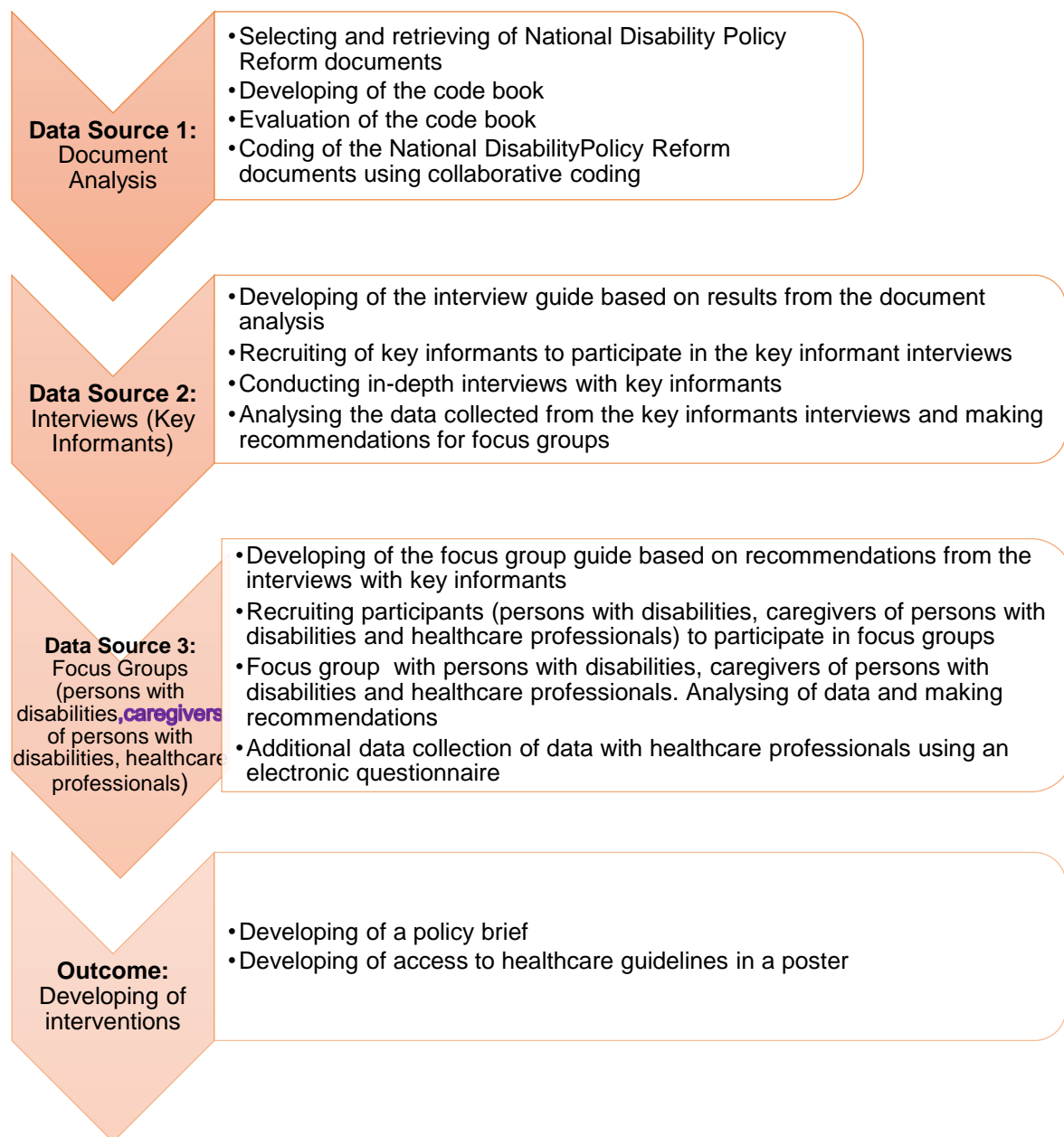


Figure 3: Schematic Representation of the Case Study Research Design

3.3 STUDY SETTING

The Kingdom of Eswatini (formerly known as Swaziland and officially re-named in 2018) is a landlocked country in Southern Africa. It is an absolute monarchy ruled by King Mswati III since 1986, with constitutional provisions and Swazi law and custom, afforded by Parliament (Tsabedze, Mutula & Jacobs, 2012). After gaining independence from the United Kingdom on 6 September 1968, it was granted United Nations membership on 24 September 1968. The parliament of Eswatini consists of

two chambers (the House of Senate and the House of Assembly) and is composed of members who are partly elected by the King and partly nominated by constituencies (Tinkhundla centres) (Langwenya, 2005). The executive functions of Parliament are bestowed upon the cabinet which is led by the Prime Minister. The King appoints the Prime Minister and all other cabinet ministers. There are currently 55 Tinkhundla centres in Eswatini (Mabundza & Dlamini, 2018). Each Inkhundla centre produces a winner who goes to the House of Assembly, with the King appointing an additional ten members, as well as the attorney general as the ex officio member (Mzizi, 2005). The House of Senate on the other hand consists of 30 members. Ten of these members are elected while the King appoints the remaining 20 members (Mzizi, 2005).

The Swati population faces major health issues, such as HIV/AIDS, as well as TB. At 58 years of age, the population of Eswatini had the 12th lowest life expectancy in the world (Magagula 2017). In-patient mortality statistics from 2013 indicated that HIV/AIDS and TB jointly accounted for about one-third of all deaths in Eswatini (World Health Organisation, 2016). An estimated 33% of health cases were as a result of non-communicable diseases (Ministry of Health, 2014). It is estimated that 63% of Emaswati live below the poverty line due to of the high burden of communicable and non-communicable diseases (United Nations Children Emergency Fund, 2015).

Eswatini's health system is based on a primary healthcare approach, organised at four levels; (i) Community-based care, where rural health motivators, faith-based healthcare providers, volunteers and traditional practitioners provide care, support and treatment; (ii) Primary healthcare facilities, including health centres, public health units, rural clinics and a network of outreach sites; (iii) Regional hospitals, of which there are five spread across the country and (iv) National (referral) hospitals, of which there are three in the country (Magagula, 2017).

Eswatini is 17 364 km² and shares a border with the Republic of South Africa on the north, west and south and the Republic of Mozambique on the east (Amnesty International, 2018). The latest available data shows that as of 2017, the population of

Eswatini was approximately 1.1 million (Central Statistics Office, 2017), with 75.8% of the population residing in rural areas (Central Statistics Office, 2010). Persons with disabilities constitute approximately 16.8% of the total population of Eswatini (Central Statistics Office of Swaziland, 2010) with 86% of persons with disabilities residing in rural areas (Eide & Jele, 2011).

The Kingdom of Eswatini consists of four geographical regions namely Hhohho, Manzini, Lubombo and Shiselweni which are further divided into 55 local authorities (Tinkhundla Centres) and 365 chiefdoms (Magagula, 2017). The Hhohho region, where Mbabane is situated and which is the focus of the study, is the Highveld of Eswatini and has a population of about 331 000 (Ministry of Health, 2010). This region consists of one referral hospital, one regional hospital and 62 clinics (Ministry of Health, 2010). Figure 4 shows a map of Eswatini, specifically highlighting the setting of the study.

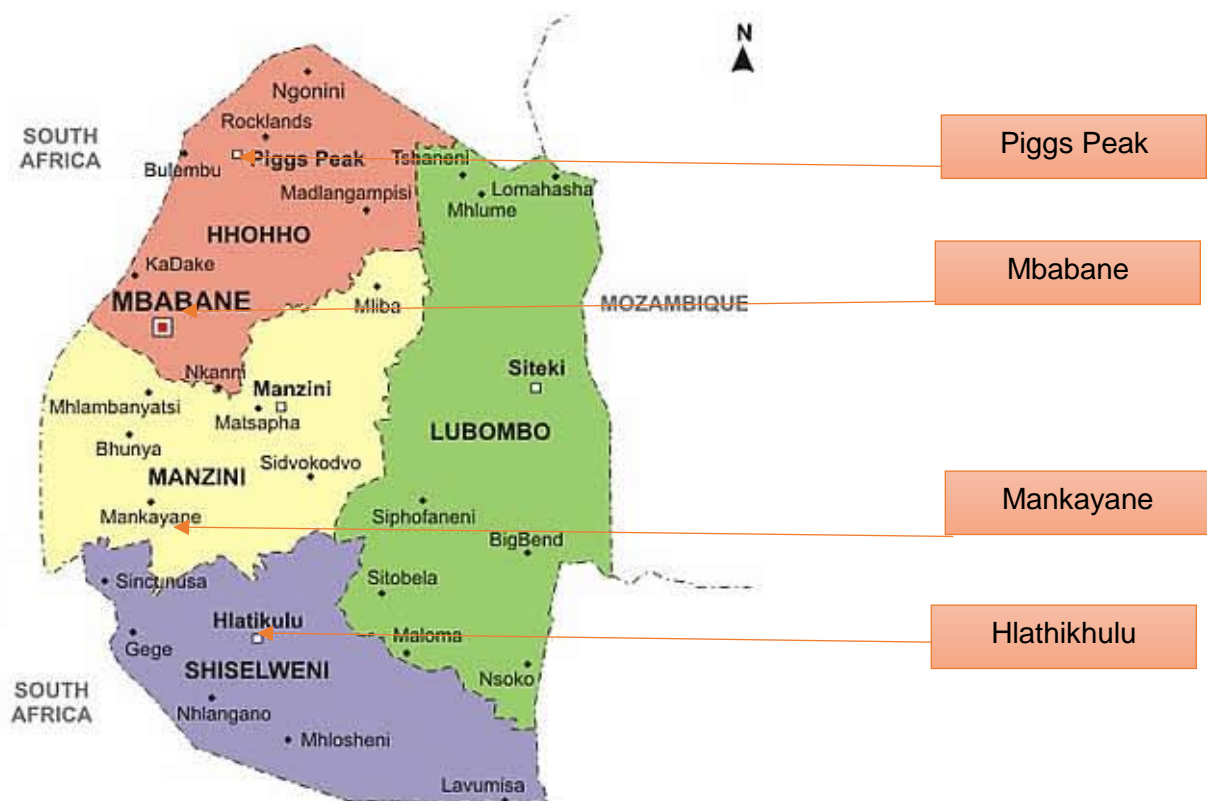


Figure 4: A Map of the Kingdom of Eswatini showing Mbabane's specific location

Mbabane is the administrative capital of Eswatini. It measures 65.08km² and has an estimated population of 19 490 households and about 70 000 people (City of Mbabane, 2019). Mbabane is densely populated, with most of the government ministries, offices of non-governmental organisations, United Nations affiliated organisations and the governing body of all disability organisations located there. It is also where the Mbabane government hospital, the main referral and biggest hospital in the country is situated (City of Mbabane, 2019). Mbabane government hospital serves as a primary healthcare facility for the population of Mbabane while also being a referral hospital from surrounding clinics, rural health centres and district hospitals (City of Mbabane, 2019). Persons with disabilities, who reside in rural areas, also come to Mbabane for rehabilitation and other specialised services (City of Mbabane, 2019). This hospital is better resourced than others in terms of the variety of healthcare professionals and therefore provides a source of diversity of participants for this study.

The main setting where in-depth interviews with key informants and focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals took place in Mbabane in the Hhohho geographical region in the Kingdom of Eswatini. Mbabane was selected because the majority of participants had easy access to the city. For example, all the selected key informants' offices are located in the city, making access to participants easier during the day as most of them preferred to be seen for the interviews during their working hours. The organisation of persons with disabilities which was used to recruit persons with disabilities and caregivers of persons with disabilities participants is located in Mbabane and most of the members who had agreed to be part of the focus groups resided within the vicinity of Mbabane. They therefore preferred the capital city as the common meeting place for their focus group as it would be easier to access public transport from the city centre. The healthcare professional participants in the focus group were recruited from the Mbabane government hospital, the same venue where the other two focus groups took place.

Apart from the focus group with healthcare professionals, there was a need for the researcher to obtain additional data from this participant group. Therefore, an

electronic questionnaire with the same questions asked in the focus groups was then emailed to other potential healthcare professional participants who could not attend the focus group due to time and work constraints. For this reason, healthcare professionals who worked at healthcare facilities in Piggs Peak, Mankayane and Hlathikhulu were also included as part of the study to ensure that more healthcare professionals participate. By including these additional healthcare professional participants, a more diverse group of healthcare professionals participated, e.g. nurses, doctors and therapists. These geographical areas are also highlighted on the map in Figure 4.

3.4 RESEARCH FIELDWORKER

Since the study was mainly conducted in Hhohho Region in Eswatini and the researcher (who is of Swati origin) resided in Johannesburg, Gauteng (South Africa), the assistance of an Eswatini-based research fieldworker was deemed crucial. The research fieldworker was recruited to assist with data collection, translation and transcription. The role of the research fieldworker was to organise participants for the study, organise venues and logistics pertaining to data collection and transcribe the data collected in SiSwati to English, which was checked for correctness by the researcher. The research fieldworker also had to translate the SiSwati transcripts into English.

She was selected specifically because she had access to the community of Eswatini (Green & Baxen, 2002). She is of Swati ethnicity and resides full time in Mbabane, Eswatini, and is therefore inclined to the language (SiSwati), rich cultural heritage and traditions of emaSwati which are aspects that are imperative in researchers gaining successful entry into the field and vital in building trust amongst participants of a study (Shenton & Hayter, 2004). Competency in the language of the participants was imperative if substantial conversations were to be held between the research fieldworker and the participants (Green & Baxen, 2002). Both SiSwati and English proficiency were also important for this qualitative research study, in which language

is a crucial tool across all the stages of the research from data collection and analysis to the interpretation and discussion thereof (van Nes, Abma, Jonsson & Deeg, 2010).

The research fieldworker's deep-rooted understanding of the culture, the people and the areas of Eswatini assisted the researcher in understanding the day-to-day activities in that community, especially the power and dynamics of participants. This was particularly important in accessing key informants (participants for Data Source 2) who would have otherwise declined to be part of the study if they had not been recruited by the research fieldworker. Certain protocols of engagements specifically related to permission seeking and directions to the different offices where participants were located were followed appropriately because the research fieldworker was familiar with the culture and hierarchy structures of the community. A researcher's success in gaining access to the field is important in qualitative research as it has a significant and direct effect on the nature and quality of data (Shenton & Hayter, 2004).

The research fieldworker also holds an Honours degree in Biochemistry, is a recipient of an outstanding international research award and is currently a second year Master of Science (MSc) student, confirming her research experience. This background, qualifications and research experience were necessary and critical as it ensured that she was ideally disposed to understanding the research process (Green & Baxen, 2002). Her skills and experience in research predisposed her to the following qualities that are significant for a successful research project: Competency in computer skills; appropriate writing skills for ease of translating data into English and capturing it in writing; coping with the organisational demands of data collection, capturing, transcribing and translating; and making appropriate field notes.

Even though the research fieldworker has significant knowledge and skills in research processes, she was, however, not skilled in working in the field of disability and therefore did not have specific knowledge of disability-related constructs. The researcher therefore trained the research fieldworker for a total of eight hours on the following: Aim and sub-aims of the study; access to healthcare as it pertains to persons

with disabilities, the research design, and her role in data collection. This was done so that she did not only have insight into the topic of disability, but also had a deeper understanding on the purposes and processes of the research as well as the specific qualitative research methodology which was different to the quantitative measures with which she was more familiar (Green & Baxen, 2002).

3.5 INDEPENDENT OBSERVER

An independent observer was recruited to assist during the process of obtaining informed consent with participants who are blind. The independent observer ensured that the process of informed consent between the researcher and the participants who are blind was explained well and was understood by the participants and also that the participants were not coerced into signing and giving consent.

The independent observer was selected to act as a neutral witness of the process of consenting to be part of the study by blind participants since the consent forms for this study were not available in braille (Monica, 2012). This independent observer was a government employee who did not meet the inclusion criteria for the study and was thus not involved at any point as a participant in the study and happened to be available at the date and time when the in-depth interviews for Data Source 2 were to be conducted (Monica, 2012). The observer was also not known to and not related to the participants in any way, as recommended by Monica (2012). The independent observer ensured that the information sheet explaining the purpose of the study, the role of the participants in the study, the participant's right to withdraw at any time without explanation or any negative consequences and that the study did not pose any potential risks to the participants. The maintenance of confidentiality was also thoroughly addressed and explained to the participants who are blind. The observer also ensured that these participants were not coerced into participating in the study and that they were indeed consenting to participating in the study and to being audio recorded.

3.7 ETHICAL CONSIDERATIONS

Before the study commenced, ethics approval was obtained from the Faculty of Humanities Research Ethics Committee, University of Pretoria, (Project number: GW20160721HS, Appendix A). Permission to conduct the study was sought from the Research Ethics Committee of the Ministry of Health in Eswatini (Appendix B), from the Organisation of Persons with Disabilities in Eswatini (Appendix C) and from the hospital where the study was conducted (Appendix D). Informed consent to participate in the study and to be audio recorded was obtained from all participants included in Data Sources 2 and 3 in the form of written consent and verbal consent in the case of blind participants.

The researcher upheld the principles of the Helsinki Declaration by paying particular attention to ensuring that the rights of participants who are vulnerable, in particular persons with disabilities, were not violated (World Health Organisation, 2001). Therefore, ethical guidelines specific for research involving persons with disabilities, as proposed by Good (2005), were considered throughout the study. First and foremost, the study contributes towards the advancement of social justice and human rights for persons with disabilities in Eswatini (Good, 2005). To ensure that the voice of the persons with disabilities was heard, the inclusion and participation of persons with disabilities across Data Sources 2 and 3 was facilitated (Shakespeare & Kleine, 2013).

Throughout the study, the following ethical principles were upheld: the respect for human rights, dignity, equality and diversity of all involved in the research process (Good, 2005). Participants were informed of their rights to voluntarily participate in the study with the option to withdraw at any point if they felt uncomfortable or ill-disposed to continue in any way.

Participants of in-depth interviews were assured that confidentiality would be guaranteed and that no identifiable information would be used during the reporting of

the results and discussion of the research findings. Even though confidentiality could not be guaranteed to participants in the focus groups due to the nature of focus groups, the importance of respecting individual opinions and the value of confidentiality was explained to focus groups participants. Participants committed to respecting the confidentiality of discussions, by not at any point repeating what was discussed outside of the focus group discussions.

The dignity of the persons with disabilities was considered in the selection of the venues for the focus groups with persons with disabilities and caregivers of persons with disabilities. Venues were selected based on their physical accessibility and the additional support that it could offer for persons with disabilities. Comfort breaks were offered to participants during interviews and focus groups. Transportation and lunch stipends were provided to participants to ensure that they did not incur extra financial costs as a result of their participation (Good, 2005).

To ensure that participants were not disadvantaged as a result of language and literacy level barriers, all information pertaining to the study was made available in both SiSwati and English. Information was not only presented in written formats but was also presented verbally in the first language of all participants. The verbal responses were recorded in the presence of an independent observer.

3.8 TRUSTWORTHINESS CONSIDERATIONS

Table 2 describes the different strategies that were used to increase the trustworthiness of this research study, along with a description of the specific techniques that were employed to elicit these strategies.

Table 2: Strategies Used to Increase Trustworthiness

Strategy and reference to qualitative terminology	Technique	How the technique was addressed in the current study
Credibility (in preference to internal validity) is defined as <i>“How congruent are the findings with reality?”</i> (Merriam, 1998).	Triangulation of the data.	<p>The use of three different data sources were used, namely, document analysis, in-depth interviews with a diversity of key informants from different organisations, focus groups with three different groups (persons with disabilities, caregivers of persons with disabilities and healthcare professionals) with additional completion of electronic questionnaires by more healthcare professionals.</p> <p>Collaborative coding of all data was done.</p> <p>The same theoretical and conceptual model (Integrated Disability Policy Analysis Framework) was used to analyse all data.</p>
	Member checks.	<p>Member checks were conducted after each interview or focus group to confirm the accuracy of the data and strengthen the study's credibility (Lincoln & Guba, 1985). This process allowed participants to also expand on or add more data.</p>
	Peer scrutiny.	<p>The project was subjected to peer scrutiny through discussions with ten PhD peers and supervisors during online and onsite forums thus giving the researcher a fresh perspective from which to view the project. This also ensured that the researcher was held accountable for upholding ethical data collection, analysis and reporting principles.</p> <p>Moreover, a part of this thesis was presented at a conference where colleagues in the field also gave input as part of peer scrutiny. Refer to Appendix E for an example of the poster presentation.</p>
	Prolonged engagement in the field.	<p>The researcher who grew up in Eswatini and the research fieldworker (who currently resides in Eswatini) engaged constantly with disability organisations and personnel prior to and during the study. This ensured familiarity with the culture, customs and traditions of the organisation and the context.</p>

Strategy and reference to qualitative terminology	Technique	How the technique was addressed in the current study
Transferability (in preference to external validity or generalisability) is concerned with the extent to which the findings of one study can be applied to other situations (Merriam, 1998).	Researcher's previous research experience.	Prolonged engagement also assisted the researcher to establish rapport with contact persons where recruitment of participants was granted. The researcher's previous experience in qualitative research methodology at Master level and as a supervisor of qualitative research projects at both Bachelor's and Master's levels, validated her credibility to conduct this qualitative study (Patton, 1990).
	Debriefing sessions.	Debriefing sessions between the researcher and fieldworker and between the researcher and her supervisors were held after each interview as a way of providing a sounding board for the researcher to test her developing ideas and interpretations (Shenton, 2004).
	Providing in-depth descriptions.	Dependability in the study was addressed through providing in-depth descriptions of the methodology to allow for the study to be repeated (Shenton, 2004). Thus, a detailed methodological description was provided through the researcher's documentation of the audit trail of the study and keeping a detailed reflection journal.
	Representative-ness of participants.	Specific inclusion and exclusion criteria for participants were stipulated beforehand. Subsequently a biographical questionnaire provided the participants' information to ensure representativeness.
	Piloting of the interview script.	The measuring instrument for the in-depth interview (Appendix G) was piloted to determine if the answers yielded the kind of data that it was meant to provide.
Confirmability (in preference to objectivity) refers to attempts to ensure as far as possible that the study's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher (Patton, 1990).	Audit trail.	The researcher kept an audit trail of the study. In this audit trail, records of the research path from the start of the research project to data collection and development and reporting of the key findings were kept (Lincoln & Guba, 1990).
	Collaborative coding.	Transcripts were analysed by two coders using collaborative coding (Saldana, 2009). Discussions between coders were held until consensus was reached before codes and themes were decided upon.

3.9 THE INTEGRATED DISABILITY POLICY ANALYSIS FRAMEWORK

A new framework, the Integrated Disability Policy Analysis Framework was employed in this study. Since the Walt and Gilson (1994) Health Policy Analysis Framework was not sufficient to address the aims of the study, it was further enhanced to include the Peters et al. (2008) Access to Healthcare Framework. The Integrated Disability Policy Analysis Framework is presented in Figure 5.

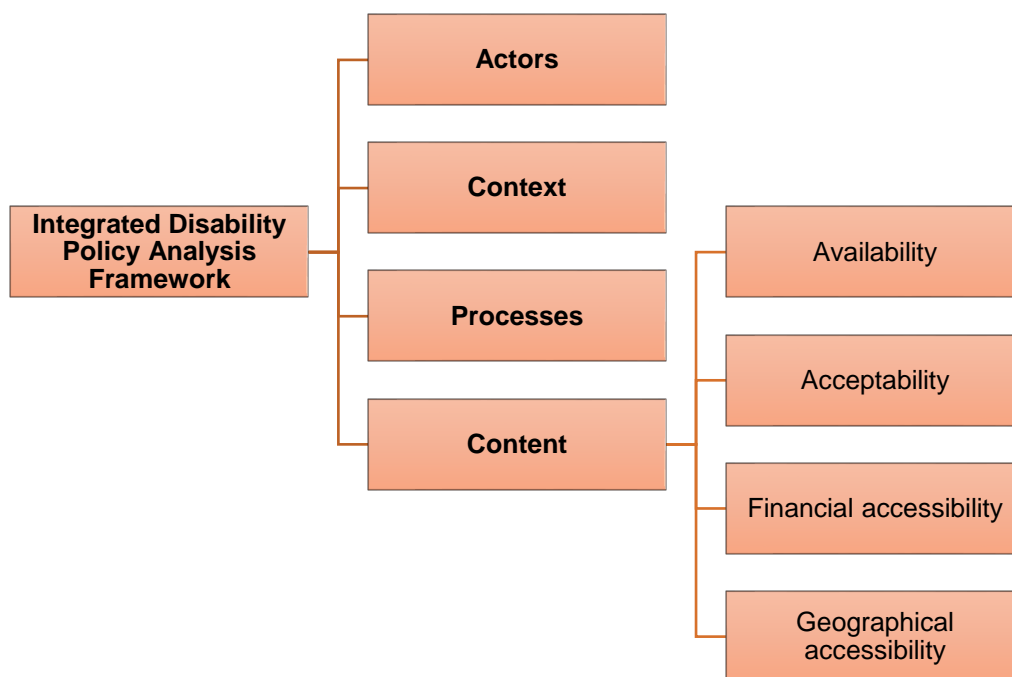


Figure 5: The Integrated Disability Policy Analysis Framework combining the frameworks of Walt and Gilson Policy (1994) and Peters et al. (2008).

The integrated disability policy analysis framework encompasses all four aspects that influence policy development and implementation as proposed by Walt and Gilson (1994) which are: (i) the actors who are involved in all of these processes (Buse et al. 2005); (ii) the context of the policy; (iii) the content of the policy; and (iv) the processes of the policy. It further delineates the content of the policy to include the pillars of access to healthcare as proposed by Peters et al.'s (2008) which are i) availability; ii) acceptability; iii) geographical accessibility; and iv) financial accessibility. It is important to note that, in as much as the Walt and Gilson (1994) Health Policy Analysis Framework is comprehensive in analysing policies, it would not have been sufficient,

as a stand-alone for the purpose of the study at hand, hence the inclusion of the Peters et al. (2008) framework. The integrated disability policy analysis framework was used in the analysis of data across all the three data sources. To grasp a comprehensive understanding of the new Integrated Disability Policy Analysis Framework, a detailed discussion of the two frameworks that were combined, is necessary.

3.9.1 The Walt and Gilson Health Policy Analysis Framework

The Walt and Gilson (1994) Health Policy Analysis Framework argues that historically, the analysis of policies focused mainly on the contents of the policies and neglected other dimensions such as actors, context and processes, yet effective or ineffective policy choice and implementation is influenced by all of these factors combined. This policy analysis framework was also established on a political economic perspective (Buse et al. 2008; Walt & Gilson, 1994). Even though the Walt and Gilson (1994) Health Policy Analysis Framework was developed to specifically address health policy reforms and the fact that it has been used extensively in influencing health policy research in diverse countries, its relevance extends beyond the health sector (Buse, 2005; Walt et al. 2008). This framework further considers how four policy aspects interact to inform policy making (Walt et al. 2008).

Actors: Refer to the individuals who are said to be at the centre of the policy reform agenda (Buse et al. 2005). These are both state and non-state individuals and organisations that may influence the political agenda either locally, nationally, regionally and internationally, based on their power and authority within the study setting (Buse et al. 2005).

Context: Refers to systemic political, economic and social factors, which may have an effect on health policy, both nationally and internationally (Buse et al. 2005). The context is further categorised into (i) situational factors, which are more or less transient, impermanent, or idiosyncratic conditions which can have an impact on policy (Buse et al. 2005); (ii) structural factors, which are explained as unchanging elements

of a society such as the political system, the type of economy and employment base, demographic features and national wealth (Buse et al. 2005); (iii) cultural factors and (iii) international and exogenous factors.

Content: Refers to the substance of a specific policy which details its constituent parts (Buse et al. 2005).

Processes: Refers to the manner in which policies were initiated, developed, negotiated, communicated, implemented and evaluated (Buse et al. 2005).

The three data sources in the study, namely document analysis, key informants' in-depth interviews and focus groups with persons with disabilities; caregivers of persons with disabilities and healthcare professionals were analysed according to the four policy aspects described in detail in the previous section. The content component was further analysed using the Peters et al. (2008) Access to Healthcare Framework.

3.9.2 The Peters et al. (2008) Access to Healthcare in Developing Countries Framework

The Peters et al. (2008) Access to Healthcare Framework is based on established explanations of access to healthcare services and also includes a practical application in LMIC's, such as Eswatini. The framework places the quality of healthcare at the centre of access to healthcare and also considers the determinants of healthcare access at the policy, household and individual levels. In this framework, access to healthcare is explained according to four main dimensions, namely;

- i. **Availability:** Refers to having the right type of care available to those who need it, such as hours of operation and waiting times that meet the demands of those who would use care, as well as having the appropriate type of service providers and materials to address the needs of those who seek care (Peters et al. 2008).

- ii. **Acceptability:** Refers to the match between how responsive healthcare service providers are to the social and cultural expectations of individual users and communities (Peters et al. 2008).

- iii. **Financial accessibility:** Refers to the relationship between the price of services (in part affected by their costs) and the willingness and ability of users to pay for those services, as well as be protected from the economic consequences of health costs (Peters et al. 2008).

- iv. **Geographic accessibility:** Refers to the physical distance or travel time from service delivery point to the user (Peters et al. 2008), i.e. from their home to the clinic or hospital.

These two frameworks by Walt and Gilson, (1994) and Peters et al. (2008) were enhanced to form the new Integrated Disability Policy Analysis Framework, which was used to analyse data across all the data sources. The Integrated Disability Policy Analysis Framework was used to ensure that the main aims of the study were achieved.

3.10 CONCLUSION

Chapter 3 presented an elaborate description of the overall research methodology that was used in the study and a detailed motivation for the appropriateness of the method to achieve the main aim of the study. The chapter introduced the next three chapters which will each detail the methodologies, results and discussions of results from the respective data sources, while at the same time, showing how each data source relates to the other.

In particular, Chapter 3 outlined the aims of the study. The chapter also described the constructivist research paradigm and a rationale for the selection of the research

paradigm. This was followed by the research design. Mbabane as the main study setting for the study was described, along with an explanation for the inclusion of Mankayane, Hlathikhulu and Piggs Peak as additional study settings. The research fieldworker and the independent observer were described next, along with an explanation of their contribution. The ethics principles that were considered in the thesis, in particular, ethics related to research with persons with disabilities was discussed next. Strategies to ensure trustworthiness were then addressed. Finally, the two frameworks that were combined to develop the new Integrated Disability Policy Analysis Framework were delineated.

CHAPTER 4: DATA SOURCE 1: DOCUMENT ANALYSIS

4.1 INTRODUCTION

This chapter describes the procedures followed during Data Source 1, the document analysis section of this study. It commences with the aims of this data source which is then followed by the processes and justification for selection of the documents analysed in this study. The development of the code book that was used for the document analysis is subsequently described. Next, the document analysis process is explained, and this is followed by an outline of the results obtained from the document analysis and the discussion of these results. The chapter ends with implications of the current data source for the next data source and a conclusion.

4.2 AN OVERVIEW OF THE DOCUMENT ANALYSIS PROCEDURES

A procedure similar to that used to analyse the inclusive education policies in South African research universities (Ramaahlo, Tönsing & Bornman, 2018) was followed during this document analysis. The document selection, theoretical underpinning and construction of the code book that informed data analysis and the data analysis process as proposed by Ramaahlo et al. (2018) is included.

4.3 AIM OF DATA SOURCE 1

The aim of Data Source 1 was to describe the actors, context, content and process of the development and implementation of the National Disability Policy Reform Documents (namely the National Disability Policy of Swaziland, the National Disability Bill of Rights and the National Disability Plan of Action).

4.4 DOCUMENT SELECTION

As explained earlier, Eswatini ratified the CRPD (United Nations, 2006) and its optional protocol in 2012 (Deputy Prime Minister's Office, 2013). As part of the mandate of being a signatory to the CRPD, Eswatini subsequently developed the National Disability Policy of Swaziland in 2013, the first ever policy document to comprehensively address the human rights of persons with disabilities in Eswatini, including access to healthcare. Eswatini then established the National Disability Bill of Rights in 2014 and the National Disability Plan of Action 2015. The year 2018 marked the fifth-year anniversary since the inception of the National Disability Policy of Swaziland. Chichaya, Joubert and McColl (2018) propose that policy documents should be reviewed every five years, hence the current study undertook to understand the multifariousness of drafting, implementing and reviewing the National Disability Policy Reform documents to improve access to healthcare for persons with disabilities in Eswatini.

The president of the National Organisation of Persons with Disability in Eswatini was first contacted telephonically and then followed up with an email to establish the different kinds of National Disability Policy Reform documents which addressed access to healthcare in Eswatini. The National Organisation of Persons with Disability is the umbrella body for all disability organisations in Eswatini and liaises with the Deputy Prime Minister's Office and the National Disability Unit to address disability related matters. The National Disability Unit reports to the Deputy Minister's Office, which in turn, reports to the Prime Minister's office. Both the Deputy Prime Minister's office and the Prime Minister's office form part of the executive arm of the parliament which consists of the cabinet. They are responsible for the development, administration and execution of policies in Eswatini (The Government of the Kingdom of Eswatini, 2019).

At the time of data collection (February 2018), the only comprehensive policy document that addressed disability and disability rights in Eswatini was the National Disability Policy of Swaziland. The president of the National Organisation of Persons

with Disability emailed the National Disability Policy of Swaziland to the researcher, further advising her to contact the National Disability Unit in the Deputy Prime Minister's Office, which acts as the main custodian of disability in Eswatini and where all National Disability Policy Reform documents are kept. The National Disability Programme Manager at the National Disability Unit of Eswatini was contacted telephonically and a meeting was arranged. At the face-to-face meeting, the reasons for requesting the said policy documents were explained. It was confirmed that the National Disability Policy of Swaziland existed and that there were two other documents supporting the policy, namely the National Disability Bill of Rights and the National Disability Plan of Action. All the requested documents were emailed to the researcher by a clerk of the National Disability Unit.

Upon receipt of the National Disability Policy Reform documents, the researcher perused all three documents before commencing with a content analysis of these documents. After the perusal of the three documents, it was decided to include both the National Disability Policy of Swaziland and the National Disability Plan of Action in the document analysis as these documents provided a comprehensive account on the provisions of access to healthcare for persons with disabilities. The National Disability Bill of Rights on the other hand was a condensed version of the National Disability Policy of Swaziland and the National Disability Plan of Action, with no new information included on the provisions for accessibility to healthcare than those already stipulated in the other two policy reforms. It outlined the background and purpose of both the National Disability Policy of Swaziland and the National Disability Plan of Action and also emphasised the commitment of the National Government of Eswatini towards improving the livelihood of persons with disabilities. It further proposes the establishment of the national statutory body and the national disability advisory council and further stipulates the roles of these two bodies. Therefore, the National Disability Bill of Rights was not included in the analysis.

4.5 DEVELOPING OF THE CODE BOOK

With the input from two independent coders, the researcher developed a code book, based on the eight concepts of the Integrated Disability Policy Analysis Framework. Coder 1 is a speech language therapist and audiologist, who holds a Masters degree in Public Health and is currently a PhD candidate in Public Health. The coder has a special interest in health policies and has nine years' experience working with persons with disabilities and caregivers of persons with disabilities in a public healthcare institution in South Africa. Coder 2 is a clinical psychologist who is also a PhD candidate with a specific focus on disability policy analysis in institutions of higher learning and has published in the area of disability. Coder 2 has also had experience in developing a policy analysis code book and is currently a director of a disability unit at one of the institutions of higher learning in South Africa. The two coders scrutinised and approved the operational definitions of the eight concepts of the Integrated Disability Policy Analysis Framework which the researcher had developed. The two coders and the researcher also perused the National Disability Policy Reform documents and agreed on access to healthcare related policy excerpts before they were imported into the code book (Nili, Tate & Barros, 2017).

Figure 5 provides a visual presentation of the new Integrated Disability Policy Analysis Framework based on a combination of the Walt and Gilson (1994) and Peters et al. (2008) frameworks. The themes of the coding system were operationally defined to assist the researcher and the two independent coders with working themes to analyse access to healthcare for persons with disabilities in the National Disability Policy Reform documents (Ramaahlo et al. 2018). The eight concepts of the Integrated Disability Policy Analysis Framework, which constituted the themes of the coding system, were operationally defined for access to healthcare in Table 3. First defining operational concepts is in line with the procedure suggested by Ramaahlo et al. (2018).

Table 3: Operational Definitions of Concepts used In the Integrated Disability Policy Analysis Framework

Concepts	Definition from Literature	Operational definition used in the current study
Actors (Walt & Gilson, 1994).	Refers to the stakeholders or interest groups and their power, interests, values and roles in relation to developing and implementing the reforms of interest (Walt & Gilson, 1994).	Refers to individuals and representatives of governmental and non-governmental organisations, national government ministries, disability interest groups, policy advisors who were involved at different stages during the development and implementation of the National Disability Policy Reform documents. It also refers to the power dynamics and the influence that these actors had on the policy process (Buse et al. 2005).
Context (Walt & Gilson, 1994).	Refers to situational, structural, cultural and exogenous factors. The latter include the events and values outside of any one country or system which influence policy formation (Walt & Gilson, 1994).	Refers to the background of the National Policy Reform documents. It specifically refers to the set of political, social, economic and cultural factors that have influenced the development and implementation of the policy reform documents. (Buse et al. 2005).
Content (Walt & Gilson, 1994).	Refers to the specific nature and design of reforms; the interaction between the specific policies of focus and between these policies and parallel institutional changes and implementation guidelines (Walt & Gilson, 1994).	Refers to the subject addressed in the different sections pertaining to access to healthcare (Buse et al. 2005). It is the promises that the National Disability Policy Reform documents make in relation to access to healthcare specifically in geographical accessibility, financial accessibility, availability and acceptability (Peters et al. 2008).
<ul style="list-style-type: none"> Availability (Peters et al. 2008). 	Refers to the match between the number and type of existing services and resources to the clients' specific needs (Penchasky & Thomas, 1981).	Refers to the existence of healthcare institutions with comprehensive services such as rehabilitation. Available healthcare professionals to attend to persons with disabilities and available healthcare supplies including assistive devices. The definition

also includes the availability of disability programmes within healthcare institutions and within communities where persons with disabilities reside. Also includes community outreaches of healthcare professionals to communities where persons with disabilities reside.

<ul style="list-style-type: none"> • Acceptability (Peters et al. 2008). 	<p>Pertains to the manner in which services and resources are organised to accept clients and their specific needs (Penchasky & Thomas, 1981).</p>	<p>Refers to the preparedness of the healthcare professionals to serve persons with disabilities. This includes knowledge and attitudes regarding disability designing healthcare services so that they are accepting and accommodating to persons with disabilities such as ramps, wheelchair friendly, help desks, health information in accessible formats, based on the principles of universal design (United Nations, 2006).</p>
<ul style="list-style-type: none"> • Geographical accessibility (Peters et al. 2008). 	<p>Refers to the relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance and cost (Penchasky & Thomas, 1981).</p>	<p>Refers to the location of healthcare services in close proximity to where persons with disabilities reside. Geographical and financial accessibility is relevant considering that in Eswatini, 86% of persons with disabilities reside in the rural areas (Eide & Jele, 2011).</p>
<ul style="list-style-type: none"> • Financial accessibility (Peters et al. 2008). 	<p>Refers to the financial costs associated with accessing health services (Peters et al. 2008).</p>	<p>Refers to costs related to accessing healthcare services and these include prices for consultation, costs related to the acquiring and maintaining of assistive devices (Souliotis, Hasardzhiev & Agapidaki, 2016).</p>
<ul style="list-style-type: none"> • Processes (Walt & Gilson, 1994). 	<p>Refers to the way in which policies are identified, formulated and implemented, their timing, the strategies used with each stage of the policy process, and the specific mechanisms or bodies established to take forward any of the steps (Walt & Gilson, 1994).</p>	<p>Refers to the procedures that were followed during the initiation, development, implementation and evaluation of the National Disability Policy Reform documents (Buse et al. 2005).</p>

4.6 DOCUMENT ANALYSIS

A framework analysis approach (Srivastava & Thomson, 2009) was employed as a second step of reviewing the National Disability Policy Reform documents. The framework analysis approach encompasses familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretations. In line with these recommendations, the National Disability Policy documents were systematically read line by line by the researcher and the two coders (referred to in section 4.5), according to the Integrated Disability Policy Analysis Framework. They aimed to identify the different policy segments within the documents that relate to access to healthcare (content, actors, context and processes) using collaborative coding. Specific provisions that are addressed in the specific policy reform documents are marked with a tick in Table 4.

Collaborative coding relies on intensive group discussion and simple group consensus as an agreement goal (Saldana, 2009). Collaborative coding is advantageous as multiple minds afford different ways of analysing and interpreting the data (Saldana, 2009). A total of 44 policy segments that qualify as points that address access to the healthcare (content, actors, context and processes) in the National Disability Policy Reform documents were identified and used as a basis for the code book (Ramaahlo, et al. 2018).

4.7 RESULTS FROM THE DOCUMENT ANALYSIS

Table 4 indicates the extent to which the National Disability Policy Reform documents have addressed the themes identified in the Integrated Disability Policy Analysis Framework for persons with disabilities in Eswatini. A tick in Table 4 denotes that a particular extract addresses that specific concept of access to healthcare in the Integrated Disability Policy Analysis Framework.

Table 4: Provisions of the National Disability Policy Reform Documents for Access to Healthcare for Persons with Disabilities

All segments were extracted from the National Disability Policy of Swaziland, (2013) and the National Disability Plan of Action, (2015)

Segments from the National Disability Policy Reform Documents	Integrated Disability Policy Analysis Framework				
	Actors	Context	Content	Processes	
			Availability	Acceptability	Geographical Accessibility Financial
1. Build and strengthen partnerships with relevant government, non-governmental, private sector agencies and organisations of persons with disabilities.	✓	✓		✓	✓
2. Ensure support services including provision of assistive devices and resettlement.			✓		
3. Harmonising and strengthening of partnerships between Disability Persons' Organisations, and relevant government, non-governmental organisations and private agencies to ensure inclusion of persons with disabilities in all services planned to benefit them.	✓	✓		✓	
4. Facilitate community awareness and community mobilisation on health promotion to prevent disability.		✓		✓	✓
5. Ensure provision of effective medical intervention for the prevention, early detection, diagnosis and treatment of disability and disabling conditions.			✓		
6. Provide rehabilitation and necessary referrals and counselling for individuals who have disability and their family members.			✓	✓	

7. Ensure human resource development to ensure adequate trained personnel at all levels of health service delivery and rehabilitation.	✓		
8. Ensure access to health information for all persons with disabilities.	✓		
9. Provide training of health workers in relevant communication skills such as braille and sign language.	✓		
10. Hospitals and healthcare facilities to be disability friendly/compliant.	✓	✓	
11. Hospitals and healthcare facilities to include free and affordable health care services.	✓		✓
12. Create an enabling environment to ensure availability and accessibility of family planning information for all including persons with disabilities.	✓	✓	
13. Secure resources for the provision of comprehensive family planning services.	✓		
14. Ensure accessible to information and communication technology.	✓		
15. Provide technical guidance and tools on adolescent sexual and reproductive health issues at all levels of service provisions.	✓	✓	
16. Provide comprehensive adolescent sexual and reproductive health issues information and services to persons with disabilities.	✓	✓	

17. Secure resources including competent and skilled human resources required for management of sexually transmitted infections, HIV and AIDS.		✓		
18. Improve monitoring and evaluation systems of sexually transmitted infections HIV and AIDS intervention.		✓		
19. Increase accessibility and availability of commodities and supplies for prevention.		✓	✓	
20. Management of supplies for prevention and management of sexually transmitted infections, HIV and AIDS at all levels of service provision.		✓		
21. Provide comprehensive information and management of sexually transmitted infections, HIV and AIDS.		✓		
22. Engage communities on sexually transmitted infections, HIV and AIDS prevention and treatment activities.	✓		✓	
23. Facilitate that those who are severely disabled and vulnerable get subsidies or even free treatment at public health facilities.				✓
24. Government will encourage local innovative, production, maintenance and distribution of assistive device services.		✓	✓	✓
25. Private sector to make available assistive devices at affordable means.	✓			✓
26. Government shall set standards on the distribution of assistive devices.		✓	✓	✓

27. Government shall ensure that assistive devices are prescribed and issued by qualified and trained personnel.	✓		
28. All buildings and related structures which are public will be periodically audited for their accessibility to persons with disabilities.		✓	✓
29. Communication needs of persons with disabilities will be met by making information services and public documents accessible.		✓	
30. Special programmes will be developed for education, employment and providing of other rehabilitation services to women, girls, boys with disabilities keeping in view their special needs.	✓	✓	
31. To promote inclusiveness and ensure that all institutions provide services to persons with disabilities in the same manner as they provide to the non-disabled except where necessary.	✓		✓
32. Advocacy for the establishment or refurbishment of public buildings such as schools, places of worship, banks, healthcare facilities, so that they become user friendly for persons with disabilities.	✓		✓
33. Ensure capacity building for personnel involved in all spheres catering for all age groups including para-social workers, traditional midwives, assistant nurses and other community based workers.		✓	✓
34. To ensure that all persons with disabilities have equal access and opportunities to education and health services at all levels.	✓	✓	✓
35. The policy is aimed at ensuring the full commitment by government towards improving the livelihoods of persons with disabilities.	✓		
36. It has been realised that a majority of persons with disabilities can lead a better quality of life if they have equal opportunities and effective access to rehabilitation measures yet they live in poverty and society tends to exclude, discriminate thus, ultimately disabling them.	✓	✓	✓

37. The disability movement has been advocating for the formulation of a National Disability Policy of Swaziland.	✓	✓					
38. The policy is then a fundamental tool for providing both stimulus and momentum to the process of social development that will change the situation of persons with disabilities.		✓	✓				
39. It was developed to promote, protect and ensure a full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities in the country.		✓	✓				
40. Until the year 2013, Swaziland did not have a comprehensive policy, strategy or legislation for addressing the rights and needs of persons with disabilities hence the National Disability Policy of Swaziland.		✓					
41. Swaziland ratifies this convention in September 24, 2012 thus emphasising the importance of the National Disability Policy of Swaziland. The basis of the policy therefore is on the UNCRPD and all its optional protocols.		✓					
42. The National Disability Policy of Swaziland is the outcome of the contribution from numerous stakeholders and individuals such as the Deputy Prime Ministers Office; the Government Sector Ministries; Save the Children; non-governmental organisations; organisations of persons with disabilities, community based organisations and private sector companies.	✓						
43. We extend gratitude to the United Nations Population Fund for financial assistance and the Ministry of Justice and Constitutional Affairs for availing the service of Mr Francis Wilson, a legislative drafting consultant from the commonwealth secretariat.	✓						
44. This has been essentially participatory with the Deputy Prime Minister's Office seeking collaboration from other line Government Ministries non-governmental organisations, the private sector (culminating in a consultative workshop at the Happy Valley Resort at Ezulwini from the 24 th -28 th September 2012).	✓						✓
Totals number of times addressed	9	9	26	19	4	3	2

4.8 DISCUSSION

4.8.1 Actors

The participation and inputs from various stakeholders and individuals resulted in the development of the National Disability Policy Reform documents. These key stakeholders had a vested interest in disability and disability issues and were involved at different levels for different reasons in the development of these documents (Deputy Prime Minister's Office, 2013). This collaborative effort included members of The Deputy Prime Minister's Office, the different Government Sector Ministries with special mention of the Ministry of Justice which was instrumental in facilitating the involvement of the legislative drafting), a consultant from the Commonwealth Secretariat; non-governmental organisations such as Save the Children, Organisations of Persons with Disabilities, community based organisations and private sector organisations. From critically appraising the combination of actors stipulated in the National Disability Policy Reform documents, it appears that there was a balanced representation from sectors which was important for the quality of the content of the policy. The representation from different actors holding different power dynamics and authority is important and necessary for successful initiation, formulation and implementation of the policies (Buse et. al., 2005). The document analysis in itself was not sufficient to provide an extensive and exhaustive list of the actors and their specific geographical locations. A detailed account of the nature of the role that actors played during the policy processes was not stated in the National Disability Policy Reform documents. It was therefore necessary to engage with key informants through in-depth interviews to establish information that could not be obtained from the document analysis. This aspect is described in more detail in Chapter 5, Data Source 2, from data collected from in-depth interviews with key informants.

4.8.2 Context

Information obtained from the document analysis indicated that the National Disability Policy Reform documents were specifically developed to confirm the full commitment by the National Government of Eswatini towards fulfilling the mandate of the CRPD

and improving the livelihoods of persons with disabilities and ensuring the promotion, protection and full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. Eswatini had established through the advocacy from Organisations of Persons with Disabilities that in the country, there was no formal legislature protecting persons with disabilities. Additionally, persons with disabilities were excluded from mainstream activities and discriminated against, ultimately disabling them. Organisations of Persons with Disabilities rallied for the formulation of National Policy Reform documents for addressing the rights and needs of persons with disabilities. Subsequently, Eswatini ratified the CRPD on 24 September 2012, which resulted in the development of the National Disability Policy of Swaziland and National Disability Plan of Action in 2013 and 2014 respectively. The CRPD and all its optional protocols formed the basis of the policy reforms. While the current study solely focused on the access to healthcare aspect of the National Disability Policy Reform documents, these documents were comprehensive in taking into consideration all of the articles of the CRPD during the drafting stage. More in-depth details on the context of the National Disability Policy Reform documents were obtained from Data Source 2 during the interviews with key informants.

4.8.3 Content

Findings from the policy review indicate that the content of the National Disability Policy Reform documents, with specific reference to access to healthcare, has provided in-depth consideration to availability. These documents stipulate the different services that persons with disabilities can expect to be provided with across healthcare facilities. The National Policy Reform documents have promised effective healthcare, sexual health, rehabilitation, family planning and counselling services to all persons with disabilities and their families from adequately trained professionals at all levels of healthcare. Furthermore, the National Disability Policy Reform documents have undertaken to provide support services in the provision of assistive devices to persons with disabilities (e.g. including not only the distribution of these devices, but also the maintenance thereof). Especially highlighted in these documents are the provisions for specific programmes for persons with disabilities, such as sexual health and

HIV/AIDS programmes; persons with disabilities had previously been excluded from several health and family planning initiatives because of stereotypes and misperceptions surrounding their sexuality (Eide & Jele, 2011).

While the promises provided by the National Disability Policy Reform documents on the availability of healthcare for persons with disabilities across healthcare facilities are commendable, the practical application of these are however, questionable, considering the distribution of healthcare facilities in Eswatini. According to the essential package for healthcare services in Eswatini (Ministry of Health, 2010), there are only three national referral hospitals, five regional hospitals and the rest of the healthcare facilities are either public health units, primary healthcare centres or clinics in rural communities. A comprehensive package of care is therefore only offered at national and regional hospitals that are situated in the cities (Ministry of Health, 2010). This implies that services such as administering diagnostic tests, diagnosis of conditions, managing of chronic conditions and provision and maintenance of assistive devices, to name only a few, are only offered at limited facilities across Eswatini. Therefore, regardless of the fact that the majority of the population of Eswatini live within an 8km radius from a healthcare facility, there is unfortunately no equitable access to these services throughout the country due to the skewed distribution of healthcare facilities and the level of care offered by each healthcare facility. Persons with disabilities therefore run the risk of not having access to these services, despite the fact that they are theoretically provided for in the policy reform documents, as part of their health-related human rights.

Moreover, in the year 2012, the ratio of doctors to patients was 10 per 100000, that of nurses to patients was 56 nurses per 100000 and that of midwives was 64 midwives per 100000 in healthcare facilities. This translates to an impossibly high case load (Ministry of Health, 2012). To note is that the statistics of rehabilitation healthcare professionals such as therapists, was not even reflected.

The National Disability Policy Reform documents also give due regard to acceptability as it makes physical, information, communication and attitudinal provisions for the acceptance of persons with disabilities in healthcare facilities. This is encouraging as historically, persons with disabilities had been disadvantaged and deprived of their rights to health by the healthcare system due to various reasons, such as negative attitudes of healthcare professionals and others, financial constraints, health systems, physical and communication barriers (Hussey, McLachlan & Mji, 2017). This also portrays the commitment of the country towards ensuring the rights of persons with disabilities especially in accessing healthcare.

The National Disability Policy Reform documents have made promises to meet the communication needs of persons with disabilities through the training of healthcare professionals on a range of communication skills, such as braille and sign language, and by ensuring that health information and public documents are made accessible to individuals with limited language and literacy skills by employing easy language formats. Emphasis has been placed on translating health information specifically related to sexual health and HIV/AIDS into language formats that could be understood by persons who are deaf or blind, with specific mention of sign language and braille respectively. These formats are imperative since Eswatini has a high incidence of HIV/AIDS (Justman, Reed & Bicego, 2016) and a large percentage of persons with disabilities in Eswatini are blind (46%) or deaf (11%) (Deputy Prime Minister's Office, 2011). Persons with disabilities are also at a higher risk of HIV infection due to increased risk factors such as poverty, their increased vulnerability to sexual abuse (Schenk et. al. 2018), limited access to health promotion, education and healthcare itself (DeBeaudrap, et al. 2019).

While the translation of health information into braille or sign language is praiseworthy, there is a need for all National Disability Policy documents to address the importance of presenting health information at a level that can be understood by persons with disabilities who typically present with low literacy skills (Eide & Jele, 2011) and therefore may not be able to read at all or who may have limited reading ability (United Nations, 2006). There is a need to introduce strategies such as easy language formats

to make health information more understandable to persons with disabilities (Geukes, Bruland & Latteck, 2018). Easy language strategies may include pictorial support, using clear typography and using large prints (Cremin, 2016). Access to healthcare information has implications for privacy and confidentiality for persons with disabilities as well as access and adherence to treatment and consumption of medication, specifically for patients who are blind.

The importance of ensuring physical accessibility to buildings across all hospitals and healthcare facilities and of conducting audits to ensure that buildings and related structures are accessible has been indicated in the National Disability Policy Reform documents. The National Disability Plan of Action specifically mentions wheelchair friendly spaces and wide enough spaces in the waiting areas in outpatient departments to accommodate patients in wheelchairs. The National Disability Policy Reform documents could also have included signage in healthcare facilities in easily accessible formats that would enable persons with disabilities to navigate more independently in healthcare facility spaces.

The National Disability Policy Reform documents have also discouraged discrimination against persons with disabilities by emphasising inclusiveness, social justice and equal access to healthcare by persons with disabilities. While the above provisions are admirable, one of the core elements that negatively influences acceptability which has been highlighted in literature on disability, is the negative attitude of healthcare professionals towards persons with disabilities, especially towards women with disability (Devkota, 2017; Ganle et al. 2016). These negative attitudes are usually driven by ill-informed beliefs about disability and its causes and have not been acknowledged in the National Disability Policy of Swaziland and National Disability Plan of Action. The need for training of healthcare professionals by persons with disabilities on various disability aspects is thus emphasised (Iezzoni & Long-Bellil, 2012). Training alone is not sufficient. There needs to be mechanisms in place for monitoring levels of discrimination, reviewing laws and policies. Monitoring is important to ensure that legislation is supportive of persons with disabilities and assures access to healthcare reparation systems in the event that discrimination

involves reporting, monitoring and evaluation of the said discrimination. These mechanisms should be mentioned explicitly in National Disability Policy Reform documents to address the rights of access for persons with disabilities.

From the findings of the document analysis, it is also clear that the National Disability Policy Reform documents have not adequately considered the influence that geography has on access to healthcare for persons with disabilities (Vergunst, 2016). This is evident in the limited mentioning of geographical accessibility. Other than the mobilisation of communities to provide awareness and health promotion programmes to prevent disabilities, insignificant mention has been made in the National Disability Policy Reform documents on the distance and location of healthcare facilities from the homesteads of persons with disabilities. This is concerning especially considering the current distribution of healthcare facilities with comprehensive healthcare services only available in the three national referral hospitals and five regional hospitals, as previously discussed in the availability section. Additional expenses have to be paid for transport to hospital, a finding that has been stated in literature (Badu et al. 2016; Moodley & Ross, 2015). Persons with disabilities have to pay extra costs should they have a wheelchair (Vergunst, 2016). Critical evaluation of the existing package of healthcare indicates that persons with disabilities would have to cover long distances and incur significant travelling expenses to these healthcare facilities to access the comprehensive services that they need. The challenges of having healthcare facilities far away from homesteads of persons with disabilities has negative implications for the health outcomes of persons with disabilities; a challenge that has been documented extensively in literature (Sherry, 2014; Vergunst et al. 2017).

The National Disability Policy Reform documents did not adequately address financial accessibility. These documents present with ambiguous statements such as *“that financial accessibility in the form of free and affordable healthcare services will be afforded to persons with disabilities at public health facilities”* (Deputy Prime Minister’s Office, 2013, p. 40). The policy reforms further highlight that vulnerable persons with severe disabilities will receive subsidies and free treatment at public healthcare facilities. Contradictory to free healthcare services and assistive devices promised to

persons with disabilities in the public healthcare facilities, healthcare services and assistive devices should be made available at “affordable means” in private healthcare facilities. This could imply that there are inconsistencies and uncertainties with regards to free healthcare options for persons with disabilities. This is alarming, considering the fact that persons with disabilities are overrepresented amongst the poor in Eswatini (Eide & Jele, 2011). Their lack of education and literacy translates to slim prospects to secure employment. Additionally, the fact that Eswatini still has no dedicated subsidies for persons with disabilities (such as social support grants) to help them meet their basic day-to-day needs adds to the concern that persons with disabilities cannot afford to pay for their healthcare services. Policy makers in Eswatini therefore need to reconsider their stance in ensuring that healthcare is provided free of charge to persons with disabilities as in their current position, financially, persons with disabilities would be unable to afford to pay for healthcare. This could influence persons with disabilities’ treatment or rehabilitation resulting in decline of their overall well-being (Vergunst 2016).

4.8.3 Processes

The processes that were followed at the different stages of developing and implementing these documents were not clearly stated in the National Disability Policy Reform documents. This is expected as the majority of policy reform documents typically do not stipulate this process (Walt & Gilson, 1994). Information on processes is often obtained through engagements with stakeholders who were involved in these processes to shed some light on the missing details (Walt & Gilson, 1994). From the limited information presented in the National Disability Policy Reform documents, it was established that the development of the National Disability Policy of Swaziland was a participatory effort of all actors mentioned earlier, with the facilitation of the Deputy Prime Minister’s office through a workshop that was held at the Happy Valley Resort at Ezulwini in Eswatini from 24-28 September 2012. In contrast to the National Disability Policy of Swaziland, each individual ministry was responsible for developing its individual National Disability Plan of Action. Tasking each individual ministry with developing its individual National Disability Plan of Action meant that the role of

implementing the policy would rest on these individual ministries. Ministries were additionally responsible to commit finances and human resources towards the implementation process. Allocating a budget for disability from the already stretched ministerial budgets could potentially pose a challenge. Ultimately, the amount of funds allocated towards the implementation of the National Disability Policy of Swaziland by the individual ministries would depend on the level that disability is prioritised by each ministry.

4.9 IMPLICATIONS FOR DATA SOURCE 2

The findings from the document analysis revealed several implications for the in-depth interviews with key informants. The National Disability Policy Reform documents were not exhaustive in their listing of the key actors involved in the development of these documents. It also did not provide a detailed explanation of the roles of these actors and the stages of development at which they were involved. No details pertaining to the processes of implementing these documents were provided. While some detail of the context of the National Disability Policy Reform Documents were provided, it was insufficient to draw conclusions on the background of these documents. These gaps in findings therefore necessitated the need for an additional data source that could potentially elaborate further and give more details. An additional data source was also important as it would reveal some of the achievements since the inception of the National Disability Policy Reform documents, including some barriers and facilitators to the inception of the documents with specific reference to access to healthcare.

4.10 CONCLUSION

Chapter four provided the procedures followed during Data Source 1 of the study. The aims of the data source were stipulated first. This was then followed by the processes and the justification of the selection of the National Disability Reform Documents that were analysed for the purposes of the study. The development of the coding manual that was used for document analysis was described next followed by the processes

involved in the analysis of the policy documents. The results emanating from the policy analyses were outlined along with a detailed discussion of these results supported by literature. The implication of the results of this data source for Data Source 2 were explained.

CHAPTER 5: DATA SOURCE 2: IN-DEPTH INTERVIEWS WITH KEY INFORMANTS

5.1 INTRODUCTION

This chapter describes the process that was followed during the in-depth interviews with key informants. The chapter launches with an outline of the aims of Data Source 2. This is followed by a detailed description of the participants included in this data source which is done according to specific selection criteria and demographic information. Succeeding this is a brief description of the settings of the in-depth interviews which is followed by a detailed portrayal of the materials and equipment used during the in-depth interviews. A comprehensive explanation of the methods employed for data collection and analysis follows as well as the findings. The chapter concludes with the implications for Data Source 3 and a conclusion.

5.2 AIMS OF DATA SOURCE 2

In order to fulfil the main research aim of the study, Data Source 2 has the following two specific aims:

- i. To describe the provisions of the National Disability Policy Reform documents for access to healthcare for persons with disabilities in Eswatini as reported by key informants.
- ii. To describe the processes of design and implementation of the National Disability Policy Reform documents as reported by key informants by focusing on the actors, content, context and processes.

5. 3 PARTICIPANTS OF DATA SOURCE 2

The participants of Data Source 2 consisted of key informants who were part of the group of actors involved in the development and implementation of the National Disability Policy Reform Documents. These actors and their respective roles are described in Table 9.

The actors of the policy can, however, not be understood without providing a brief background of how disability matters are set in Eswatini. The Deputy Prime Minister's office is the main custodian of social welfare matters, including all disability related matters, and hosts the National Disability Unit. The latter is responsible for the co-ordination of all disability related matters addressed by different disability organisations. The National Disability Unit is also the liaison between disability organisations and all government ministries. The different Organisations of Persons with Disabilities in Eswatini, were formed to address and lobby for specific types of disability groups. All the different disability organisations report under FODSWA which is the coordinating body for all disability organisations in Eswatini. FODSWA in turn, reports to the Co-ordinating Assembly of Non-Governmental Organisations (CANGO) in Eswatini, a body that is responsible for co-ordinating all non-governmental organisations. Due to the fact that the different disability organisations are non-governmental, they rely primarily on donor funding. Additional to disability organisations and other non-governmental organisations, are United Nations Agencies. The purpose of these agencies is to promote international laws and mandates and to support both initiatives from the government and from organisations of persons with disabilities (United Nations, 2013). The Council of Churches is also active in serving the needs of the society of Eswatini and regards the advocacy for disability rights as one of its roles. Attempts were made to include the total number of actors from all those represented organisations mentioned in Table 9, but this was unsuccessful as the development process occurred almost seven years ago. This data was also not available from the National Disability Unit.

5.3.1 Participant Selection Criteria

Participants were selected based on the criteria stipulated in Table 5. A total of 12 key informants were purposively selected and approached to participate as key informants stratified across the six sectors listed in Table 9 (four participants representing the national government sector; two participants representing the National Disability Unit; two participants representing the United Nations; and two participants representing the council of churches). This was done to ensure that the key informants' interviews yield rich data from a diverse set of representatives with different backgrounds and from different groups and sectors.

Key informants were intentionally selected because of the role that they played during the development and implementation of the National Disability Policy Reform documents, which resulted in particular insights and knowledge on these policy reforms. These characteristics would therefore enable them to provide more detailed information with deep insights into the development and implementation of the National Disability Policy Reforms documents (Elmusharaf, 2012).

The final sample for key informants' interviews were seven participants, because three government representatives cancelled their appointments closer to the time and it was difficult to identify the representatives from council of churches due to the unavailability of records. A detailed discussion of the challenges of recruitment is presented in chapter seven.

Table 5 presents an outline of the selection criteria employed to identify and recruit key informants who were involved in the development and implementation processes of the National Disability Policy Reform documents. Table 5 also provides a theoretical justification for the criteria and further indicates the methods employed to ensure that the criteria are met.

Table 5: Criteria for the Selection of Key Informants for Data Source 2

Criteria	Method	Theoretical justification
Language: Participants had to be proficient in SiSwati or English.	Biographical Questionnaire (Appendix F)	SiSwati and English are the two official languages in Eswatini that residents can speak and understand (Constitution of the Kingdom of Swaziland, 2005). The researcher is also fluent in both languages; thus interviews were conducted in languages that both the researcher and participants could understand and speak.
Place of work: Participants had to be working for an organisation that was directly involved at any stage of the initiation, drafting and implementation of the National Disability Policy Reform documents.	Biographical Questionnaire (Appendix F)	A key informant is in some way a proxy for her or his associates at the organisation or group (Parsons, 2011). Different organisations who were represented in the initiation, drafting and implementation of the National Disability Policy Reform Documents in the policy representation included organisations from public and private sector.
Involved in the National Disability Policy Reforms: Participants had to have been involved at any stage of the initiation, drafting and implementation of the National Disability Policy Reform documents.	Biographical Questionnaire (Appendix F)	Key informants are chosen because they are believed to have the most knowledge of the subject matter (Parsons, 2011) and were regarded as actors during the initiation, drafting and implementation of the National Disability Policy Reforms.

5.3.2 Description of the Participants

The biographical information of the key informant participants in the in-depth interviews is presented in Table 6. To ensure confidentiality, the seven participants are referred to as P1 to P7

Table 6: Biographical Information of Key Informants (n=7)

Category	P1	P2	P3	P4	P5	P6	P7
Gender	Female	Female	Male	Male	Male	Male	Male
Languages spoken	SiSwati	SiSwati	SiSwati	SiSwati	SiSwati	SiSwati	SiSwati
	English	English	English	English	English	English	English
Job title during the development of the National Disability Policy of Swaziland.	Director	Director	Director	Director	Co-ordinator	Director	Clerk
Length of time in the job	10 years	5 years	20 years	5 years	6 years	11 years	5 years
Professional background	Nursing	Disability Activist	Disability Activist	Economics	Teaching	Public Health	Administration
Institution of employment during development of the National Disability Policy of Swaziland.	Eswatini Government	Non-governmental organisations	Disability Organisation	Eswatini Government	Disability Organisation	Non-governmental Organisation	Eswatini Government

Of the seven key informant participants, five were male and two were female. Five participants held director positions in their respective organisations at the time of policy development and implementation. Participants were either employed by the government (n=3), by a disability organisation (n=2) or by a non-governmental organisation (n=2). All seven participants were involved in the initiation, drafting or implementation of the National Disability Policy Reform documents.

5.3.3 Participant Recruitment

The National Policy Reform Documents were perused to establish the key role players in the development and implementation of the National Disability Policy Reform Documents. To confirm the information obtained from the policy documents, a follow up telephonic conversation was held with the co ordinator of the National Disability Unit who confirmed the key informants. Participants representing the respective organisations were first contacted telephonically to invite them to participate in the interviews. A follow up email with information detailing the purpose of the study and the expected role of participants in the study was sent to potential participants. Interview dates and venues were confirmed with participants who committed to participating in the study. All interviews were conducted at a time and place convenient for participants.

5.4 SETTING FOR IN-DEPTH INTERVIEWS

In-depth interviews were conducted in Mbabane, the capital city of Eswatini, as mentioned in section 3.4., between the 23rd April 2018 and the 7th May 2018. It is also where the offices of the Deputy Prime Minister, the National Disability Unit and the non-governmental organisations are located. Due to the busy schedules of the key informants, interviews were set up at their respective offices and at a time that was convenient for them. The key informants selected both the location and time to suit their schedules so that the researcher would not interrupt them in any way.

Six of the seven interviews were conducted by the researcher and one interview was conducted by the research fieldworker. Participant P6 had originally agreed to conduct the interview telephonically due to challenges with distance. However, due to difficulties with audibility and accuracy of the telephonic conversation for recording purposes, the researcher requested that the research fieldworker rather conducted the interview face-to-face. All other interviews were conducted by the researcher in a face-to-face manner. Procedural integrity was upheld as the same interview procedures were followed for all interviews, using an interview script (Appendix G).

5.5 MATERIAL AND EQUIPMENT

5.5.1 Information Letters and Consent Forms

Potential participants had to agree to participate in the study by signing an informed consent form (Appendix H). All but one participant could independently sign the consent form. This was due to the fact that the specific participant was blind. The procedures for obtaining informed consent in an ethical manner from blind participants was described in detail under ethical considerations in Chapter 3, section 3.7, were followed.

5.5.2 Biographical Questionnaire

The development of the biographical questionnaire for the participants of the in-depth interviews is presented in Table 7. Also refer to Appendix I for an example of the comprehensive biographical questionnaire in English (I1) and SiSwati (I2).

Table 7: Development of the Biographical Questionnaires for Key Informants

Question number	Aspect	Type of question	Reason for inclusion	Theoretical justification for inclusion of the question
1	Job title	Open ended	To determine the position held by the participant in the organisation	The position held by actors in different organisations has a bearing on the kind of power that they may have and this will in turn, have an effect on the kind of influence that they may have during policy development and implementation (Lehmann, 2016; Lehmann & Gilson, 2013).
2	Institution of employment	Open ended	To determine the organisation that the participant represents	Actors may seek to influence policy, but the extent to which they will be able to do so will depend, among other things, on their perceived or actual power (Buse et al. 2005).
3	Department of employment	Open ended	To determine the specific department in which the participant is employed in the specific organisation	Power may be characterised by a mixture of individual wealth, personality, level of or access to knowledge, or authority, but it is strongly tied up with the organisation and structures (including networks) within which the individual actor works and lives (Buse et al. 2005).
4	Participants' involvement in the development of the National Disability Policy Reform documents	Open ended	To determine the degree of involvement of the participant and their organisation in the development of the National Disability Policy Reform documents	Policy actors and processes by which agenda items and alternatives come into prominence are key factors that affect policy agenda setting and choice (Kingdon, 2002).
5	Participants' involvement in the implementation processes of the National Disability Policy Reform documents	Open ended	To determine the degree of the involvement of the participant and their organisation in the implementation processes of the National Disability Policy Reform documents	Typically, a variety of actors from different interest groups, governmental agencies, and legislatures at different levels of government, researchers, journalists, and judges are involved in one or more aspects of the policy process (Lehmann, 2016).

Table 7 reflects the compilation of the biographical questionnaire, featuring the question number, the aspect covered, the type of question used to elicit this information as well as the theoretical justification for the inclusion of the question. The biographical questionnaire was developed in English. Thereafter, the bilingual

researcher translated the biographical questionnaire into SiSwati which is her first language. The translated SiSwati biographical questionnaire was then checked for accuracy by the bilingual research fieldworker who is also a first language SiSwati speaker who is proficient in English. She then compared the translation with the original English questionnaire. Apart from the one participant who was blind, all the other participants completed the biographical questionnaires independently. Due to the fact that the biographical questionnaire was not available in braille, the researcher read the biographical questions to the blind participant who gave verbal responses that were captured by the researcher on behalf of the participant. This process was also observed by another person to confirm the voluntary participation (Please refer to section 3.6 in Chapter 3 for the role of the observer).

5.5.3 Interview Script

A description of the development of the interview script is reflected in Table 8. Similar to the biographical questionnaire, the interview script was designed in English and then translated into SiSwati by the research fieldworker. Both were checked for accuracy by the research fieldworker. Please refer to Appendix G for an example of the comprehensive interview script in both English and SiSwati.

Table 8: Development of the Interview Script

Question number	Question	Type of question	Reason for inclusion	Theoretical justification for the inclusion of the question
Section A: Information on the actors involved in the National Disability Policy of Eswatini				
1	Which actors or bodies were involved in the initiation of the National Disability Policy Reform documents?	Open ended	To establish the different stakeholders who initiated the National Disability Policy Reform documents	It is imperative to note the different people who were involved in the policy development and implementation and that they had obvious and non-obvious roles as their actions could influence the policy positively or negatively (Lehmann, 2016).
2	What was the selection criteria for the actors involved in the development of the National Disability Policy Reform documents?	Open ended	To establish who the different stakeholders were responsible for the development of the National Disability Policy Reform documents	Different actors may have different understanding of policy and policy goals, yet policy goals are based on their beliefs, values, interests and context (Nxumalo, 2017). The work experiences, positions, background perspectives and training related to these stakeholders' jobs could have an influence on their understanding of policy goals.
3	Who was involved in the implementation processes of the National Disability Policy Reform documents?	Open ended	To establish the different stakeholders who implemented the National Disability Policy Reform documents and the processes that were followed during policy implementation in the National Department of Health	Actors who made and implemented policy decisions (those with power) and how decisions were made (process) largely determine the content of the health policy and thereby, ultimately people's health (Buse et al. 2005).
Section B: Contextual factors that may have influenced the initiation, development and implementation National Disability Policy Reform documents.				
4.	What would you say are the contextual factors that have influenced the development of the National Disability Policy Reform documents?	Open ended	To deduce the different external and internal factors that influenced the development of the National Disability Policy Reform documents	Contextual factors may serve as a source of power to influence policy actors' action, inaction and choice (Koduah, Dijk & Agyepong, 2015). The influence of different sets of values and feelings over key decision makers is likely to strongly influence the nature of the policy that is developed and implemented (Lehmann, 2016). History and traditions also need to be considered as they could influence the
5.	What would you say are the contextual factors that have influenced the	Open ended	To deduce the different external and internal factors that influenced the	

	implementation of the National Disability Policy Reform Documents?		implementation of the National Disability Policy Reform Documents in the National Department of Health	environment in which a policy is developed or implemented (Koduah et al. 2015; Lehmann, 2016). Contextual factors can be categorised into situational, structural, cultural and international factors (Leichter, 1979).
Section C: Processes followed during the implementation of the National Disability Policy Reform documents				
6.	Describe the steps that were followed during the implementation process of the National Disability Policy Reform Documents by all departments	Open ended	To establish the steps that were followed during the implementation of the National Disability Policy Reform Documents across different departments and stakeholders	Every policy change process takes place over time, and understanding the chronology of the steps within it, is always important to thinking about and understanding the process of change. Within any process of policy change, a range of specific processes and strategies may be deployed (or overlooked) that will enable or support the decision making entailed in developing the policy, as well as its implementation (Lehmann, 2016).
7.	Describe the steps that were followed during the implementation of the National Disability Policy Reform Documents in the National Department of Health	Open ended	To establish how the policy was implemented in the National Department of Health	Please see justification in Questions 4 and 6 above.

Table 8 reflects the compilation of the key informant interview script by highlighting the question number, the aspect covered, and the type of question and the theoretical justification of the inclusion of the specific questions. This script showed consistency between the various interviews.

5.5.4 Recording Equipment

An audio recorder (Philips DVT 2510) was used to record the in-depth interviews. All participants consented to being recorded before the commencement of the interviews.

5.6 METHODS

5.6.1 Pilot Study

The interview script was piloted before the commencement of the in-depth interviews. Kazi and Khalid (2012) emphasised piloting questionnaires to ascertain if instruments measure what they were intended to measure and if they did so reliably. Even though pilot studies do not guarantee success in the main study, they increase the likelihood of success (van Teijlingen & Hundley, 2002) and hence formed an important part of this data source. The pilot study was also carried out to determine the average time that it would take to complete the in-depth interview. Furthermore, it was also used to gauge whether the questions in the data collection tool yielded the desired results and if the language used was appropriate and understandable for the specific group of participants (Hassan, Schattner, & Mazza, 2006).

The selection criteria for the pilot study participant was the same as those of the key informants as stipulated in Table 5. Due to the limited pool of people from which to select key informants, only one participant was included in the pilot. The participant was male, had a disability, was fluent in both English and SiSwati and worked in the National Disability Unit and was therefore familiar with the initiation, development and implementation of the National Disability Policy Reform documents. To ensure that there was no data contamination, the participant was informed that other members of the same disability unit were going to be approached to participate in Data Source 2 and therefore he was asked not to divulge any information pertaining to the content of the questions of the interview, to which he agreed.

The pilot study revealed that all the questions in the interview were clear and that they addressed the aims of this section of the study, thus no amendments were made to the data collection tool (interview script). The pilot study further revealed that at least 40 minutes would be required per in-depth interview. This information was useful when the researcher was setting up appointments with prospective key informants. Due to

the fact that the pilot study did not reveal the need for significant changes to the data collection tool and the data collection processes, the data obtained from the pilot participant was added to the other data of Data Source 2.

5.6.2 Data Collection

Initial telephonic contact was made with potential participants who met the selection criteria and requests for interviews were made. The purpose of the study was explained during this telephonic contact. Thereafter an information letter stipulating the details of the research was emailed to all potential participants. Next, an appointment was made for the interviews with potential participants at a place and time that suited all parties. After the seventh interview, it was evident that data saturation had occurred as no new or additional data were added in discussions with participants (Saunders et al. 2016). As a result, no further data collection was deemed necessary.

Before the commencement of each interview, the purpose of the research was reiterated and verbal or written informed consent was obtained from participants to participate and to be audio recorded (Appendix H). Reasons why they had been purposively selected for the interviews were provided and participants were reminded that participation was voluntary and that they were allowed to discontinue their participation at any given time without any negative consequences. Participants were further assured of confidentiality as no identifiable information would be shared when reporting on Data Source 2. The researcher conducted the interviews and audio recordings while the research fieldworker took field notes to facilitate data analysis. Participants spontaneously language switched between SiSwati and English, therefore the in-depth interviews were conducted in both SiSwati and English, even though the initial plan was to conduct the interviews exclusively in SiSwati. Language switching in adults typically occurs to reflect the speaker's awareness of the social factors such as the setting and the topic, the language background of their conversational partner and to mark the identity and creation of intimacy and ethnic

solidarity with others of the same language and culture (King, 2019). At the end of each interview, member checking was done by the researcher summarising the main responses to the participants and allowing them to confirm that their responses were captured accurately (Birt, Scott, Cavers, Cambell, & Walter, 2016). Member checking enhances the credibility of the data of a study (Birt et al. 2016).

All recorded interviews were transcribed verbatim by the research fieldworker who is proficient in both SiSwati and English. She then translated the SiSwati sections in the transcriptions to English. Keeping a record of all transcripts and translations was part of the audit trail of the study, a measure that ensured rigour (Akkerman, Admiral, Brekelmans, & Oost, 2008). The researcher checked all the transcripts (100%) against the original recordings and translations, which further increased the procedural integrity of the transcripts (Boyatzis, 1998). In cases where there were discrepancies between the transcriptions checked by the researcher and those of the research fieldworker, discrepancies were discussed and clarified until 100% agreement was reached.

5.6.3 Data Analysis

Data analysis of the in-depth interviews was conducted by the researcher and a second coder (a researcher with a PhD), using principles of collaborative coding (Saldana, 2009). The second coder is the main supervisor of the study, has supervised qualitative research at both masters and PhD level and is therefore has vast knowledge on qualitative data analysis. The use of more than one coder improved the consistency or reliability of analysis (Saldana, 2009). Thematic analysis of all the transcripts was conducted using both inductive and deductive approaches (Braun & Clarke, 2006). Data analysis began with importing the transcripts into an Excel spreadsheet. The framework analysis approach was used to initially deductively classify data into the spreadsheet according to the categories of the Integrated Disability Policy Analysis Framework, as structured in the interview scripts. The spreadsheets were then printed and inductively analysed (Maguire & Delahunt, 2017).

First, the interviews were read line by line by the coders to familiarise themselves with the data. Next, the data were sorted into meaning units before initial codes were generated. They proceeded across the data set, comparing new data with previous codes, either labelling it with a previously coded code or new one if none of the existing codes applied. The codes were then grouped together into categories of meaning or themes according to units of analysis that are similarly coded (Braun & Clarke, 2006). Excerpts from participants were included along with the themes and sub-themes as findings to enable the readers of this thesis to detect the patterns identified in the analysis (Yardley, 2000).

5.7 FINDINGS FROM IN-DEPTH INTERVIEWS

The findings of the in-depth interviews are presented using the eight components of the Integrated Disability Policy Analysis Framework. A discussion of the results follows thereafter.

5.7.1 Actors

The responsibility of the actors who were involved in the development and implementation of the National Disability Policy Reform documents are outlined in Table 9. Participants of Data Source 2 also formed part of the panel that informed the development and implementation of the National Disability Policy Reforms. It should however be noted that the participants were not spread across the six sectors.

Table 9: Actors Involved in the National Disability Policy of Swaziland and their Respective Roles and Responsibilities

Actors	Roles in the development and implementation of the National Disability Reforms	Participants involved in the in-depth interviews
All government ministries including the Deputy Prime Minister's Office	<ul style="list-style-type: none"> • Custodian of social welfare including disability • Initiated and facilitated the process of developing and implementing the National Disability Policy Reform documents. • Read and edited drafts of all the policy documents. • Liaised with the Department of Justice to translate the draft policy documents into acceptable policy language. • Responsible for implementing the National Disability Policy Reforms documents. • Responsible for ensuring funding for the implementation of the National Disability Plan of Action in different departments. 	n=1
National Disability Unit	<ul style="list-style-type: none"> • Co-ordination of all activities pertaining to the development and implementation of the National Disability Policy Reform documents. • Collating ideas contributed to inform the content of the National Disability Policy Reform documents. 	n=2
Disability Organisations	<ul style="list-style-type: none"> • Involved in the development stage of the National Disability Policy Reform documents. • Responsible for providing recommendations on what the content of the National Disability Policy Reform documents should be and disability rights issues in Eswatini. • Following up with government on the progress of policy implementation. 	n=2
United Nations Organisations	<ul style="list-style-type: none"> • Involved in the development stage of the National Disability Policy Reform documents. • Responsible for providing recommendations on the content of the National Disability Policy Reform documents. • Supporting the lobbying for disability rights issues in Eswatini. • Providing funding of disability related initiatives. 	n=2
Council of Churches	<ul style="list-style-type: none"> • Involved in the development stage of the National Disability Policy Reform documents. • Responsible for providing recommendation on the content of the National Disability Policy Reform documents. 	n=0
Commonwealth Officer	<ul style="list-style-type: none"> • Knowledgeable on policy development and implementation. • Advisory role during the development of the National Disability Policy Reform documents. • The commonwealth officer who was involved in this process was visiting the Ministry of Justice at the time when the National Disability Policy Reforms were developed as part of a once-off 	n=0

visit. Follow-up consultation was therefore not possible.

Total

n=7

The seven participants were able to clarify the process and provide rich data that answered the questions pertaining to the National Disability Policy Reforms. Their individual comments supported each other and led to data saturation.

5.7.2 Context

In Table 10, the five themes derived from Data Source 2 characterised the context within which the National Disability Policy Reforms were initiated. Excerpts from participants were also included as examples.

Table 10: Themes on the Context of the National Disability Policy Reforms Derived from Data Source 2

Themes	Subthemes	Excerpts from participants
Disability law	Need for laws to protect persons with disabilities	<ul style="list-style-type: none"> “What was happening was that persons with disabilities had no law protecting them and holding people who treat them inappropriately accountable. So, we knew that after the policy we would come up with the Bill which is the law” (P6).
	Need for laws to operationalise the National Disability Policy Reform documents	<ul style="list-style-type: none"> “We did the policy, when I left, we had already drafted the act that supports the policy because you can have your policy, what does it matter nothing. So, we need to have the law that is going to then operationalise that policy because policy is just talk, oh”. (P4). “And then we pushed for the disability policy, but then the disability policy was not enough, there was also a need for the Bill. So, we pushed for the Bill so that the policy could be law” (P2).
UN mandate	Mandate by the CRPD	<ul style="list-style-type: none"> “So, the CRPD is what was ratified in 2012. The ratification had to be domesticated into what we could do as a country for persons with disabilities. That is why we started by developing the disability policy and then from the disability policy we developed the National Disability Plan of Action and the Bill” (P2). “We as a country had signed for the CRPD and as such saying we are committing to support the cause for persons with disabilities. Drafting policies and bills was part of the commitment as part of being party to the CRPD” (P6).
	Pressure from UN	<ul style="list-style-type: none"> “So, I think that the government felt the pressure to explain why we did not have a policy. It pointed to everyone. So, we had to stand up and make the policy happen. It was from the

United Nations that by this time, you should have done this and that in place what is your problem?” (P3).

Financial support for persons with disabilities	Need for grant support for persons with disabilities	<ul style="list-style-type: none"> “Especially for us, persons with disabilities, we are poor, it is common that in most cases persons with disabilities come from poor families. So, we thought that a lot of things would change after the policy and that social support would be given to persons with disabilities to access things like healthcare” (P3). “Also was the need to support persons with disabilities financially. And not it continue being a by the way thing and not formalised” (P6).
	Need for consistency in grant allocation	<ul style="list-style-type: none"> “If you had a child with a disability and you talked a lot, you would get a grant and if you were that parent that did not talk a lot and knew nobody, you wouldn’t get a grant. So, we had to formalise grants for persons with disabilities” (P4).
Accessibility for persons with disabilities	Need for accommodation of persons with disabilities across all entities	<ul style="list-style-type: none"> “So, the policy had to speak to the modification of all these things, to remove barriers and to alter the existing infrastructure to accommodate persons with disabilities” (P2). “We needed and still need to be able to go to school, we need infrastructure that is conducive for us, we need to be able to go to hospitals everything as we have learnt from other countries that maybe if there were certain things that could be financially subsidised so that persons with disabilities can access things that they need” (P3).
Disability mainstreaming	Need for bringing disability into mainstreaming thinking	<ul style="list-style-type: none"> “We wanted tangible mainstreaming in every ministry, so that disability could be mainstreamed in all ministries. Right now, that still doesn’t happen” (P5). “Mainstreaming was important. Mainstreaming is making sure that we don’t treat disability activities separately and that they are inculcated in different parts with other stakeholders of government and civil society” (P1).

Summary of the context of the National Disability Policy Reforms

The background of the National Disability Policy of Swaziland indicates that prior to the development of the National Disability Policy Reforms documents, there was no formal law that was protecting persons with disabilities in Eswatini. Persons with disabilities were therefore not accommodated across all entities in the country and there was no consistency in the allocation of social support. The unavailability of legislation protecting persons with disabilities in Eswatini caused United Nations agencies to apply pressure on Eswatini to enact laws that could and would protect persons with disabilities. As a result, Eswatini ratified the CRPD in 2012. As part of the mandate of the CRPD, Eswatini had to develop a National Disability Policy of Eswatini. As much as the development of the National Disability Policy indicated

progress, the policy as a standalone document did not hold much weight, therefore the National Disability Bill was developed as a legal document that would then hold violators of disability rights accountable. However, at the time of submitting this thesis, the Bill had not yet become official law.

5.7.3 Content

The four domains that characterise access to health for persons with disabilities as proposed by the Integrated Disability Policy Analysis Framework were used as themes that denote the content of the study. Table 11 provides the sub-themes that emerged from the data in Data Source 2 within each of the four domains that pertain to access to healthcare. In the table, excerpts from participants are included to substantiate the sub-themes.

Table 11: Themes and Sub-themes Related to Content as Reported by Key Informants

Themes	Sub-themes	Excerpts from participants
Availability	Availability of assistive devices	<ul style="list-style-type: none"> • “We, the government system issues out wheelchairs and I have always encouraged recycling of these” (P4). • “The Taiwanese embassy would donate wheelchairs to persons with disabilities or the municipality would donate to me and then I would distribute them” (P3). • “I had wheelchairs late last year donated by the municipality which I had to distribute. After that they were all looking for me because they wanted wheelchairs since it was election period” (P3).
	Availability of disability programmes	<ul style="list-style-type: none"> • “Some of the other programmes in the Department of Health have outreaches to the community, but the challenge with disability is that they do not offer those programmes anymore” (P1). • “Our biggest concern is in the health sector priority programmes because persons with disabilities don’t feature. This includes issues such as HIV/AIDS, even CHANGE the national communication strategy didn’t reach the deaf and visually impaired” (P5)
	Restricted availability of healthcare professionals	<ul style="list-style-type: none"> • “There is a serious shortage of healthcare professionals, especially allied health. But I am sure that you can also see the challenge, if for example they have only one speech language therapist against a nation, what does that mean?” (P1). • “Even filling of posts in the healthcare is a challenge as a result of the current economic climate in the country. The shortage of healthcare professionals is a problem” (P6).

Acceptability	Challenges with physical access	<ul style="list-style-type: none"> • “So, when I go there, I need to stand back and shout because there are steps and an even larger one by the window. So, I shout and ask for help or maybe someone will see that I can’t walk and then they will help” (P3). • “We have to acknowledge the progress that has been made, because this country has come a long way in making buildings accessible to wheelchair users” (P4).
	Access to augmented communication	<ul style="list-style-type: none"> • “There have been nurses who have been trained in sign language, but there is a problem in that because some of them do not use the sign language, they lose it” (P3). • “It’s a challenge for the visually impaired because information is not available in braille. Either way you lose your right to confidentiality because you will always need someone to constantly be there” (P3). • “We trained all civil servants including healthcare professionals on sign language. We hired and paid consultants because they are the custodians of the language” (P1).
	Poor access to health information	<ul style="list-style-type: none"> • “They don’t consider the person they are giving the medication to. What they do is take the paper, the prescription from you and just give you the pills, they don’t even explain. And sometimes they are going to throw this to a visually impaired person, they are going to throw this to a deaf person and who explains that?” (P2). • “As far as they are concerned, people are taught on sexual and reproductive health, but actually the blind and the deaf are left out because they compile this information assuming that everyone can see and hear and is therefore not in sign language or braille” (P5).
	Negative attitudes of healthcare professionals	<ul style="list-style-type: none"> • “There is also the negative attitude of healthcare professionals towards persons with disabilities. Their attitudes towards persons with disabilities needs to change. Maybe we are not doing enough advocacy as persons with disabilities” (P3). • “It is true that they [healthcare professionals] accept everyone coming in there but there are still so many people are coming through to us to say that I was in hospital and nurses were asking that I also engage in sexual intercourse” (P2).
Geographical accessibility	Transportation challenges	<ul style="list-style-type: none"> • “The infrastructure has changed, even though it’s not at the level that we want it to be, however transport is lacking, we are still trying because they need to modify their transport” (P2). • “Transportation to healthcare facilities for persons with disabilities is a complex challenge and unfortunately at this point, I can’t even offer possible solutions, but as is the case with other African and international communities” (P6).
Financial accessibility	Inconsistent financial support	<ul style="list-style-type: none"> • “Free healthcare is covered for persons with disabilities as well. We might not have been explicit about it, which might have been an error, but persons with disabilities are not supposed to pay, so they can go and get services without paying because they have a disability” (P4). • “The government put together a budget to promote interventions targeted towards such as finances for research, buy assistive devices and advocacy” (P1).

Summary of Content of the National Disability Policy Reforms

In terms of availability, Eswatini has made assistive devices available to persons with disabilities either through donations or through government allocations. Disability programmes are not yet in place and as a result, persons with disabilities are excluded

from programmes such as HIV/AIDS. Due to Eswatini’s current economic climate (Eswatini reported a per capita income of \$3,390 in 2014); (Ministry of Economic Development and Planning, 2016), the country has not been successful in filling vacant healthcare professional posts and consequently, there is a shortage of healthcare professionals. While the country has made significant progress with ensuring physical access for persons with disabilities in healthcare facilities, communication access, specifically for persons with visual and hearing impairments remains challenging. Persons with visual and hearing impairments therefore struggle to access health information as it is not available in all language formats e.g. braille, sign language and other accessible formats such as easy language or pictures with text. Persons with disabilities unfortunately still experience negative attitudes from healthcare professionals in healthcare facilities as was also mentioned in the document analysis. Transportation continues to pose a barrier to accessing healthcare for persons with disabilities in Eswatini due to the distances that they have to travel to receive treatment. Although it appears that free healthcare is provided for persons with disabilities in Eswatini, (including assistive devices) there was no clarity on free healthcare services as it was not stated explicitly.

5.7.4 Processes

Table 12 captures the themes of the processes followed during the initiation, development and implementation of National Disability Policy Reforms. Once again, excerpts from participants’ comments were added as examples of sub-themes.

Table 12: Processes of the National Disability Policy Reforms as Reported by Key Informants

Themes	Sub-themes	Excerpts from participants
Procedures of implementations	The development of the National Disability Plan of Action	<ul style="list-style-type: none"> • “We were also responsible for the development of the National Disability Plan of Action, which is the ‘how to’ of implementing the policy” (P4). • “The National Disability Plan of Action was developed by different government ministries as the blueprint of implementing the National Disability Policy of Swaziland” (P6).

	The development of the National Disability Bill of Rights	<ul style="list-style-type: none"> • “We then requested that every ministry develop a costed National Disability Plan of Action, which was a way of saying this is how my ministry will be implementing the policy” (P1). • “The National Disability Bill was actually one of the pillars of the programme of implementing the National Disability Policy of Swaziland” (P4). • “To operationalise the policy, we developed the National Disability Bill as a way of implementing the National Disability Policy of Swaziland as law” (P6).
	Lack of commitment from policy implementers	<ul style="list-style-type: none"> • “Let us say that with such things to be successful you need commitment at all levels. I am not going to say that you need commitment from junior staff, politicians and senior management. Once we have agreed on the implementation, we should all commit to it” (P4). • “I think that the kind of personnel that is to drive implementation requires time, understanding of disability and commitment” (P2).
Progress of implementation	The National Disability Bill of Rights has not been legalised	<ul style="list-style-type: none"> • “But in terms of implementation, the current government is leaving office and Bill has not been signed and passed as law” (P5). • “So, I believe that we also still have a long way. I am personally concerned that this law that I left as a draft Bill when I left office still has not seen the light of day” (P4).
Financial resources for policy implementation	Prioritise funding for policy implementation	<ul style="list-style-type: none"> • “During the implementation, I can look at an idea and how to implement it, but the government looks at what funding they have available and what they can prioritise at that time with the finances available” (P2). • “Policy implementation requires a level of funding. Effective implementation requires funding that needs to from the state, and I am not certain that that is happening” (P6).
Knowledge and skill resources	Lack of knowledge and skills of implementers	<ul style="list-style-type: none"> • “Part of the reason that implementation is slow is because people who are tasked with implementation do not have an understanding of disability” (P2). • “The success of policies also lies in having personnel who are trained in disability and who have knowledge on implementers“(P6).

Summary about the Processes of the National Disability Policy Reforms

It was the sole role of the government of Eswatini to implement the National Disability Policy Reforms as it is the norm that state governments are typically responsible for legislation as the custodians of the laws of the country. The disability organisations in Eswatini in the implementation process acted in an advocacy role. They followed up with the state government on the progress of implementation. As a way of implementing the National Disability Policy of Eswatini, the Deputy Prime Minister’s office instructed, through the National Disability Unit, all ministries to develop a costed National Disability Plan of Action to stipulate how each ministry, including the Ministry of Health, intended to make changes to accommodate persons with disabilities. To

further operationalise the National Disability Plan of Action, the Deputy Prime Minister's office along with the Ministry of Justice developed the National Disability Bill of Rights, which will be the law that supports the National Disability Policy of Eswatini and National Disability Plan of Action. To date, this bill not been passed as law. The implementation process of this bill has encountered challenges such as the lack of prioritisation from policy makers, lack of funding and the lack of implementation skills from policy implementers.

5.8 DISCUSSION OF THE RESULTS FROM DATA SOURCE 2

5.8.1 Context

In line with findings from the Data Source 1, results from Data Source 2 confirmed that Eswatini had no specific law that protected persons with disabilities and their rights to access healthcare prior to the initiation of the National Disability Policy of Eswatini. This disability policy was subsequently initiated following the government's ratification of the CRPD. These findings were also echoed in a study conducted by Eide and Jele (2011) on disability in Eswatini. Although the said study focused on the living conditions of persons with disability in Eswatini and not necessarily on analysing the National Disability Policy Reforms, the authors did report on the context and background of the National Disability Policy of Eswatini and highlighted the need for disability laws to facilitate access for persons with disabilities to different entities (Eide & Jele, 2011). They also addressed the protection of the rights of persons with disabilities (Eide & Jele, 2011).

In a country report aimed at documenting the progress that Eswatini has made in addressing the rights of persons with disabilities in the country, the findings of Data Source 2 were reiterated (Mavundla, 2015). The fact that Eswatini did not have a disability law prior to the ratification of the CRPD, is in contrast to findings from literature on disability policies of fellow African states. For example, fellow African states that have recently ratified the CRPD, such as Namibia, Tanzania and Zimbabwe

had existing disability policies and legislature, prior to them commissioning the CRPD (Chichaya et al. 2018; Dziva, Shoko & Zvobgo, 2018; Shumba & Moodley, 2018). Even though these states' disability policies and legislature had not been grounded on the principles of the CRPD, they were developed to ensure and uphold the human rights and inclusion of persons with disabilities across different entities (Dziva et al. 2018).

Data Source 2 also brought forth some new findings which could not have been established from Data Source 1 alone. For example, the financial plight of persons with disabilities due to inconsistencies in them receiving any financial support from the government was described as one of the reasons why the policy was initiated while highlighting the need to provide persons with disabilities with social support. These findings confirmed and echoed the research of Eide and Jele (2011). However, these findings are recommendations of the World Health Organisation that suggested that every state should ensure that persons with disabilities are financially supported so that they are able to live and have access to, for example, healthcare (World Health Organisation, 2011). These findings also underscore the differences of funding structures for persons with disabilities when comparing Eswatini to other countries in the Sub-Saharan African region, such as South Africa, where an established system such as the disability grant (which is a social protection mechanism aimed at financially supporting persons with disabilities and their families) is incorporated (Hanass-Hancock & McKenzie, 2017).

While Data Source 1 focused on the National Disability Policy Reforms, Data Source 2 highlighted the important role of the National Disability Bill of Rights and the National Disability Plan of Action in the implementation of the policy. It was reported that ultimately as a standalone document, the National Disability Plan of Action held no value. Similarly, Longley (2011) posits that National Policy Reform documents merely outline the goals different government ministries hope to achieve and the methods and principles they will use to achieve them. As such, the Policy Reform documents are not a law. A bill, on the other hand, is the potential law that sets out standards, procedures and principles that should be followed, with resultant repercussions if that law is not followed (Longley, 2011). Should a law not be followed, perpetrators could

be prosecuted in court. Since Eswatini has not yet passed the National Disability Bill of Rights, this could delay the goal to access for persons with disabilities.

5.8.2 Content

5.8.2.1 Availability

Findings from Data Source 2 revealed that persons with disabilities obtained assistive devices from either the government or through donations. This finding confirms the recommendations for supporting persons with disabilities through providing them with assistive devices (World Health Organisation, 2011). Matter and Eide (2018) reported that in Eswatini, persons with physical disabilities were likely to gain access to assistive devices (such as wheelchairs). As such, the authors stated that there was an unfulfilled need for assistive devices for all persons with other disabilities such as hearing loss, deafness and communication disabilities (Matter & Eide, 2018).

Matter and Eide (2018) also confirmed that the Government of Eswatini provided only 11.5% of assistive devices to persons with disabilities who required them, with private providers accounting for 32.7% of assistive devices. This indicates that there still remain significant gaps between the demand and supply of assistive devices for persons with disabilities in Eswatini. In a study conducted in Sub-Saharan Africa, Shumba and Moodley (2018) it was further reiterated that the issuing and maintenance of assistive devices to persons with disabilities were hampered by the lack of adequate budget allocation from governments to provide assistive devices due to poor supply chain processes. Findings in the study at hand also focused on the provision of assistive devices and not on maintenance, repair or replacement. These findings were expected as provision is seen as a first step.

Even though the National Department of Health had different health programmes available, there was no programme specific to persons with disabilities or one that

accommodated them. Therefore, disability was still not included in health sector programmes. This was concerning as the Policy Reform documents stated explicit commitment to health programmes, particular to persons with disabilities (Deputy Prime Minister's Office, 2013).

Data Source 2 also highlighted a shortage of healthcare professionals, especially allied health professionals. For example, the ratio between speech language therapists to patient ratio was high. This might be in part due to the lack of finances to fund existing healthcare professionals' posts, despite the fact that the Policy Reform documents had promised adequately trained personnel at all levels of service delivery and rehabilitation. The Republic of South Africa is experiencing similar challenges, where the speech language therapist to population ratio is reported to be at an estimated 1:25,000 (Kathard & Pillay, 2013). Similarly, Shumba and Moodley (2018) identified a shortage of rehabilitation services in the public sectors of Sub-Saharan African countries. The authors attributed this to a low budget allocation for rehabilitation services in the public sector and the fact that most rehabilitation staff were attracted by private sector posts. These findings were further echoed in Gupta, Castillo-Laborde, and Landry (2011), where it was noted that the lowest number of rehabilitation healthcare professionals in comparison to the demand were found amongst LMICs, including many located in Sub-Saharan Africa. Yet this is where the disease burden related to causes requiring rehabilitation professionals' skills tended to be the highest.

5.8.2.2 Acceptability

In Data Source 2, some improvements in terms of physical access were reported, although it was not consistent across all healthcare facilities, despite the fact that the Policy Reform documents have pledged physical access across all healthcare facilities. While the government of Eswatini should be commended for rolling out sign language training for all healthcare professionals as a way of ensuring accommodation of persons with deafness in healthcare facilities, the programme has unfortunately

been largely unsuccessful. This may be due in part to healthcare professionals that they had not been using sign language often and therefore lost their signing skills.

Although access to health information and disability programmes in all language formats has been guaranteed by the Disability Policy Reform documents, it was still a major challenge for persons with disabilities. This resonates with the findings in a South African study where it was apparent that communication difficulties were a prominent barrier in accessing healthcare, specifically for persons presenting with deafness (Kritzing et al. 2014). Health information, including information related to sexual and reproductive health and disability programmes, was available at healthcare facilities, but not in other formats such as braille, easy language and symbols systems for ease of understanding for persons with disabilities or persons with low literacy skills (Rugoho & Maphosa, 2017). Studies in South Africa and Namibia concluded that families of persons with disabilities were frustrated by information obstacles experienced by persons with disabilities and that medical care of persons with disabilities was hindered by the lack of braille and sign language respectively (Fisher & Shang, 2013; Shumba & Moodley, 2018).

Furthermore, regardless of the National Disability Policy Reform documents having vowed to protect persons with disabilities from any form of discrimination, Data Source 2 confirmed negative attitudes of healthcare professionals towards persons with disabilities as still rife. Other studies have also noted similar discriminatory tendencies of healthcare professionals, specifically against persons with disabilities and women (Shakespeare, Bright & Kuper 2018; Smith et al. 2004). These studies have ascribed discrimination against women to beliefs by healthcare professionals that persons with disabilities are not sexually active and should therefore not receive education and care regarding social and reproductive health.

5.8.2.3 Geographical Accessibility

Even though the healthcare facilities are reported to be within an 8 kilometre radius from persons with disabilities in Eswatini (Magagula, 2017), transportation challenges were identified as hindering access to healthcare for persons with disabilities. Transportation had unfortunately not been addressed in any of the policy documents. The National Disability Policy Reform documents, therefore, need to be revised to factor in transportation for persons with disabilities to healthcare facilities or provision of healthcare services in all areas and not only in the city should be considered. An alternative option is to ensure that all services are provided within the community for persons with disabilities (Russell et al. 2013). Numerous studies have highlighted transportation as a major barrier to access healthcare for persons with disabilities in different Sub-Saharan countries (Masuku et al. 2018; Vergunst, 2016; Vergunst et al. 2015).

5.8.2.4 Financial Accessibility

Following the enactment of the National Disability Policy Reform documents, Data Source 2 also reported that healthcare was supposedly made free for persons with disabilities, even though this was not made explicit. The Eswatini national government had allocated budgets to promote interventions for research, assistive devices and advocacy for persons with disabilities. However, there is a lack of clarity on how these budgets are implemented. This is in contrast to studies done in other African countries, where financial constraints have been identified as still one of the major factors that contribute to the challenges of accessing healthcare for persons with disabilities (Masuku et al. 2018; Senghor, Diop & Sombié, 2017; Vergunst, 2016).

5.8.3 Processes

Data Source 2 clarified the processes followed during the implementation of the National Disability Policy Reform documents, particularly the role of the government of Eswatini. This is because the responsibility of administering and implementing of public policies lies with state governments. This finding is consistent with Roux (2002), where it transpired that policy implementation was the primary role of governments. The only role that disability organisations were allowed to play was to follow up on the progress that the government had made with regards to implementing the National Disability Policy Reform documents. The National Disability Plan of Action was developed as a blueprint for implementing the National Disability Policy of Eswatini and it was accompanied by the National Disability Bill of Rights which was a way of adopting the policy as a law. The implementation process did encounter challenges such as the lack of commitment from policy implementers; their lack of skills necessary for policy implementation and funding not being prioritised for policy implementation. In a study where the challenges of implementing a disability policy in the South African context was investigated, the above findings were confirmed (Brynard, 2010). It was also concerning that it was reported in Data Source 2 that at the time of data collection, the National Disability Bill of Rights had still not been passed by parliament as law. Policies only become relevant after they have been passed as legislation (Roux, 2002). This therefore could have implications for the protection of the rights of persons with disabilities in Eswatini.

5.9 IMPLICATIONS FOR DATA SOURCE 3

While the results on the actors and context of the National Disability Policy Reforms documents from Data Source 1 were somewhat confirmed by Data Source 2, there were mostly discrepancies between the promises of the policy documents (content) and reports with regards to the content of the National Disability Policy Reforms. While these documents committed persons with disabilities to participate in all programmes, this data source revealed the contrary. Also, the availability of healthcare professionals in healthcare facilities was lacking due to financial constraints, resulting in state health

personnel posts being frozen, which led to the shortage of healthcare professionals. Communication and information shared with persons with disabilities continued to be challenging despite the National Disability Policy Reform documents committed to ensuring accessibility to all health literacy and health programmes in different language formats e.g. sign language, easy language formats and braille, as captured in Article 21 of the CRPD which focused on information in accessible formats (United Nations, 2006). It was therefore necessary to consult another data source to obtain the viewpoints and experiences of persons with disabilities and caregivers of persons with disabilities who are the end users of healthcare services and for whom the National Disability Policy Reforms documents were designed and are sources in Data Source 3. Furthermore, in Data Source 3, the perspectives of healthcare professionals who are responsible for administering these services to persons with disabilities and their families is also obtained to ensure a holistic perspective.

5.10 CONCLUSION

This chapter discussed the methodology, results and discussion for Data Source 2 of the study, in-depth interviews with key informants. The chapter outlined the aims, participants, settings, materials and equipment used in Data Source 2 of the study. It furthermore detailed the processes followed during the collection and analyses of the data obtained from in-depth interviews with key informants. The findings from the in-depth interviews were outlined followed by a detailed discussion of these results. Implication of the findings of this data source for Data Source 3 were explained and a conclusion drawn.

CHAPTER 6: DATA SOURCE 3: FOCUS GROUPS

6.1 INTRODUCTION

This chapter describes the process that was followed during the focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals. The chapter commences with a description of the aims of Data Source 3. This is followed by an overview of the selection criteria for participants involved this data source. Next, an explanation is given of how participants were recruited. A detailed description of participants of each focus group is then provided. A brief reference is made to the setting of the study which is followed by an outline of the different materials and equipment that were used in this data source. Data collection and data analysis are then described, followed by a presentation of the results for each focus group. The results are presented according to actors; context; content (experiences of persons with disabilities when they access healthcare) and processes. A detailed discussion of the results follows, after which the chapter ends with the implications of this data source for the overall study, as well as a conclusion.

6.2 AIMS OF DATA SOURCE 3

- i. To establish the knowledge of persons with disabilities, caregivers of persons with disabilities and healthcare professionals on the National Disability Policy of Swaziland and its content, specifically pertaining to access to healthcare.
- ii. To establish the experiences of persons with disabilities when they access healthcare services as reported by persons with disabilities themselves, by caregivers of persons with disabilities and by healthcare professionals.
- iii. To establish the perceived effectiveness of the National Disability Policy Reform documents in facilitating access to healthcare for persons with disabilities.

6.3 PARTICIPANTS OF DATA SOURCE 3

6.3.1 Selection criteria for participants

Purposive sampling was used to select the participants for this data source (Creswell & Poth, 2018), as it allowed for the selection of participants who could provide relevant rich information on the experiences of persons with disabilities when they access healthcare services in Eswatini. Focus groups were deemed an ideal method of data collection because, the intention of the researcher was to provide a safe space that was conducive for conversation between a homogenous group of individuals thus encouraging the sharing of insights, perceptions and experiences (Kruegar, 2006). This was necessary since the topic of discussion was a sensitive one and the study participants were a group that was previously unreached (Kruegar, 2006). Even though the group participants were homogeneous, the focus group environment ensured that their differences were still captured thereby fostering different viewpoints (Nyumba, Wilson, Derrick & Mukherjee, 2017).

Even though focus groups presented an advantage for this research study, the following pitfalls related to this method of data collection are acknowledged. The recruitment of participants and co ordinating their schedule to ensure that they could meet at the same place and time was challenging (Kruegar & Casey, 2000). This challenge was mitigated by using a person with disabilities' organisations to recruit participants for the persons with disabilities aswell as the caregivers of persons with disabilities focus groups. Facilitating a focus group and ensuring that every member is meaningfully contributing to the discussion is also often challenging especially when the groups is large (Nyumba et al. 2017). The researcher alleviated this by ensuring that group participant numbers did not exceed eight participants per groups so that it was easier to manage as recommended by Kruegar and Casey (2000). Focus groups have the potential to be biased in favour of participants who have dominant and aggressive personalities (Nyumba et al. 2017). It was therefore necessary for the researcher to upfront negotiate rules of engagement with participants and also ensure that equal opportunities are afforded to each participant during the engagement. There may be the uncertainty that all the participants that are recruited for the focus groups

will attend the discussion on the scheduled dates and time. The researcher therefore over recruited. This is a strategy that is supported by Rabiee (2004). The researcher recruited twelve participants for each focus group, to ensure that in the event that some participants do not arrive, there is still enough participants to convene a focus groups with a robust discussion.

The selection criteria used to recruit the persons with disabilities; caregivers of persons with disabilities and healthcare professionals to participate in the focus groups (Data Source 3) are outlined in Table 13.

Table 13: Selection Criteria for Participants for Data Source 3

Criteria	Method	Theoretical Justification
Persons with disabilities		
Age: Participants had to be 18 years or older	Biographical Questionnaire (Appendix I)	The legal consenting age in Eswatini is 18 years of age (Swaziland National Youth Policy, 2014).
Language: Participants had to have conversational spoken skills in SiSwati and/or English	Biographical Questionnaire (Appendix I)	Many persons with disabilities have low literacy levels and therefore have difficulties expressing themselves in any other language besides SiSwati (Eide & Jele, 2011).
Disability: Participants had to present with a disability, diagnosed as captured by the relevant database	Database of the National Disability Organisation of Eswatini	Because the study focussed on persons with disabilities, it was thus important to include persons presenting with disabilities as they provided rich data based on first-hand experiences. Hearing from those with direct experience of disability is likely to make more impact and be more memorable (Shakespeare & Kleine, 2013). Including persons with disabilities is empowering as it provides them a voice as there is a gap in research concerning voices of individuals who experience disability themselves.
Communication abilities: Participants had to be able to orally express themselves.	Self-report	Focus groups can be challenging, especially if participants use different means of communication (Kroll, Barbour & Harris, 2007).
Caregivers of persons with disabilities		

Age: Participants had to be 18 years and older	Biographical Questionnaire (Appendix I)	Same as for persons with disabilities.
Language: Participants had to be fluent in SiSwati and/or English	Biographical Questionnaire (Appendix I)	Same as for persons with disabilities, except for the section that refers to literacy levels that may affect English language proficiency.
Number of years as caregivers: Participants had to be primary caregivers of persons with disabilities, at least 6 months or more	Biographical Questionnaire (Appendix I)	Caregivers who have cared for a person with disabilities for longer periods would be better informed on disability issues and would have a better idea of the experiences of accessing healthcare (Findlay, Williams, Baum & Scior, 2015)

Healthcare Professionals

Language: Participants had to have conversational spoken skills in SiSwati and/or English	Biographical Questionnaire (Appendix I)	There are two official languages in Eswatini, namely SiSwati and English (Constitution of the Kingdom of Swaziland, 2005). SiSwati is the mother tongue that is spoken by the overwhelming majority of the Eswatini community. Services are therefore often provided in SiSwati
Work Experience: Participants had to have at least 12 months' experience of assessment, management and rehabilitating persons with disabilities	Biographical Questionnaire (Appendix I)	Professionals with more working experience with persons with disabilities, demonstrated more positive attitudes towards disability (Sahin & Akyol, 2010; Satchidanand, McGuigan, Symons & Akl, 2012) and would therefore be familiar with disability issues and be able to engage in a meaningful discussion on accessibility to healthcare for persons with disabilities.
Professional Qualification and Registration: Participants had to be registered with the medical, nursing and allied health or rehabilitation health council of Eswatini	Biographical Questionnaire (Appendix I)	

6.3.2 Participant Recruitment

Prior to the recruitment of participants, ethics approval was obtained from the Research Ethics Committee at the Faculty of Humanities, University of Pretoria

(Appendix A), the Eswatini Health Research Review Board (Appendix B), the president of the National Disability Organisation in Eswatini (Appendix C) and from the Director of the Ministry of Health in Eswatini and the superintendent of the public tertiary state hospital in Mbabane, Eswatini (Appendix D).

In order to achieve the main aim of Data Source 3, three different participant groups who met the criteria stipulated in Table 13 were recruited to participate. Twelve persons with disabilities and twelve caregivers of persons with disabilities as potential participants were recruited via the National Disability Organisation, which is the governing body for persons with disabilities in Eswatini. The president of the National Disability Organisation was contacted telephonically to request permission to use his organisation to recruit participants for the study. This request was followed by a formal letter of request which included details about the study. The formal letter allowed him to make an informed choice regarding the participation in study and also afforded him the opportunity to provide written permission to allow the researcher to recruit participants through the organisation. The president made contact with potential participants himself, informing them of the study purpose and method and also provided them with the researcher and the research fieldworker's contact details. He also clearly explained what would be required of the participants. Participants who were interested in participating made contact with the research assistant, after which further information pertaining to dates and venues for the focus groups were communicated to them. Five persons with disabilities and six caregivers of persons with disabilities came to the pre-arranged venues on the agreed upon dates and times. Before the focus group commenced, all participants gave verbal and written consent to be recorded and to take part in one of the focus groups respectively.

Twelve healthcare professionals were recruited from a public tertiary state hospital in Mbabane. The Director of Health, who is also a superintendent of the hospital, was contacted telephonically and then a follow-up letter outlining study details and requesting permission was hand-delivered to her. The Director informed the researcher that the study would only be permitted after it has been approved by the Eswatini Health Research Review Board. After permission had been granted by this

board (Appendix B), the Director subsequently approved the study (Appendix D). The researcher proceeded to approach healthcare professionals who met the selection criterion on an individual basis, starting with the speech and language therapy department at the hospital. After explaining the research to the speech language therapist who had agreed to be part of the study, she offered to assist with recruiting other allied healthcare professionals. The speech language therapist approached allied healthcare professionals and provided verbal and written information on the study (Appendix J). Potential participants who agreed to participate were given the date and venue for the focus group. At the same time, the researcher approached nursing and medical staff, also giving them verbal and written information about the study (Appendix J). Those who agreed to participate were given the date and venue for the focus groups, which was scheduled over their lunch hour to allow the least interference with work schedules as possible. Seven healthcare professionals honoured the appointment for the focus group, and provided written consent to participate, and to also be audio recorded.

On closer analysis of the healthcare professionals focus group composition, it was evident that only rehabilitation staff members, specifically speech language therapists, an audiologist, occupational therapists, physiotherapists and an orthopaedic technician were part of the focus group participants and that no medical and nursing staff participated. This was therefore not representative of healthcare professionals. It was concerning that the voices of medical doctors and nursing staff were not represented at all. The researcher addressed this by again making telephonic contact with the Director of Health in Eswatini requesting her assistance in recruiting specifically medical officers and nursing professionals. The Director indicated that the busy and unpredictable schedules of these medical officers made participation in focus groups challenging due to the fact that it necessitated synchronous time, making it difficult for them to participate in focus group discussions. She therefore suggested that the questions rather be emailed to these potential participants. A questionnaire with the same questions to those asked in the focus group with healthcare professionals (Appendix M) was emailed to the Director of Health, who in turn, distributed it, not only to medical officers and nursing professionals, but also other rehabilitation health professionals. The same biographical questionnaire that was

used by focus groups participants was also completed by participants (Appendix I). Participants were informed that by completing the electronic questionnaire, they were giving consent to participate in the study. A total of seven participants completed and returned the electronic questionnaire.

6.3.3 Participant Description

6.3.3.1 Focus Group 1: Persons with disabilities

Despite recruiting 12 potential participants with disabilities, only five participated in this focus group. This falls within the suggested focus group size of between three and eight participants as this allows for a rich discussion while being manageable in terms of logistical arrangements (Braun & Clarke, 2013). This group size is also well suited when discussing more sensitive topics where there may be a risk for distress or intense responses (Smith, 1995). Even though smaller focus groups are advantageous, they do, however, run the risk of producing less diverse viewpoints (Morgan, 1997). This was not the case in the study because even though the group was relatively small, the group was diverse in terms of the number of years that they had lived with a disability and sufficient data were collected. Participants of the persons with disabilities focus group are described in Table 14 according to a number of biographical characteristics.

Table 14: Description of the Participants in the Persons with Disabilities Focus Group

Criteria	PWD 1.1	PWD 1.2	PWD 1.3	PWD 1.4	PWD 1.5
Age	50 years	44 years	48 years	41 years	40 years
Gender	Male	Male	Female	Female	Female
Languages spoken	SiSwati English	SiSwati	SiSwati; English	SiSwati; English	SiSwati; English
Place of residence	Matsapa (urban)	Makholokholo (peri-urban)	Mahwalala (peri-urban)	Ezulwini (urban)	Fonteyn (peri-urban)
Type of disability	Visual impairment	Physical impairment	Physical impairment	Visual impairment	Visual impairment

Number of years living with a disability	50 years	19 years	31 years	20 years	18 years
Frequency of visits to healthcare facility	8 times a year	6 times a year	6 times a year	4 times a year	2 times a year

Three of the five participants were female, and save for one male who only spoke SiSwati, all spoke both SiSwati and English. Only one participant was born with a disability (PWD 1.1), whilst the other four had acquired disabilities, due to illness (PWD 1.4; 1.5) and accidents (PWD 1.2; 1.3). Participants visited a healthcare facility on average five times (range 2-8), a year and three of the five participants reside in the outskirts (peri-urban) of the Mbabane, the capital city (PWD 1.2, 1.3 and 1.5) while two participants (PWD 1.1; 1.4) reside within a radius of between 14 and 28 kilometres from the capital city, Mbabane, in Ezulwini and Matsapa respectively.

6.3.3.2 Focus Group 2: Caregivers of Persons with Disabilities

A total of six caregivers of persons with disabilities participated in this focus group. As mentioned earlier, 12 participants initially agreed to participate following the recruitment, but on the day of the focus group, only six were available. This is an adequate focus group size as it allowed for all participants to engage and contribute meaningfully to the discussion (Krueger, 2002). Stewart, Shamdasani and Rook (2007) caution that groups with participants less than six tend to be dull and reveal less information while larger groups are difficult to control and can be difficult to get informative conversations. On the contrary, the group size and composition of the focus group for caregivers of persons with disabilities in this study proved ideal as it allowed for constructive engagement and yielded rich data on the experiences of the participants. Participants are described in Table 15 according to their biographical profile, including seven variables.

Table 15: Description of Participants in the Caregivers of Persons with Disabilities Focus Group

Question	CPWD 2.1	CPWD 2.2	CPWD 2.3	CPWD 2.4	CPWD 2.5	CPWD 2.6
Age	36 years	40 years	35 years	50 years	48 years	42 years
Gender	Male	Female	Female	Male	Female	Female
Languages spoken	SiSwati	SiSwati	SiSwati	SiSwati	SiSwati	SiSwati; English
Type of disability of person cared for	Physical	Physical and communication	Physical	Visual and communication	Intellectual	Communication
Place of residence	Nkwalini (peri-urban)	Mahwalala (peri-urban)	Mncitsini (peri-urban)	Matsapa (urban)	Mahwalala (peri-urban)	Mangwaneni (peri-urban)
Years caring for a person with a disability	10 years	7 years	5 years	15 years	8 years	7 years
Frequency of visits to healthcare facilities	12 times a year	12 times a year	3 times a year	3 times a year	6 times a year	6 times a year

From Table 16, it is clear that all but two (CPWD 2.1; CPWD 2.4) of the caregivers of persons with disabilities were women. All caregivers of persons with disabilities had been caring for a person with disabilities on average 8.7 years (range 5-15 years). Persons with disabilities being cared for presented with physical disabilities; communication disabilities and intellectual disabilities and the caregivers of persons with disabilities had been accompanying them to access healthcare services on average seven times (range 3-12 times) per year. All caregivers of persons with disabilities resided in the outskirts of the capital city, with one participant (CPWD 2.4) residing within a radius of 28 km from Mbabane.

6.3.3.3 Focus Group 3: Healthcare Professionals

A total of seven purposively selected healthcare professionals participated in this focus group which was considered an ideal size as it is big enough to generate rich

data, yet still small enough to facilitate discussion (Krueger, 2014). The focus group participants were comfortable with each other, because they worked closely on a day-to-day basis. As a result, rapport was quickly established, and participants felt free to share openly their experiences and perceptions. Participants of the healthcare professional's focus group are described in Table 16 according to the same biographic characteristics such as age, gender, languages spoken, level of education, years of experience practising and the frequency of them treating persons with disabilities is also mentioned in Table 16.

Table 16: Description of Participants in the Healthcare Professionals Focus Group

Criteria	HCP 3.1	HCP 3.2	HCP 3.3	HCP 3.4	HCP 3.5	HCP 3.6	HCP 3.7
Age	54 years	34 years	39 years	31 years	46 years	44 years	30 years
Gender	Female	Female	Female	Female	Female	Male	Female
Languages Spoken	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English
Profession	OT	PT	OT	PT	SLT/A	Orthopaedic Technician	SLT
Highest level of education	BSc Degree	BSc Honours Degree	BSc Honours Degree	BSc Honours Degree	BA Degree	Diploma	MSc Degree
Number of years practicing	26 years	10 years	15 years	8 years	18 years	17 years	8 years
Years working with persons with disabilities	26 years	10 years	15 years	13 years	23 years	20 years	8 years
Frequency of management of persons with disabilities	Daily	Daily	Daily	Daily	Daily	Daily	Daily

The healthcare professionals' participants were all employed by the Ministry of Health in Eswatini and were based in a public tertiary state hospital with some of them outreaching to other healthcare facilities, specifically community health centres on certain days of the week. Five of the seven participants (HCP 3.1, 3.2, 3.3, 3.4 and 3.5) had undergraduate degrees while one participant each had a diploma (HCP 3.6) and a Masters degree respectively (HCP 3.7). Their professional backgrounds and

work experiences varied (range 8-26 years) with an average of 16 years' experience working with persons with disabilities (range 8-26 years). However, no medical officers or nurses participated. All participants worked with persons with disabilities on a daily basis.

6.3.3.4 Electronic questionnaires completed by Healthcare Professionals

The electronic questionnaire was used as an additional data collection to the healthcare professionals' focus group source, to ensure that the study included the voices of medical officers and nurses since they were not represented in the focus group with healthcare professionals. A total of seven participants who were purposively selected using exactly the same criteria as for the focus groups completed the questionnaire that was emailed to them. The data from the electronic questionnaire was added as an extension of the focus group discussion to determine if new information was shared that was not reflected in the healthcare professionals' focus group.

Table 17: Description of Healthcare Professionals Participants who Completed the Electronic Questionnaire

Criteria	HCP 3.8	HCP 3.9	HCP 3.10	HCP 3.11	HCP 3.12	HCP 3.13	HCP 3.14
Age	49 years	31 years	30 years	36 years	39 years	43 years	37 years
Gender	Female	Female	Female	Female	Male	Female	Male
Languages	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English	SiSwati; English
Highest Qualification	MBCHB with additional qualification in MPH	BSW	BSC	BOccTher	MBCHB	MBCHB with additional qualification in MPH and Psychiatry	BCur
Profession	Medical officer	Social worker	Physiotherapist	Occupational therapist	Medical officer	Medical Specialist (Psychiatry)	Nurse
Number of years practising	18 years	2 years	6 years	6 years	15 years	16 years	5 years

Employer	MOH	DPMO	MOH	MOH	MOH	MOH	MOH
Frequency of management of persons with disabilities	Twice a week	Daily	Daily	Daily	Daily	Only when referred for conditions related to Psychiatry	Daily

Except for one participant who was employed by the Deputy Prime Minister's Office, all participants were employed by the Ministry of Health in Eswatini and based at public tertiary state hospitals. Five of the seven participants obtained a bachelors level degree (HCP 3.9, 3.10, 3.11, 3.12 and 3.14) while one each had a master's degree in public health (HCP 3.8) and a specialist degree in psychiatry (HCP 3.13), respectively. Three participants were qualified as medical officers; one participant was an occupational therapist; one a physiotherapist; one a social worker; and one a nurse. Participants had between two and 18 years' (m=9 years) practising experience.

6.4 SETTING FOR FOCUS GROUPS

The setting for all three focus groups was Mbabane in Eswatini, with additional electronic questionnaire data collected from healthcare professionals' participants who work in hospitals located in Piggs Peak, Mankayane and Hlathikhulu. The study setting is described in detail in section 3.4 of Chapter 3. The focus groups for persons with disabilities and caregivers of persons with disabilities were conducted in a seminar room offered by the Mbabane National Library. For both these focus groups, the room was arranged in a circular manner around a table at the centre. The microphone was placed at the centre of the table. A similar arrangement was used for the focus groups with healthcare professionals, in a boardroom that was offered by the hospital.

6.5 MATERIALS AND EQUIPMENT

6.5.1 Information Letter and Consent Forms

The same consent forms that were used in Data source 2 (Appendix H) were used for participants of the focus groups and who completed the electronic questionnaires.

6.5.2 Biographical Questionnaire

A biographical questionnaire was developed to obtain background information from persons with disabilities, caregivers of persons with disabilities and healthcare professionals who participated in Data Source 3 (Appendix I). Table 18 reflects the development of the biographical questionnaire according to the question number, the question, the type of question and the theoretical justification for the inclusion of each question.

Table 18: Development of the Biographical Questionnaire for Persons with Disabilities; Caregivers of Persons with Disabilities and Healthcare Professionals respectively

Question Number	Question	Question Type	Theoretical Justification
Biographical Information of Persons with Disabilities			
1.	What is your gender?	Closed ended, two options	Females with disabilities may experience different healthcare experiences than their male counterparts, with a suggestion that female persons with disabilities experience more unmet healthcare needs than their male counterparts (Sakellariou & Rotarou, 2017)
2.	What is your age?	Open ended	The legal consenting age is 18 years in Eswatini (National Youth Policy, 2014).
3.	What language do you speak?	Open ended	SiSwati and English are the two official languages in the Kingdom of Eswatini (Constitution of the Kingdom of Swaziland, 2005). Participants should therefore be able to express themselves in either of these languages
4.	Where do you reside?	Open ended	Healthcare access for persons with disabilities is poorer for those residing in LMICs especially if they reside in rural contexts (Vergunst, 2016)
5.	What type of disability do you present with?	Open ended	Persons with different disabilities have different experiences of access to healthcare. On the disability spectrum, persons with severe disabilities are most likely to experience more unmet healthcare needs

			than these with less severe disabilities (Sakellariou & Rotarou, 2017)
6.	How Long have you been living with a disability	Open ended	Living with a disability for longer periods may bring about rich experiences to share (Williams & Moore, 2011)
7.	How frequent access healthcare services?	Open ended	The frequency of accessing healthcare will enable participants to have richer stories to tell on their experiences (Williams & Moore, 2011)
Biographical Information of Caregivers of Persons with Disabilities			
1.	What is your gender?	Closed ended, two options	Literature has suggested a difference in the caregiving experience of male and female caregivers, resulting in contrasting views (Sharma, Chakrabarti, & Grover, 2016)
2.	What is your age?	Open ended	Caregivers of persons with disabilities at different ages present with different caregiving experiences (Masuku et al. 2018)
3.	Where does the persons with disabilities you are caring for reside?	Open ended	Access to healthcare services is challenging for persons with disabilities residing in LMICs especially rural contexts (Vergunst et al. 2015)
4.	What type of disability does the person you are caring for present with?	Open ended	The type of a disability that the caregivers of persons with disabilities is caring for has an influence on the caregiving experience of the caregiver (McNally & Mannan, 2013). The health needs of persons with disabilities also vary with the type of disability (Krahn, Walker & Correa-De-Araujo, 2015)
5.	How often do you accompany the persons with disabilities you care for to a healthcare facility?	Open ended	The frequency of visits to healthcare facilities will have an influence on the kind of experiences that caregivers have of access to healthcare for persons with disabilities
Biographical Information of Healthcare Professionals			
1.	What is your gender?	Closed ended, two options	Gender might have an influence on the way that the HCP participants view access to healthcare for PWD as demographic factors such as gender and age influence people's attitudes towards persons with disabilities (Leutar & Raic, 2008)
2.	What is your age?	Open ended	The consenting age in Eswatini is 18, and it was therefore important that participants are over 18 years (Swaziland National Youth Policy, 2014)
3.	Where do you currently work?	Open ended	The context in which Healthcare professionals work, will have an influence on the kind of experience of access to healthcare for persons with disabilities as the majority of healthcare providers were found to have been exposed to persons with disabilities

			through the provision of services (Devkota et.al., 2017).
4.	What is your profession?	Open ended	Undergraduate healthcare professionals training programmes which incorporate disability in various universities, regardless of speciality, result in healthcare professionals having positive attitudes toward persons with disabilities, especially those that highlight values, understanding the possible effect on patients and their families, and information about disability (Al-Abdulwahab & Al-Gain, 2003)
5.	What is your highest level of education?	Open ended	Knowledge and education regarding disability results in a positive attitude towards disability and persons with disabilities (Al-Abdulwahab & Al-Gain, 2003)
6.	How many years have you been practising in your profession?	Open ended	The amount of years spent practising might have an influence on the amount of exposure and interactions that the healthcare professionals will have had with persons with disabilities. Younger healthcare professionals were more positive in their attitudes towards persons with disabilities than the older providers owing to generational change in how disability is viewed, with disability increasingly becoming more culturally acceptable along with the notion of human rights as was observed in the study by Devkota et al. (2017)
7.	How many years have you been working with persons with disabilities?	Open ended	The amount of years spent working with persons with disabilities will have an influence on the experiences of healthcare professionals as research has suggested that those who experience more contact with persons with disabilities, appeared to have a more positive attitude and reduced fear of the unknown persons with disabilities (Al- Abdulwahab & Al-Gain, 2003)

6.5.3 Focus Group Script

A custom-designed focus group script (Appendix K) was used for all three focus groups to ensure consistency between the three groups and to increase the procedural integrity of data collection. The focus group script comprised three broad questions aimed (i) to extract information on the knowledge of the availability of the National Disability Policy of Swaziland and its contents pertaining to access to healthcare; (ii) to establish the participants' opinions on the perceived effectiveness of the National Disability Policy of Swaziland in ensuring accessibility with specific reference to healthcare services; (iii) to establish the experiences of persons with disabilities when they access healthcare services in Eswatini. Table 19 outlines the different questions

which were included in the focus group script, the probes that were used and the theoretical justification for the inclusion of each question. The same questions were also used in the electronic questionnaire completed by additional healthcare professionals.

Table 19: Questions Included in the Focus Group Script with Theoretical Justification

Questions	Theoretical Justification
<p>1. Could you tell me what you know about the National Disability Policy of Swaziland?</p> <p><i>Probes</i></p> <p>How were you made aware of the policy?</p>	<p>In the first data source of this study, there was an indication of poor implementation of the National Disability Policy of Swaziland, which would translate into the lack of awareness and knowledge of the policy (Shumba & Moodley, 2018). It was thus important to establish if it was indeed the perceptions among persons with disabilities, caregivers of persons with disabilities and healthcare professionals as Duncan, Sherry and Watson (2011) maintain that effective implementation of a policy depends on the empowerment of the stakeholders to policy content in order to encourage commitment.</p>
<p>2. What improvements have you seen since the inception of the National Disability Policy of Swaziland?</p> <p><i>Probes</i></p> <ul style="list-style-type: none"> • What improvement have you seen with regards to accessibility for persons with disabilities? • What improvements have you seen with regards to accessibility to healthcare services for persons with disabilities? • What other disability programmes and services have been implemented in the National Department of Health for the benefit of persons with disabilities as a result of the National Disability Policy of Swaziland 	<p>Governments often create disability policies simply as a symbolic gesture which results in gaps between policy and implementation. There is therefore a need for people on the grassroots level to hold governments responsible for policy implementation (Alant, Emmett & Samuels, 2007).</p>
<p>3. What are the experiences of persons with disabilities when they access healthcare services in Eswatini?</p> <p><i>Probes</i></p> <ul style="list-style-type: none"> • What are the difficulties that are experienced by persons with disabilities when they access healthcare services in Eswatini? 	<p>There is often a disconnect between what the policy promises and the actual experiences of the people at the grassroots level. It was therefore important to establish the actual experiences of persons with disabilities when they access healthcare services (Shumba & Moodley, 2018) from the perspectives of persons with disabilities, caregivers of persons with disabilities and healthcare professionals.</p>

- What support services are available in healthcare for persons with disabilities in Eswatini?
- What support services should be made available for persons with disabilities in Eswatini?
- What actions could be put in place to facilitate access to healthcare for persons with disabilities in Eswatini?

6.5.4 Recording Equipment

A digital recorder (Panasonic DVT 2510 for notes) along with an iPhone 6 were used to audio record discussions in all focus groups for data transcription and analysis.

6.5.5. Procedural Checklist

A procedural integrity checklist was developed by the researcher (Appendix L) as a quality assurance tool to ensure that the same steps were followed during data collection across discussions in the three focus group discussions. An independent coder calculated the procedural integrity of the focus groups scoring each of the 12 steps across the three focus groups. If the step was correctly followed, a score of 1 was given; if not followed, a 0 was given. A score out of 36 was calculated and converted into a percentage. The focus group process for the persons with disabilities focus group was 100%, that of the caregivers of persons with disabilities was 100% and that of healthcare professionals was 98%.

6.6. DATA COLLECTION

6.6.1 Focus Groups

Following the specific focus groups' recruitment, 12 steps were followed during the data collection process as outlined in Figure 6. All focus group discussions followed

the same steps as stipulated in the procedural integrity checklist (Appendix L), which was developed using guidelines stipulated by Braun and Clarke (2013). The same focus group questions outlined in the focus group script (Appendix K) were asked across all three focus groups. Focus groups were conducted over a two-week period, with four to five days between each focus group. The focus groups with persons with disabilities lasted for 125 minutes; that of caregivers of persons with disabilities lasted 108 minutes and that of healthcare professionals lasted 51.43 minutes. Figure 6 describes the 12 steps followed during data collection for Data Source 3.

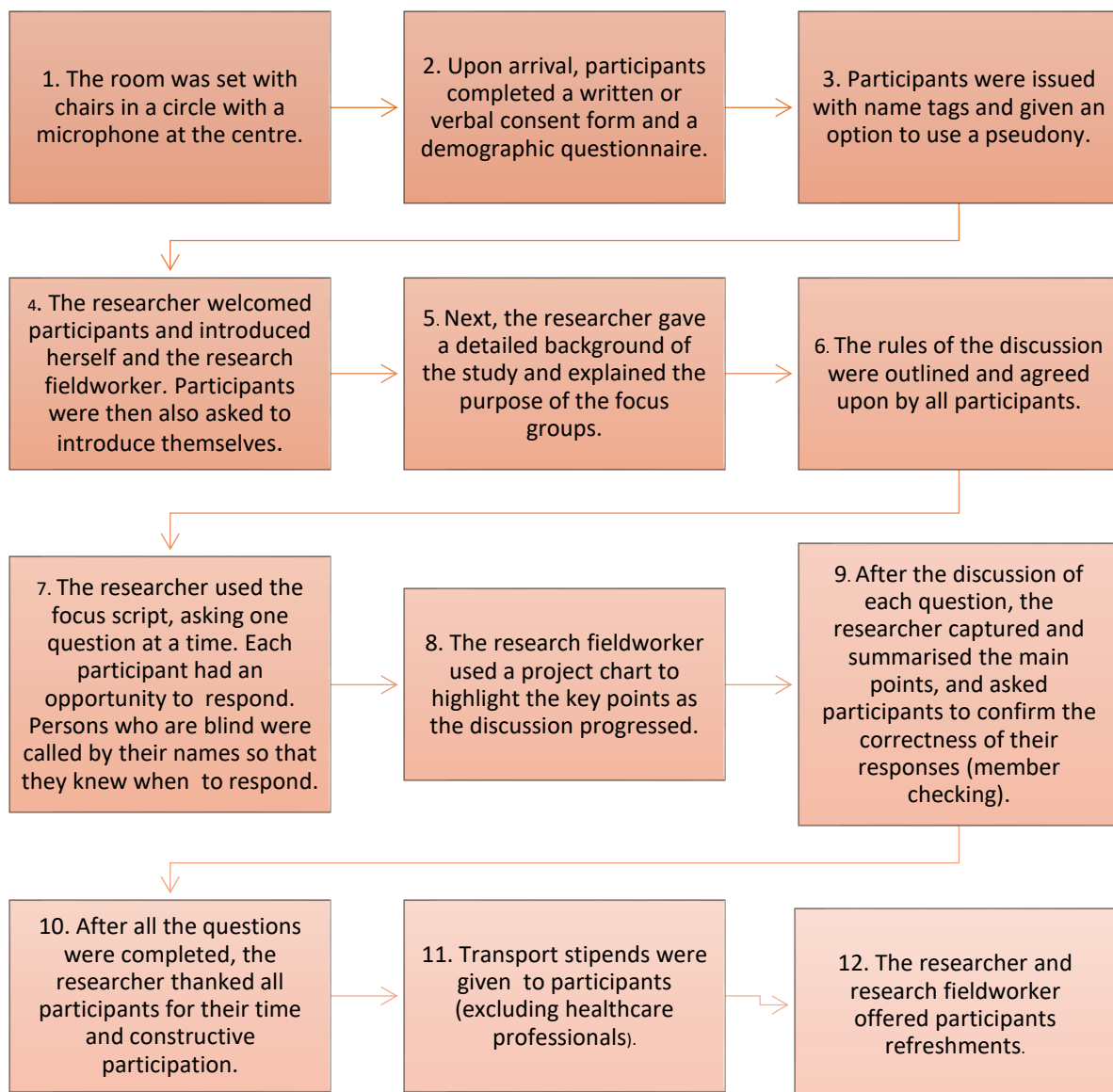


Figure 6: Data Collection Steps followed in Data Source 3

6.6.2 Electronic questionnaire

Telephonic contact was made with the Director of the Eswatini National Department of Health to request the recruitment of healthcare professionals with specific emphasis on medical officers and nurses. Once permission was granted, the electronic questionnaire was emailed to the Director who then approached potential participants who met the selection criteria of the study. Electronic questionnaires along with an information letter were emailed by the Director to these potential participants. They were informed that by completing the questionnaire, they were consenting to being part of the study. Healthcare professionals who consented and agreed to participate in the study completed the questionnaire and emailed it back to the Director. The Director then forwarded all completed questionnaires to the researcher, who subsequently started the process of analysing the data.

6.7 DATA ANALYSIS

A framework analysis approach, as proposed by Srivastava and Thomson (2009), was employed in the analysis of data collected from Data Source 3. In accordance with this approach, all the audio recordings from the focus groups were transcribed verbatim by the research fieldworker. The researcher then checked all the transcriptions against the original recordings to confirm the correctness of the transcriptions. Next, the transcribed data was translated from SiSwati to English by the research fieldworker. The researcher then checked all the translations for accuracy. Data from the electronic questionnaires did not have to be transcribed or translated as this was already available in written format and in English. The data from both methods of data collection of healthcare professionals (focus groups and electronic questionnaires) were collapsed into one and treated as one data corpus.

Inductive thematic analysis, a bottom up, data driven process of identifying patterns within qualitative data was used (Braun & Clarke, 2013). The aim of identifying important or interesting themes and to further use the themes to address the research question allowed the researcher to deeply explore the essence of the data (Maguire &

Delahunt 2017). This method is appraised as being flexible because it is not associated with a specific epistemology. First, the researcher familiarised herself with the data by reading it over and over again so that she could develop a deeper understanding and meaning of the data while at the same time developing insight into participants' experiences through their worldview. Next, the researcher and a second coder who has a PhD and has experience in the discipline of disability and study matter collaboratively coded the data, a process that was described in detail in section 5.6.3.

The entire data set was coded, identifying everything that was of interest and relevance to answering the research question (Braun & Clarke, 2013). The entire data set was read line by line by the researcher and the second coder who sat together to determine codes relevant to answering the research question. Coding was done on hard copy data, where codes were written in different coloured pens, with the text related to the code clearly marked with the same colour pen. Codes were allocated on agreement between the two coders. In instances where there was a disagreement, differences were discussed until consensus was reached. Coding was concluded by collating all the codes on a spreadsheet and under each code, with all the data excerpts that pertain to a specific code.

Once the coding was completed the researcher and the second coder examined the codes and coded data for recurring patterns or themes. In order for a theme to be included, there had to be an agreement between the researcher and the second coder. After the themes had been generated, the two coders then went back to compare the codes, the coded data and the themes to make sure that all three aspects fit, a process recommended by Braun and Clarke (2013) for quality control. Following that, the generated themes were further mapped into the pre-determined themes (components) of the Integrated Disability Policy Analysis Framework.

6.8 FINDINGS FROM DATA SOURCE 3

The findings are presented using the Integrated Disability Policy Analysis Framework which encompasses the actors, context, content and processes. The content component is further sub-divided into availability, acceptability, financial accessibility and geographical accessibility. Furthermore, themes pertaining to knowledge of and perceived effectiveness of the National Disability Policy Reform documents in facilitating access to healthcare are reported. The findings from each different stakeholder focus group are presented separately. Thereafter, a discussion follows.

6.8.1 Reports by Persons with Disabilities on the Actors

Persons with disabilities reported as far as they knew that disability organisations and the National Government of Eswatini were the two actors who were involved in the development and implementation of the National Disability Policy Reform documents. Disability organisations advocated for the development and implementation of these policy reforms, while the National Government's role was that of implementation of the policy reforms, as the main custodians of all national policy documents.

6.8.2 Reports by Persons with Disabilities on the Context

The following two themes reported by persons with disabilities on the context within which the National Disability Policy Reform documents were initiated.

Table 20: Context of the National Disability Policy Reform Documents as Reported by Persons with Disabilities

Themes	Sub themes	Excerpts from participants
CRPD Mandate	The state had ratified the CRPD	What prompted the disability policies was the passing of CRPD protocols (PWD 1.1)

Themes	Sub themes	Excerpts from participants
Need for disability awareness	The need for awareness on disability	<ul style="list-style-type: none"> There would be awareness about disability and a clear way forward because all along everyone was relaxed about it [Disability issues] (PWD 1.4).

Participants with disabilities indicated that the National Disability Policy Reform documents came about as a mandate from the United Nations after Eswatini ratified the CRPD. The policy and its supporting documents also came into being to create awareness around disability and disability rights of the citizens of Eswatini.

6.8.3 Reports by Persons with Disabilities on the Access

The content domains of the Integrated Disability Policy Analysis Framework are used as themes that denote the experiences of persons with disabilities when they reported on their experiences when accessing healthcare.

Table 21: Self-report Experiences of Persons with Disabilities when Accessing Healthcare Services

Themes	Sub themes	Excerpts from participants
Availability	Not mentioned	Not mentioned
Acceptability	Lack of Reasonable Accommodation across health care facilities	<ul style="list-style-type: none"> People in the ministry of health ask what you are doing and what you are thinking about when you get to home affairs it's the same thing; all ministries are not well versed with what to do in order to accommodate persons with disabilities (PWD1.1). One day they even had to call their supervisor because they didn't want me to jump the queue to get my blood pressure tested (PWD 1.4). At the dispensary, there is step that makes it difficult for a on a wheelchair to get closer when they go and collect medication. When I pick up medication I sometimes have to should for the attention of the person at the dispensary window (PWD 1.3)
	Negative attitudes of community health workers	<ul style="list-style-type: none"> We have community health worker, but when it comes to persons with disabilities, they don't pay much attention to persons with disabilities; they once admitted to me that they don't really

Themes	Sub themes	Excerpts from participants
		<p>bother visiting homes where there are persons with disabilities (PWD 1.3).</p> <ul style="list-style-type: none"> You have to maintain a good relationship with community health workers because in instances where you have a disagreement with them you will suffer, they won't help you (PWD 1.4) Sometimes they call us. They called me about a child from another area where the community health workers were refusing to give nappies to a child with a disability because she had had a disagreement with the mother of the child (PWD 1.3).
	Lack of Inclusion	<ul style="list-style-type: none"> There is lack of disability mainstreaming because disability is seen as a single entity (PWD 1.3). We do need disability inclusiveness so that issues of persons with disabilities are mainstreamed whether in the private sector or government (PWD 1.5).
	Inconsistency in the standards of care for persons with disabilities	<ul style="list-style-type: none"> So I feel like if there is someone who helps you and treats you well, it is because they personally have a sense of humility and not necessary because it is standard procedure to treat persons with disability with dignity (PWD 1.4) As far as I am concerned, I think that when you get to the hospitals it depends on the good kindness and humility of the person that you will find there and not necessarily because it is something that they are all trained in (PWD 1.5).
	Unavailability of health information in accessible language formats	<ul style="list-style-type: none"> When you go to the dispensary, sometimes you find that the security guards have taken you there and they the tables at you and the instructions are not written in braille (PWD 1.4). They could atleast tell you and say "this fat tablet, you take this many times a day or this small one you take this many times a day...at the dispensary window, they just give you the tablets and not emphasise how many times you are supposed to take them (PWD 1.5). That happened to me recently, it was written in red but I couldn't make out what it said, because I can't see, I took them and wondered why they were making me sick and then I asked a child to read the out to me only to find out that I was taking two tablets instead on one (PWD 1.4). They just give you the medication without asking and knowing whether you can read or not or whether you understand what is written on the pills (PWD 1.3).
	Discrimination against persons with disabilities regarding sexual health	<ul style="list-style-type: none"> I think that they also have a bad attitude especially towards women because we also have sex like everybody else but because they keep asking you what you were doing (PWD 1.3).

Themes	Sub themes	Excerpts from participants
	Lack of disability representation across all sectors	<ul style="list-style-type: none"> • Yes, the nurse will ask you what you were doing when you fell pregnant. You feel embarrassed because you feel like nothing like you have committed a sin (PWD 1.5). • I was thinking this morning that there should be someone who is living with a disability who will correct them and say that “this ramp is too steep; it is not right (PWD 1,1) • The solutions have always been there; the problem is that it’s what we have always been saying that they do what they think is the best to do for us. What we say is that they shouldn’t ever think for us (PWD 1.1). • I just don’t know who we could tell or teach so that when we plan anything the person with disabilities should be there (PWD 1.3).
Geographical Accessibility	Not mentioned	<ul style="list-style-type: none"> • Not mentioned
Financial Accessibility	Unavailability of social support grants	<ul style="list-style-type: none"> • But if they [persons with disabilities] are not protected socially how do they contribute to economic life. First though their own lives and then that of their children because they have children at home (PWD 1.1). • And our country has that they are waiting for the bill to be passed until they are in a position to help persons with disabilities socially through social protection (PWD 1.5) • There is a friend of mine, my neighbour who has a disability and has been asking for the grant since 1999, until today, he has not received that E200.00 (PWD 1.2).

Regarding availability, Eswatini, in a quest to ensure services delivery in communities where persons with disabilities reside, has employed community health workers. Even though they have been appointed to deliver services to persons with disabilities in communities, community health workers are not perceived by persons with disabilities as delivering services of high quality to persons with disabilities. Acceptability of persons with disabilities in Eswatini is perceived by persons with disabilities as a challenge as they still experience the lack of accommodation and mainstreaming across all entities. In particular, persons with disabilities reported that they experience inconsistency in the standard of care in healthcare facilities, health information is not available in accessible language formats and they experienced exclusion from obtaining services related to sexual and reproductive health. Ultimately, persons with disabilities in Eswatini reported that they are still discriminated upon and not represented in matters that concern them. While geographical access was not

mentioned by persons with disabilities in this study, they did state that they were struggling financially owing to the fact that the government had not yet made provisions for any form of social support grants for persons with disabilities at the time of conducting this study.

6.8.4 Reports by Persons with Disabilities on the Processes

The following themes capture the processes that were followed during the initiation, development and implementation of the Nation Disability Policy Reform documents according to persons with disabilities.

Table 22: Processes Followed in the Development and Implementation of the National Disability Policy Reform documents as Reported by Persons with Disabilities

Themes	Sub themes	Excerpts from Participants
Role of the National Disability Plan of Action	Availability of the National Disability Plan of Action as the blueprint of implementation	<ul style="list-style-type: none"> • Another form of implementation was coming up with other documents especially legislation but apart from the legislation, a disability action plan because there is a disability action plan (PWD 1.1). • We were able to say that it is a road map but required fencing and the fencing was the act which is still in the bill format (PWD 1.3).
	Inadequate dissemination of policy to persons with disabilities in rural areas.	<ul style="list-style-type: none"> • You will find that especially at the grassroots level, a lot of people didn't get information. But we tried to disseminate the information, there was a challenge with dissemination (PWD1.1) • I feel like the policy should have reached constituencies, but there are persons with disabilities in faraway rural places who have no idea about it. Do you see what I mean (PWD 1.4)?
Progress on policy dissemination and implementation	Lack of resources for policy dissemination	<ul style="list-style-type: none"> • We lack the resources for disseminating the policy (PWD 1.4). • Sometimes, it us lacking the muscle in the form of resources to do things like reaching the people at the grassroots level (PWD 1.3)
	Use of media to support policy dissemination	<ul style="list-style-type: none"> • The radio programme on Friday is okay, but it is short and not enough its 15 minutes (PWD 1.4).

Roles in policy implementation	Unavailability of policy translation in SiSwati and other language formats (policy in law language).	<ul style="list-style-type: none"> We could be sitting here and talking but what about the people at grassroots they probably don't get radio frequencies, but if we could find a way of getting to where people are we could get tangible results (PWD 1.5) The policy needs to be explained in both SiSwati so that even if you did not get the opportunity to go to school you will understand what is being said (PWD 1.2) Another thing is that it (policy) is too technical because they use law language in those things you don't know what they are saying but you might understand it if they bring it to you in SiSwati (PWD 1.1).
	Responsibility of government	<ul style="list-style-type: none"> Another thing is that I want to mention that the issue of dissemination is not ours, but rather the responsibility of the government (PWD 1.1) The resource to disseminate the policy will come from the government (PWD 1.5).
	Responsibility of disability organisation	<ul style="list-style-type: none"> What is our [disability organisations] is the issue of advocacy (PWD 1.1) We just need to make noise and insist that they take it to the people (PWD 1.5).

In agreement with reports from key informants, persons with disabilities confirmed that implementation of the National Disability Policy Reform documents is the responsibility of the government and they should therefore provide the financial and human resources for the processes, while the responsibility of disability organisations is advocacy for policy implementation. The National Disability Plan of Action was mentioned as the blueprint for implementation. The dissemination and implementation process has been hampered by the lack of resources for dissemination, the lack of translation into SiSwati and other understandable or easy language formats. Dissemination within rural areas is especially lacking. Even though dissemination of the policy reform documents has been challenging, disability organisations have also been trying to assist persons with disabilities by using media, such as radio, to support disseminate policy information.

6.8.5 Reports by Caregivers of Persons with Disabilities on the Actors

Similar to reports by persons with disabilities, the caregivers of persons with disabilities also mentioned the National Government, specifically the Deputy Prime Minister's Office as one of the actors who was involved in the implementation of the National Disability Policy Reform documents. The role that persons with disabilities and disability organisations played in advocating for the policy reform documents was also highlighted.

6.8.6 Reports by Caregivers of Persons with Disabilities on the Context

Table 23 depicts the themes related to the context of the National Disability Policy Reform Documents obtained from the focus group with Caregivers of Persons with Disabilities.

Table 23: Themes Depicting the Context of the National Policy Reform Documents as Reported by Caregivers of Persons with Disabilities

Themes	Sub-Themes	Excerpts from Participants
Welfare provisions for persons with disabilities	Support for persons with disabilities	The policy was about the welfare of persons with disabilities in the country and what is expected of the country in supporting persons with disabilities in education, health and the like (CPWD2.1).
	Registration of persons with disabilities	...It was about how we (Eswatini) needed to register all persons with disabilities so that they could be paid a grant (CPWD2.3).
Accommodation of persons with disabilities	Access to all services	...that we needed to be assisted in trying to access all of these services for our children (CPWD2.1).
	Inclusion of persons with disabilities in communities	There was a lot of emphasis on that we (Eswatini) needed not to look down at persons with disabilities (CPWD2.2)

Caregivers of persons with disabilities participants reported that the National Disability Policy Reform documents were developed and implemented to ensure the welfare of persons with disabilities in Eswatini. Caregivers of persons with disabilities also

mentioned that the policy reform documents were developed because there was a need for persons with disabilities to be registered to allow that they would be accounted for and supported. Therefore, establishing disability laws also ensured the facilitation of the accommodation and acceptance of persons with disabilities across all entities, according to caregivers of persons with disabilities.

6.8.7 Reports by Caregivers of Persons with Disabilities on the Experiences of Persons with Disabilities when Accessing Healthcare Services

Table 24: Experiences of Persons with Disabilities when They Access Healthcare Services as Reported by Caregivers of Persons with Disabilities

Themes	Sub-Themes	Excerpts from Participants
Availability	Availability of assistive devices community meetings	<ul style="list-style-type: none"> This [community meeting] is where I actually managed to get help for my own child who needed a wheelchair at that point (CPWD2.2). I eventually got courage to speak up [at a community meeting] and I got help because they gave me a wheelchair, even though the wheelchair is not in use now (CPWD2.3).
	Strengthening of community support groups	<ul style="list-style-type: none"> I really felt supported at these community meetings. I just hope that we could have consistent support structures in our communities (CPWD2.2) To be honest with you, there are structures that have been established to support caregivers in communities, it just seems like these are not available in all communities (CPWD2.5). I know that they [disability organisations] go to different communities encouraging us to form structures as parents and caregivers of persons with disabilities, it is unfortunate that it seems like they have not reached some constituencies (CPWD2.4)
	Centralisation of healthcare facilities to referral hospitals	<ul style="list-style-type: none"> They [healthcare professionals] say that they have these services, but the problem is that these services are centralised to referral hospitals, yet the people who need these services are in the outskirts of town and it's not easy for them to come through to town (CPWD2.4). I am of the idea that these [rehabilitation] services should leave the capital city and be closer to persons with disabilities (CPWD2.1).
	Strengthening of community outreach projects	<ul style="list-style-type: none"> We as parents also have to be creative in about ways in which we can use to reach out to parents and caregivers in all constituencies to encourage them that they should not hide their children and that they should also form support groups so that they know each other and are therefore able to support each other (CPWD2.5). But the programmes [community] need to be strengthened so that they are relevant and cater for most of the conditions of persons with disabilities (CPWD2.4).

Themes	Sub-Themes	Excerpts from Participants
	Valuing of peer support	<ul style="list-style-type: none"> In the past, there were things such as community outreaches where the services would come to the community, a lot of us benefitted but it seems that our government could not sustain it, maybe because it was an Non-Governmental Organisations' initiative (CPWD2.5) It is encouraging when you meet a fellow mother who also has a child with a disability (CPWD2.2). There is value in meeting as a group that shares similar experiences and challenges to meet, discuss issues and distress (CPWD2.4). I need to mention the importance of being around people who are in a similar situation as yours, it build you emotionally (CPWD2.1).
Acceptability	Hiding persons with disabilities	<ul style="list-style-type: none"> Some of us hide our children with disabilities because we don't want our communities and community health workers to know about them. They lock the children in the houses (CPWD2.4). So, you don't want people to know that you had the bad luck of having a disability or having a child with a disability so because you don't want the community to know, you just hide the child (CPWD2.1).
	Myths about the cause of disability	<ul style="list-style-type: none"> There is still the notion that when someone is living with a disability or has a family member with a disability, they are cursed (CPWD2.1). People are still unaware that disability is part of life. It is something that happens to you or your loved ones and you can live with it (CPWD2.1). We come from a society where our background has contributed to the notion that disability is a curse or it is something that is your own different thing (CPWD2.5).
	Negative attitudes of healthcare professionals	<ul style="list-style-type: none"> Even if you do get there [hospital], there is now the struggle with attitude. They will ask you Mummy how many children do you have. You will say that this is my fourth. They will tell you that the reason why you ended up with a child with a disability is because you kept giving birth (CPWD2.4). When you have a disability, you are undermined, treated badly and embarrassed in front of other patients (CPWD2.6).
	Negative attitudes of public transport drivers	<ul style="list-style-type: none"> Because even with the wheelchairs, you have to leave it at home sometimes because it causes a problem on the bus. You have this insensitive bus conductor complaining about your wheelchair (CPWD2.5). They will tell you that you and your child with a disability, you will delay them, and they just pass you at the station (CPWD2.5).
	Caregiver burden	<ul style="list-style-type: none"> So, what makes us and other caregivers react the way that we react is that we are really pulling hard (CPWD 2.1). The challenges that come with caring for a child with a disability are too overwhelming for any human being. It is even more difficult if you as a parent, you don't even have parents to lean on (CPWD2.2).
Geographical accessibility	Long travelling distances to healthcare facilities	<ul style="list-style-type: none"> You will go to the hospital and after assessing your child, they will tell you to come once or twice a month for review, but because the hospital is far you can't keep appointments (CPWD2.5).

Themes	Sub-Themes	Excerpts from Participants
Financial accessibility	Mountainous terrain	<ul style="list-style-type: none"> • These services are in the capital city, yet most of the persons with disabilities live in the outskirts of the city and therefore have to travel to get there (CPWD2.4). • As mothers, these children become heavy and it becomes a challenge to have to carry them on your back. Especially when you have one with cerebral palsy such as mine (CPWD2.5).
	Inconsistency in allocation of social support grant	<ul style="list-style-type: none"> • Maybe what has changed is that some persons with disabilities now receive the social grant. Oh well I am amongst the few that receive the grant (CPWD2.3). • We have been placed under the public assistance [social grant] as a by the way, because it has always been a secret and not everyone has been aware of it. It has been a hidden thing and the criteria for receiving is still not clear (CPWD2.4).
	High costs related to transportation to healthcare facilities	<ul style="list-style-type: none"> • Because we live under difficult financial conditions, we don't have the money to go up and down to and from the hospital because as a mother I also have other children to look after (CPWD2.5). • As for healthcare, to be honest, I don't go anymore, it is mostly due to the fact that I don't have money to get there (CPWD2.2).

With regards to availability, caregiver participants indicated the important role that communities and community support groups play in assisting caregivers of persons with disabilities regarding obtaining assistive devices and general support. The value of peer support was specifically highlighted. While the value of community support groups was acknowledged, the need to strengthen these was also mentioned, as currently not all constituencies have functional community support groups. Due to the shortage of healthcare professionals and the centralisation of services such as rehabilitation in referral hospitals, community outreach teams were established. These community outreach programmes were, however, not functional during the time of data collection and therefore need to be strengthened. There is also a need to re-engineer the healthcare system in such a way that healthcare services are not just centralised in referral hospitals to enable persons with disabilities who live further away from the city access to rehabilitation services.

Relating to acceptability, caregivers of persons with disabilities' participants highlighted how their own prejudice and discomforts, which they viewed as a way of protecting their children with disabilities from the public, resulted in them hiding their children from public spaces, including hospitals. The belief system around the cause

of disability and disability being a curse have also contributed to the continued discrimination against persons with disabilities with caregivers of persons with disabilities being conscious of having persons with disabilities and their children with disabilities in the public domains. Caregivers further reported how persons with disabilities continued to be discriminated against by healthcare professionals. Even public transport drivers had negative attitudes towards persons with disabilities, especially discriminating against persons with disabilities who used wheelchairs. Caregiver participants additionally highlighted the burden of caring for persons with disabilities.

With reference to financial accessibility, the inconsistency of allocation of social grants and the unclear criteria for allocating support grants was mentioned by caregivers of persons with disabilities as affecting the livelihood of persons with disabilities, who mostly represent the poorest of the poor. According to caregivers, persons with disabilities also struggle with the costs related to public transportation to healthcare facilities that could result in them not attending rehabilitation services. The contributory factor to the high transportation costs that are incurred by persons with disabilities when they must access healthcare services is the geographical location of comprehensive healthcare facilities relative to where persons with disabilities live. The mountainous and rural terrain is also a factor as caregivers of persons with disabilities sometimes must walk long distances to bus stations on foot while also having to carry their children with disabilities on their backs at times.

6.8.8 Reports by Caregivers of Persons with Disabilities on the Processes

Caregivers of persons with disabilities reported an unsuccessful implementation of the National Disability Policy Reforms as a result of the lack of political will from policy implementers as this was dependent on the interest of the current incumbent of the office responsible for co-ordinating disability and disability matters.

Table 25: The Processes of the National Disability Policy Reforms as Reported by Caregivers of Persons with Disabilities

Themes	Sub-Themes	Excerpts from Participants
Political will	Lack of political will from implementers	<ul style="list-style-type: none"> • ...because most of the time it depends on the political will of the incumbent of the office. When the former Deputy Prime Minister was there things were moving (CPWD2.4). • Currently the mother ministry is sitting down and not fully committed (CPWD2.5).

Caregivers of persons with disabilities mentioned that the policy has been unsuccessful in meeting the needs of persons with disabilities in Eswatini attributing it to the lack of political will from the incumbents of the government offices who are responsible for policy implementation.

6.8.9 Reports by Healthcare Professionals on the Actors

Table 26: Actors of the National Disability Policy Reforms Documents as reported by Healthcare Professionals

Actors	Role
All Government Ministries	<ul style="list-style-type: none"> • It is sort of at the level of the strategic plan, the plan of action I mean, because it was inter-ministerial, and the different ministries were supposed to sort of contribute to it to implement the policy (HCP 3.6).
Deputy Prime Minister's office	<ul style="list-style-type: none"> • So, the deputy prime minister's office actually undertook that activity of facilitating the process (HCP 3.1).
Private Sector Organisations	<ul style="list-style-type: none"> • Private sector organisations and non-governmental organisations were offering advice and some funding (HCP 3.9).

Healthcare professionals expressed that to their knowledge, all the government ministries and private sector organisations were involved in the development of the National Disability Policy of Swaziland. They also mentioned that the National Disability Plan of Action was developed as a way of implementing the policy. The processes of development and implementation were reported to be facilitated by the Deputy Prime Minister's Office.

6.8.10 Reports by Healthcare Professionals on the Context

Table 27: Context of the National Disability Reform documents as Reported by Healthcare professionals

Themes	Sub-Themes	Excerpts from Participants
Formal Register of persons with disabilities	Need for a disability register	<ul style="list-style-type: none"> • So, the exact number of persons with disabilities was not known, this means that there will now be a record of persons with disabilities (HCP3.1). • That was one of the weak links, one of the lawyers in the meeting said that Eswatini can't really do much about the law on disability if it has no idea of the number of persons with disabilities there are, so they can't make a law that puts things in place when they are not even aware of the number of people that they are putting these things in place for (HCP3.6).
Human Rights of persons with disabilities	Protect the rights of persons with disabilities	<ul style="list-style-type: none"> • The policy was introduced to address the rights and welfare of persons living with disabilities (HCP3.9) • To promote and protect the rights of persons with disabilities (HCP3.13)
International Mandate	Recommended by World Health Organisation	<ul style="list-style-type: none"> • It came from a recommendation by the World Health Organisation¹ in a meeting I think in 2012/2013, oh yes, 2013 and they said that member countries must have plans of actions towards persons with disabilities and these had to be inter-ministerial, inter-sectoral and should involve persons with disabilities (HCP3.6).

As per the information provided by healthcare professional participants, prior to the development of the National Disability Policy Reform documents, Eswatini did not have a formal register of persons with disabilities, which was hindering progress in terms of establishing laws pertaining to disability. Therefore, the National Disability Policy Reforms were developed as part of the mandate of the World Health Organisation, according to healthcare professionals.

¹ The National Disability Policy Reform documents were developed as mandate from the UN and not by the WHO, but is reported as such because it is what participants reported.

6.8.11 Reports by Healthcare Professionals on the Experiences of Persons with Disabilities when Accessing Healthcare Services

Table 28: Experiences of persons with disabilities when they access healthcare services as reported by healthcare professionals

Themes	Sub-Themes	Excerpts from Participants
Availability	Limited availability of healthcare professionals and services	<ul style="list-style-type: none"> • At the moment, with the limited number of people, two speech therapists based at this hospital, but basically servicing all of Eswatini, because somehow everyone ends up here (HCP3.4). • Services such as rehabilitation are centralised to big hospitals. We in actual fact, are the only hospital with all the services (HCP3.7). • Mbabane is probably the only hospital that has all the health services together under one roof, if you would go to hospitals in the periphery, you would find maybe medical and nursing with a physio being the only rehabilitation professional (HCP3.6). • There is a limited number of allied professionals especially speech language therapists (HCP3.11).
	Unavailability of dedicated budget for rehabilitation services	<ul style="list-style-type: none"> • It is rehabilitation services that I have never seen being budgeted for. It is not like there was ever a budget and then it ran out, it is a matter of the budget never ever being there (HCP3.5). • So basically, there is no budget line allocated towards rehab services and this facility has to find a way of making or being able to procure stuff for their department (HCP3.6).
	Unavailability of disability outreach programmes	<ul style="list-style-type: none"> • Because at some point they facilitated outreaches for persons with disabilities, but that could not be sustained because of shortage of healthcare professionals (HCP3.4). • the main problem is that the Ministry of Health does not have a disability programme or a rehabilitation programme that is established within the ministry that you know you can go to... (HCP3.6).
	Lack of availability of certain assistive devices and limited maintenance	<ul style="list-style-type: none"> • ...persons with disabilities do receive assistance from the Phalala fund to get prosthetic limbs from South Africa once-off. The challenge comes when the prosthetics need to be repaired and fittings (HCP3.2). • Because there is no budget line that they can go to where someone will say here you guys, here is some money to buy equipment and assistive devices, acquiring these is a problem (HCP3.6). • ...we were able to procure equipment and assistive devices, because we were included as part of the budget of the new structure when the new hospital wing was constructed (HCP3.6). • There are no assistive devices and other communication aids (HCP3.11).

Themes	Sub-Themes	Excerpts from Participants
	Limited availability of support structures for caregivers of persons with disabilities	<ul style="list-style-type: none"> • There is limited communication support because of the unavailability of communication aids (HCP3.11). • The other thing is that we don't have support services for parents of children with disabilities (HCP3.6). • ...but it (information on support structures) still reaches a small percentage of persons with disabilities and mothers of children with disabilities. The majority of them do not know that it exists, it therefore does not reach the majority of people (HCP3.5).
Acceptability	Physical accessibility is addressed	<ul style="list-style-type: none"> • ...it is possible that just this hospital has a ramp, a wheelchair ramp and that the rest of the other hospital may have spaces that PWD can move around comfortably (HCP3.5) • through the Deputy Prime Minister's office so there is a general awareness that whatsoever infrastructure that you put up, you should be mindful of physical access (HCP3.6) • Even the passages are made wider to accommodate wheelchairs for ease of access for those who are in wheelchairs (HCP3.1). • Some hospitals have all rooms are accessible by wheelchair, such as Mankayane Hospital (HCP3.8). • There is availability of wheelchairs to move the disabled people around [Hospital facilities] HCP3.8). • There are wheelchair friendly walkways in some healthcare facilities (HCP3.12).
	Lack of disability knowledge amongst healthcare professionals	<ul style="list-style-type: none"> • Healthcare professionals lack knowledge on disability (HCP3.9). • Lack of knowledge of all disability conditions amongst us [healthcare professionals] (HCP3.10) • Lack of awareness and experience of healthcare workers/professionals with persons with disabilities (HCP3.11) • Not all healthcare professionals are capacitated on disability (HCP3.11) • There are no clear protocols available to healthcare professionals to assist them in caring for specific needs of persons with disabilities (HCP3.12)
	Need to address communication barriers	<ul style="list-style-type: none"> • ...my patients with speech and language impairments and those who are hard of hearing or even deaf, meeting their communication needs is difficult because sometimes at the help desk, they are not understood (HCP 3.1). • There is poor communication skills between healthcare professionals and persons with disabilities (HCP3.9). • Communication is poor amongst persons with disabilities and healthcare professionals (HCP3.10).

Themes	Sub-Themes	Excerpts from Participants
	Need for sign language training and support	<ul style="list-style-type: none"> • There are nurses and some of us here that have been trained in sign language, but the challenge, I am sure my colleagues will agree with me, that you attend the sign language training, but when you come back you do not use it and then lose it (HCP3.6). • There are people that are trained in sign language that were placed at access points to assist deaf individuals around this hospital; however, I am not sure if these services are available in other healthcare facilities (HCP 3.5). • We do not have sign language interpreters. So, accessing health information is a challenge if persons with disabilities cannot hear or see, they won't be able to access health information (HCP3.6). • Very few health workers are trained in sign language to assist those who are deaf (HCP3.8).
	Require information in braille	<ul style="list-style-type: none"> • Our health information is also not available in braille (HCP3.2). • Another thing is that in terms of braille, our policies, documents, health information and so forth are not available in braille. I have heard that National Emergency Response Counsel on HIV and AIDS (NERCHA) has something in braille, I am not sure what it is (HCP3.6). • There are no braille signs for the visually impaired to be able to navigate around the facility (HCP3.8).
	Address disability stereotypes about disability	<ul style="list-style-type: none"> • There is an attitude towards persons with disabilities as a result of stereotypes (HCP3.9) • There is a lot of negative stereotypes about disability (HCP3.10).
Financial accessibility	Financial costs related to healthcare	<ul style="list-style-type: none"> • At some point there was a rumour that persons with disabilities would not pay for health services, I heard that the ministry would provide free healthcare services (Participant HCP3.5). • Free health services for persons with disabilities has not yet been implemented (HCP3.6). • ...persons with disabilities wouldn't have to come here and tell you that I had to sell my last chicken to get to the hospital or than today someone said that they did not come because of financial reasons (HCP3.3). • There is highly subsidised and free health services for those who cannot afford (HCP3.8).
	Inconsistency in social support grants allocation to persons with disabilities	<ul style="list-style-type: none"> • The disability grants, though limited as they are not received by every individual who has a disability (HCP 3.9). • The disability grants via the Deputy Prime Minister's Office are halted or selective (HCP3.10).
Geographical accessibility	Transportation challenges	<ul style="list-style-type: none"> • ...Transportation is a big issue for persons with disabilities, especially when they have to reach facilities that have all the services that they need like this one. Transportation is a big

Themes	Sub-Themes	Excerpts from Participants
		<p>problem when they have to access healthcare services (HCP3.3).</p> <ul style="list-style-type: none"> • The distance between their homes and the healthcare facilities is quite long, so persons with disabilities struggle with transport (HCP3.5). • Inaccessibility to public transport, such as having to pay extra for wheelchairs, or paying for the person accompanying the person the disabled (HCP3.11).

Healthcare professional participants emphasised the shortage of healthcare professionals and healthcare services in Eswatini. As a result of this shortage, disability outreach programmes to communities where persons with disabilities reside, even though initiated by healthcare professionals in referral hospitals have largely been unsuccessful. Consequently, persons with disabilities are not adequately provided with support structures in their local communities. According to healthcare professionals, currently, there is no budget allocated for rehabilitation services, for issuing and repairing of assistive devices and for healthcare equipment. The government does, however, through the Phalala fund, finance persons with disabilities who require prosthetics to go to South African healthcare facilities to obtain such assistive devices. The challenges arise when those prosthetic devices require maintenance and repair as there is no specific budget allocated for repairs.

Concerning acceptability, healthcare professional participants stated that Eswatini should be commended for the strides that it has made with regards to ensure physical access for persons with disabilities in healthcare facilities. Even though progress has been made with regards to ramps and widening of passages for ease of wheelchair access, these changes are not standard across all healthcare facilities. Despite the fact that sign language training had been provided to healthcare professionals, they had lost their signing skills, because they did not continue practising it. Consequently, communication between people with hearing and/or communication disabilities have not been sustained, which resulted in communication barriers remaining. Healthcare information has also not been translated into formats that are understandable to persons with disabilities with low literacy and those with visual impairment. Policy pertaining to the payment or non-payment of hospital fees by persons with disabilities

is ambiguous and often unclear. Healthcare professionals also mentioned, similar to other stakeholder groups that the physical distance between healthcare facilities and persons with disabilities resulted in many negative financial implications.

6.8.12 Reports by Healthcare Professionals on the Processes of the National Disability Policy Reform documents

Table 29: Processes of the National Disability Policy Reforms as Reported by Healthcare Professionals

Themes	Sub-Themes	Excerpts from Participants
Strategic plan	Develop a strategic plan	<ul style="list-style-type: none"> I think that they said that we should have a strategic plan before the action plan. The action plan was meant to go with the strategic plan. The action plan was meant to go hand in hand with the strategic plan (HCP3.4). There was no strategic plan per se, that was actually put in place before the plan of action. It is sort of at the level of a strategic plan (HCP3.6).
National Disability Policy of Swaziland	Role of the National Disability Plan of Action in implementation	<ul style="list-style-type: none"> The plan of action was inter-ministerial, and the different ministries had to contribute to it as a way of implementing the policy (HCP3.1). The plan of action was based on the National Disability Policy of Swaziland as a way of implementing it (HCP3.6).
Progress in implementation	Unsuccessful implementation	<ul style="list-style-type: none"> ...the Ministry of Health cannot claim to have implemented this and this aspect of the policy, when all that we are doing is all that we have been doing before the policy, we are not guided by any document. We are providing services the same way as before (HCP3.6). There is no change in the way that we are treating persons with disabilities as a result of the policy document (HCP3.2).

There were uncertainties amongst healthcare professionals about the strategic planning meeting that occurred before the development of the National Disability Plan of Action. The National Disability Plan of Action which was based on the National Disability Policy of Swaziland subsequently followed this meeting. Since the introduction of the policy reform documents, it seems as if healthcare professionals are practicing the same way that they have always practiced with limited or no influence from the policy reform documents.

6.9 DISCUSSION OF THE FINDINGS FROM DATA SOURCE 3

6.9.1 Actors

According to findings from Data Source 3, the actors of the National Disability Policy Reform documents were disability organisations and the National Government, specifically all the Government Ministries and the Deputy Prime Minister's office, whose roles were that of advocacy and implementation respectively. These findings were in line with findings from the previous two data sources (Data Source 1 and 2).

6.9.2 Context

Findings from Data Source 3 confirmed the results on the context of the policy reforms documents as obtained from the earlier data sources, namely the document analysis and in-depth interviews with key informants. All three data sources reported that the National Disability Policy Reform documents were developed as a mandate emanating from Eswatini ratifying the CRPD (Deputy Prime Ministers' Office, 2013) and further revealed the policy as an obligation from the United Nations. Findings also showed that it was necessary to have a policy on disability as it would facilitate the creation of awareness around disability and disability rights in Eswatini, a country where disability rights had previously been ignored (Eide & Jele, 2011). The creation of awareness around disability and disability rights is one of the underlying principles of the CRPD, as Article 8 obliges signatory states to promote awareness of disability and the subsequent rights of persons with disabilities in communities (United Nations, 2006). Prior to the National Disability Policy Reform Documents, there was a lack of accommodation for persons with disabilities that resulted in these individuals struggling to access services and they felt unaccepted and excluded from their respective communities (Deputy Prime Minister's Office, 2013). This finding is consistent with the background of a South African policy where reasonable accommodation is one of the fundamental principles of disability legislature (South African Department of Public Service and Administration, 2015). Subsequently, the National Disability Policy Reform Documents were developed to ensure the welfare of

persons with disabilities through creating support structures for them and their families, and also, creating a formal register for all persons with disabilities.

6.9.3 Content

6.9.3.1 Availability

Participants indicated that there was a serious shortage of healthcare professionals in Eswatini, in particular, rehabilitation healthcare professionals due to inadequate funded posts. This shortage of healthcare professionals is a challenge that is not specific to Eswatini, but also faced by the public healthcare systems across the Sub-Saharan African countries. Data Source 2 (key informants' in-depth interview) and numerous published studies (Maart & Jelsma, 2014; Sherry, 2014; Shirazikhah et al. 2017; Shumba & Moodley, 2018; South African Presidential Health Summit Report, 2018; Visagie et al. 2013) support this finding. The shortage of rehabilitation healthcare professionals hamper rehabilitation services as evident in a Namibian study (Shumba & Moodly, 2018b) and further affect the distribution of assistive devices as seen in the case of South Africa (South African Presidential Health Summit Report, 2018; Visagie et al. 2013).

In an attempt to address the shortage of healthcare professionals who support persons with disabilities, the National Government made community health workers available to attend to the health-related needs and well-being of persons with disabilities in their respective communities. This is congruent with reports by MacGregor, Zihindula and Ross (2018), where the recruitment rural youth to train as healthcare workers was used as an initiative to keep community-based rehabilitation services functioning, regardless of the shortage of healthcare professionals (specifically, in underprivileged communities). The concept of community health workers dates as far back as the 1970s as a World Health Organisation strategy to improve the lives of persons with disabilities by providing basic rehabilitation services at the community level (Helander, Mendis, Nelson & Goerd, 1989). Even though the community health workers were appointed in communities in Eswatini, they were not adequately supporting persons

with disabilities and persons with disabilities mentioned that they were sometimes victimised by these community health workers.

The inadequate support of community health workers for persons with disabilities and their families may be attributed to their insufficient training on how to support persons with disabilities (Como & Batdulam 2012). Hartzler, Tuzzio, Hsu and Wagner (2018) outlined the role of community health workers as the following: (i) clinical services that focus on health assessment and remote care such as assessment of patients' vital signs, lifestyle, health knowledge, psychosocial factors, and care through routine examinations aided by remote communication with the treating physician; (ii) common community resource connection such as the referrals for transportation or food assistance, on-going social support and follow-up phone calls and uncommon community resource connections such as remote care, education, and literacy support and; (iii) health and education coaching, which encompasses motivational interviewing and action planning to help persons with disabilities to achieve their health goals.

The financial struggle of the country has also resulted in the Ministry of Health of Eswatini not allocating a budget for rehabilitation services for goods and services, similar to a finding by Shumba and Moodley (2018). Ergo, rehabilitation is struggling to issue and repair assistive devices. This finding is contradictory to results from the document analysis and reports from the in-depth interviews with key informants (Data Source 1 and 2) indicated that assistive devices will be issued and repaired for persons with disabilities by public healthcare facilities. Persons with disabilities, caregivers of persons with disabilities and healthcare professionals' participants reported that Eswatini inadequately followed through with the recommendations of Articles 2, 20 and 26 of the CRPD, where states are requested to promote the availability of assistive devices to persons with disabilities who require them (United Nations, 2006). The World Health Organisation (2010) also reported that, by the year 2010, only 5 to 10% of persons with disabilities in LMICs who required assistive technology had access to them. De Witte et al. (2018) also mentioned that currently, persons with disabilities in Eswatini who require prosthetics receive these from the support of Phalala Fund, a

fund that was initiated by the government of the Eswatini to support Eswatini citizens to receive special care to be provided by neighbouring South Africa. Other forms of assistive devices such as walking aids, white canes and wheelchairs were reported to be received with the assistance from communities through being involved in community meetings. De Witte et al. (2018) confirmed that in LMICs, assistive devices were often made available through non-governmental organisations which frequently resulted in the provision of a narrow range of assistive devices such as wheelchairs and prosthetics. No mention has been made of augmentative and alternative communication devices such as speech generating devices, implying that persons with communication challenges are not catered for by the government of Eswatini.

Community support groups were deemed valuable, especially in providing peer support to caregivers of persons with disabilities. Similarly, Friedman Narr and Kemmery (2014) reported positive outcomes when peer support for parents of deaf/hard of hearing children were provided by mentors who had the same experience of raising children who are deaf/blind/hard of hearing. The challenge however is that community support groups were not equally functional across all communities where persons with disabilities in Eswatini reside. Therefore, there is a need to strengthen the breadth and reach of community support outreach programmes across all communities in Eswatini.

As with findings from Data Source 2, participant reports from Data Source 3 mentioned that despite the fact that healthcare facilities (mainly clinics and healthcare centres), the centralisation of rehabilitation services to referral hospitals which are mostly based in urban areas, poses a challenge. Even the essential package of health services of Eswatini confirmed that the comprehensive package of rehabilitation care is only offered at tertiary hospitals and not at community clinics (Ministry of Health, 2010) despite the latter being the closest to persons with disabilities. Rehabilitation staff who work within tertiary hospitals therefore have the added responsibility of outreach to communities once a week to offer the needed services to persons with disabilities. These outreach programmes could not be sustained due to healthcare professionals not having sufficient time to implement these services. The situation is further

exacerbated by hospital transportation constraints (Visagie & Schneider, 2014). In a South African study that explored the implementation of the principles of primary healthcare in a rural area, the same findings were reported. The authors, Visagie and Schneider (2014), confirmed that weekly community outreach programmes were inadequate, due to the large number of patients requiring services, and that transportation challenges experienced by persons with disabilities, hampered the success of such disability programmes. Disability programmes therefore are not being run in Eswatini as effectively as they should and in some instances, they do not exist at all.

6.9.3.2 Acceptability

With regards to acceptability, participants from Data Source 3 indicated that reasonable accommodation for persons with disabilities across all entities in Eswatini remains a challenge, regardless of the policy reform documents being in place. This finding is in line with the Namibian study that reported that reasonable accommodation for persons with disabilities was still a challenge (Shumba & Moodley, 2018). Similarly, disability mainstreaming in Eswatini has not yet been realised. Progress has been observed with regards to physical access, where physical space in some hospitals has been improved to include wheelchair ramps and wider passages in waiting areas.

While physical access for persons with physical disabilities has improved, persons with communication, visual and hearing impairments continue to experience communication barriers due to a lack of reasonable accommodation. Similarly, Withers and Speight (2017) reported that persons with disabilities are excluded from health related information programmes in the healthcare system because there are inadequate numbers of available sign language interpreters or the fact that healthcare information is not provided in braille or in easy language formats that could be understood by persons with disabilities with low literacy levels. Findings from in-depth interviews with key informants (Data Source 2) echoed these findings from the focus groups (Data Source 3). The severe communication barriers experienced by persons who are deaf when accessing healthcare were also noted in a Brazilian and a South

African study respectively (Chaveiro et al. 2009; Kritzinger et al. 2014). Moreover, Neuhauser et al. (2013) also reported that persons who are deaf were excluded from health information because the health materials were not adapted to their specific communication needs. Administering medication is not adequately explained to persons with disabilities, nor is the information communicated in such a way that persons with disabilities in Eswatini can easily understand it, a finding that was also reported in a previous study conducted in various LMICs (Banks & Polack, 2014).

The negative attitudes of some healthcare professionals towards persons with disabilities continue to be mentioned across all data sources as a hindrance for access to healthcare for persons with disabilities. An overwhelming number of international and national studies have confirmed that healthcare professionals do not always treat persons with disabilities in an appropriate manner (Badu, et al. 2016; Morgon et al. 2014; Simpamba et al 2016). As a result, persons with disabilities are frequently discriminated against and excluded from educational health programmes, especially those related to sexual health. Bornman and Rathbone (2016) mentioned that the content and form of sexuality educational programmes were not accessible to women with intellectual disabilities, leading to them being excluded from training related to sexuality. Rugoho and Maphosa (2017) also reported on the exclusion of persons with disabilities (especially women) from healthcare programmes.

Along with the negative attitudes of healthcare professionals towards persons with disabilities, is the lack of a stipulated standard of care for persons with disabilities in healthcare facilities in Eswatini. Therefore, the care provided, whether good or bad, is determined by the character of the specific healthcare professionals and their values and beliefs around persons with disabilities and disability. Similarly, in a South African study, it transpired that attitudes of healthcare professionals depended on the individual, where some healthcare professionals were respectful, helpful and friendly and others were not (Visagie & Schneider, 2014). Ultimately, persons with disabilities are advocating for their involvement across entities, especially in projects related to their well-being.

The notion that disability is regarded as result of a curse in the family or some sort of misfortune has further fuelled negative attitudes towards persons with disabilities in Eswatini. Thwala et al. (2015) confirmed that for years, disability has been negatively viewed by the society in Eswatini. Disability is seen as a curse which in turn, leads to communities holding negative views on persons with disabilities and their families. Consequently, caregivers of persons with disabilities hide their children with disabilities in an attempt to protect them from a society that does not accept persons with disabilities. In so doing, persons with disabilities, especially children, end up compromising access to healthcare. Groce and Kett (2014) also reported that the negative attitudes of the society towards persons with disabilities and their families result in children with disabilities being hidden at home.

6.9.3.3 Geographical accessibility

Geographical accessibility cannot be separated from transportation challenges. The distance of comprehensive healthcare facilities located mostly in towns, from residences of persons with disabilities as well as the mountainous terrain of Eswatini impact the travel of persons with disabilities to healthcare facilities. Most of the comprehensive healthcare facilities which provides services such as speech therapy, occupational therapy and physiotherapy are located in urban areas which are long distances away from where persons with disabilities reside. The negative effect of transportation on access to healthcare for persons with disabilities has frequently been documented in numerous research studies (Badu et al. 2016; Grut et al. 2012; Kuwana, 2014; Moodley & Ross, 2015). Geographical accessibility has a direct implication to the health outcomes of persons with disabilities as they are unable to attend all their rehabilitation appointments due to extra financial constraints (Masuku et al. 2018).

6.9.3.4 Financial accessibility

At the time of writing the thesis, in Eswatini there was no functional consistent system of allocating social support grants for persons with disabilities. This is contradictory to systems in other Sub-Saharan countries, such as South Africa and Namibia, where

the state allocates consistent disability grants to persons with disabilities. These grants have proved to improve the financial status of households of persons with disabilities (Sherry, 2014; Shumba & Moodley, 2018). Coupled with that is the fact that even though free healthcare has been promised in Eswatini by the Disability Policy Reforms and also by the National Health Policy and also in section 4.30 of the National Policy of Health, 2006), it does not seem like there is clarity amongst the participants of the study on whether or not persons with disabilities currently pay for healthcare services. Fembek et al. (2013) also mentioned that in some countries, in addition to paying for healthcare services, persons with disabilities have the challenge to pay large amounts in transportation fees in order to get to the hospital or healthcare facilities for their rehabilitation services. This finding is coherent with findings from the World Health Organisation (2011) on persons with disabilities accessing healthcare in LMICs, implying that transportation costs associated with accessing healthcare poses a financial challenge for persons with disabilities (Van Rooy et al. 2012).

6.9.4 Processes

The significant role of the National Disability Plan of Action as the blueprint of implementing the policy was confirmed from the findings of Data Source 3. Participants agreed that there had been challenges in the implementation process of the policy that resulted in a lack of progress in implementation. Policy implementation is one of the difficulties facing governments in LMICs. (Makinde, 2005). Brownson, Eyler, Harris, Moore and Tabak (2018) encouraged the use of different methods, especially media, in creating awareness on policies. Awareness campaigns to create awareness around the existence of these policies have been done by disability organisations in Eswatini using media, specifically radio shows, but according to the participants with disabilities, the effectiveness was limited by a number of factors such as the lack of political commitment, inadequate dissemination of the policy in rural areas, lack of dedicated resources and the policy not being available in other language formats. This lack of policy implementation has been attributed to the inadequate dissemination of the policy in especially rural areas and persons with disabilities in these areas were not aware of it. Lack of resource allocation by the government to implement the policy

was also mentioned as a reason for poor policy implementation. Lang, Schneider, Kett, Cole and Groce (2017) also stated that unavailable or poor budgetary allocations for policy implementation in African countries could negatively influence policy dissemination. The policy reform documents are also not available in SiSwati or easily accessible written formats that persons with disabilities can understand or relate to. Other African countries, such as Zambia, have successfully translated their disability policy documents to easily accessible read formats (United Nations, 2017) and this should be investigated by the government of Eswatini to potentially improve policy dissemination.

6.10 IMPLICATIONS FOR CHAPTER 7

The methodology as it pertains to the focus groups and electronic questionnaires with persons with disabilities, caregivers of persons with disabilities and healthcare professionals was discussed in this chapter, along with the findings obtained from Data Source 3. A discussion of the findings from this data source with literature that supports these findings followed. Even though there are some commonly occurring themes across the three data sources, namely; the document analysis; key informant interviews; and focus groups, some discrepancies were also noted. Furthermore, new themes also emerged which are distinct and specific to each data source. For example, a closer analysis of the focus group results highlighted differences in the way that stakeholder groups view the policy and its role, as well as their role in fulfilling the right for access to healthcare for persons with disabilities and how they understand and interpret the experiences of persons with disabilities when they access healthcare. These views are influenced by participants' own lived experiences, to some degree, but also by how vested they are in disability and disability rights in Eswatini and their disposition. These findings therefore had implications for all stakeholders affected by the National Disability Policy Reform documents from policy makers to persons at grassroots level. To communicate these findings and recommendations, a policy brief document was developed for policy makers and simultaneously, access to healthcare guidelines were developed for persons with disabilities accessing healthcare facilities in an easy access format. Chapter 7 engages with the development of these

documents and also further highlights the values that using the Integrated Disability Policy Analysis Framework added to the study.

6.11 CONCLUSION

Chapter 6 presented the methodology, results and discussion of Data Source 3, focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals. The chapter first described the aims of Data Source 3. This was followed by a description of the participants, the selection criteria for these participants and recruitment occurred. The setting of the three different focus groups was briefly described followed by the materials and equipment used in this Data Source. A presentation of the data obtained from this data source and the discussion of the data is done. This was followed by an explanation of the implication of this data source for the whole study.

CHAPTER 7: DEVELOPMENT OF PRACTICAL INTERVENTIONS TO FACILITATE ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES

7.1 INTRODUCTION

This chapter discusses the major contributions that emerged from this study as well as the implications for practical application. Therefore, this chapter is organised according to these contributions, namely:

- The Integrated Disability Policy Analysis Framework applicable to LMICs as a model for the analysis of National Disability Policy Reforms
- The development of a Policy Brief which addresses the discrepancies between the National Disability Policy Reforms and the experiences of Persons with Disabilities when they access healthcare services
- The Development of Access to Healthcare Guidelines for Persons with disabilities

In essence, through this chapter, the value of using the Integrated Disability Policy Analysis Framework when analysing National Disability Policy Reform documents in LMICs is explained. In addition to that, the proposed Policy Brief is presented, with strategies that can be implemented by the government of Eswatini to improve the content and implementation processes of the currently existing National Disability Policy Reform documents. This is followed by a discussion of the development of the Access to Healthcare Guidelines for persons with disabilities in Eswatini. Finally, the methodological and practical considerations when conducting research with policy makers, healthcare professionals and persons with disabilities is described.

Prior to the presentation and discussion of the abovementioned interventions, it is significant to present an outline of the research aim as well as the sub-aims. In presenting the aims, the study effectively and systematically integrates all the findings

to show how the aims were addressed and how the abovementioned contributions align with the aims of the current study.

7.2 OVERVIEW OF THE RESEARCH AIM

The purpose of the study was to describe access to healthcare for persons with disability in Eswatini.

Therefore, the following sub-aims were delineated:

- i. To describe the provisions regarding access to healthcare for persons with disabilities in Eswatini as guaranteed by the National Disability Policy Reforms.
- ii. To describe the design and implementation of the National Disability Policy Reforms by focusing on the actors, context and processes involved in order to understand possible influences on the provision and realisation of access to healthcare.
- iii. To describe the perceptions of stakeholders regarding the experience of persons with disabilities in accessing healthcare and the effectiveness of the National Disability Policy Reforms in facilitating access to healthcare for persons with disabilities in Eswatini.

7.3 THE INTEGRATED DISABILITY POLICY ANALYSIS FRAMEWORK

This intervention emerged from engagement with the first and second aims of the study, which were concerned with describing the provisions intended by the National Disability Policy Reforms for persons with disabilities in Eswatini and mapping out the processes of design and implementation of these policy reforms by focusing on the actors, context and processes involved.

Data to address these two aims were collected through a document analysis and key informant interviews. During the initial stages of the document analysis process, it became evident that the intended process of the document analysis followed a more linear approach. This linear approach ran the risk of portraying content of the policy in the best possible light, particularly, when taking into account that there were no policies prior to the development and implementation of the National Disability Policy Reform documents.

In engaging with the policy reforms, certain gaps were identified, namely: i) the policy was superficial and lacked depth; ii) the policy lacked structure in how it was presented and iii) theoretically, the policy had not accounted for access to healthcare for persons with disabilities, which was the focus of this thesis. Hence, in acknowledging and addressing these identified gaps, a need for a policy analysis framework that addressed all these gaps was realised. As such, a literature search was conducted with the aim of addressing the gaps identified from the analysis. The search yielded two frameworks, the Walt and Gilson (1994) Health Policy Analysis Framework and the Peters et al. (2008) Access to Healthcare Framework, which were relevant and in line with the aims of the study. Although, in reviewing these frameworks, it was evident that, while they were useful and added value to the current study, they were also limited when used independently of each other. The Peters et al. 2008 framework focused solely on the content of the policy during analysis while neglecting factors that influence the conception, development and implementation of policies, such as actors, processes and context. The Walt & Gilson, 1994 framework addressed the lack of structure and theoretical underpinning of the principles pertaining to access to healthcare during the analysis of the content component of the National Disability Policy Reform documents. As neither of the two frameworks comprehensively addressed the aims of the study, a new Integrated Disability Policy Analysis Framework was proposed and developed. The process of how this was done is depicted in Chapter 4.

The developed framework proposes that when analysing disability policy reform documents for healthcare, it is imperative to obtain a clear background on the

stakeholders of the policy reforms (termed actors by the Walt and Gilson Health Policy Analysis Framework), the context, the processes and the content of the policy documents. In order to ensure rigour when appraising the content of the policy, policy researchers should consider analysing the content of the policy for availability, acceptability, geographical accessibility and financial accessibility as these are all aspects that are relevant in achieving the rights of persons with disabilities, which resonate with the CRPD principles (United Nations, 2006) and are contextually relevant for LMICs.

The newly developed Integrated Disability Policy Analysis Framework encompassing the Walt and Gilson Health Policy Analysis Framework (Walt & Gilson, 1994), and the Access to Healthcare Framework (Peters et al. 2008) is presented in Figure 5.

7.3.1 The Relevance of Employing the Integrated Disability Policy Analysis Framework

The Integrated Disability Policy Analysis Framework proved valuable as a method of data triangulation for a number of reasons. Firstly, it served as a frame of reference to report on all the data collected from the three data sources and data methods (Carter, Bryant-Lukosius, Dicenso, Blythe & Neville, 2014). Secondly, it introduced a strong aspect of rigour in the study as a whole and thirdly, it accounted for the voices of various policy makers, policy implementers and policy users, which is rare in policy studies.

Employing this framework in the current study also allowed for a holistic descriptive overview of access to healthcare for persons with disabilities in Eswatini from the worldview of different stakeholders, and allowed these results to be presented in a summarised and structured manner as recommended by Gale, Heath, Cameron, Rashid and Redwood (2013). Furthermore, this framework was valuable as it allowed the researcher to compare and highlight data from multiple data sources, thus providing an opportunity to engage with possible similarities, differences or

discrepancies between the promises of the different National Disability Policy Reform documents. It also provided an opportunity to capture policy makers' and policy implementers' expectations of and perceptions about the National Disability Policy Reform documents as well as the experiences of end users of the policy reform documents could also be compared.

Each data source added a pertinent and essential contribution towards understanding access to healthcare for persons with disabilities in Eswatini. For example:

- The document analysis of the National Disability Policy Reforms provided an understanding of the commitments of Eswatini in addressing the right of access to healthcare for persons with disabilities in Eswatini.
- Key informants' interviews were instrumental in providing a detailed clarification on matters related to the actors, context, content and processes which the policy documents alone could not. Furthermore, these interviews provided stakeholders' perceptions of the experiences of persons with disabilities when they accessed healthcare services in Eswatini.
- The focus groups with the three stakeholder groups, namely, persons with disabilities, caregivers of persons with disabilities and healthcare professionals, provided a human element in the form of reporting on experiences of persons with disabilities. This allowed the study to establish whether or not the intended outcomes of the National Disability Policy Reforms documents were achieved. Information on actors, context and processes were further extrapolated from the data provided by these groups.

Ultimately, this level of analysis ensured that the following research questions were comprehensively answered:

- i. What are the provisions of the National Disability Policy Reform documents for Access to Healthcare for persons with disabilities in Eswatini?

- ii. When designing and implementing the National Disability Policy Reform documents, who were the actors, what was the context and what were the processes?
- iii. According to end users, how effective have the National Disability Policy Reform documents been in facilitating access to healthcare for persons with disabilities in Eswatini?
- iv. What have been the experiences of persons with disabilities when they access healthcare services in Eswatini?

7.4 THE DEVELOPMENT OF THE POLICY BRIEF

This intervention emerged from engagement with the third and fourth sub-aims of the study, which were concerned with describing the perceived effectiveness of the National Disability Policy Reforms for persons with disabilities in facilitating access to healthcare for persons with disabilities in Eswatini and to describe the experiences of persons with disabilities when accessing healthcare services.

Data for these aims were collected through focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals, with additional online electronic questionnaires with healthcare professionals. In reviewing the data, significant discrepancies were noted between the intentions of the various National Disability Policy Reform documents and the experiences of persons with disabilities when accessing healthcare.

Despite evidence-based research as stated in previous chapters highlighting the influence of geographical location of healthcare facilities and financial constraints affecting access to healthcare for persons with disabilities, the National Disability Policy Reform documents do not address geographical and financial considerations. Additionally, the policy implementation process presented shortfalls. The implementation of the National Disability Policy Reform Documents was unsuccessful because of the following, the National Disability Bill of Rights which is key to the

implementation of the National Disability Policy of Eswatini, has not been formally passed as a law in the country. The National Disability Plan of Action which is the blueprint of implementation of the policy was developed at the level of individual ministries who are also responsible for the costing and budget requirement of the implementation. This implies that ministries are working in isolation. For the implementation to be successful, there needs to be inter-ministerial collaboration, with guidance from persons with disabilities as key stakeholders in the fights for the rights of persons with disabilities. The is lack of the state commitment to physical, human and financial commitment of resources as a result in part to the lack of a dedicated budget has also contributed negatively to the stagnant implementation of the policy. Consequently, the intended end users of the National Disability Policy Reform documents were not aware of these policy reform documents. As a result, the promises of these policy reform documents were unfortunately not translating to experiences. The policy brief was therefore developed to communicate the above-mentioned shortfalls to policy makers.

7.4.1 The Relevance of Developing a Policy Brief

Keepnews (2016) defines a policy brief as a document that provides a concise description and analysis of a policy matter or challenge. Lavis, Permanand, Oxman, Lewin, and Fretheim (2009) further explain that a policy brief is also a strategy for presenting research findings to policy makers. As such, a policy brief was selected as an ideal approach to convey the findings of the current study to policy makers. Even though policy makers are challenged on how to best improve public services through recommendations from research evidence, they are often discouraged by the enormous amounts of findings and information presented to them by researchers (Pittore, Meeker & Barker, 2017). Researchers and policy makers' competing interests further compound this process (Pittore et al. 2017). Therefore, this implies that research findings need to be presented in a concise and clear manner, specifically highlighting actionable recommendations to policy makers, if policy makers are expected to implement recommendations from research evidence. Failure to take up research evidence by decision makers has been highlighted as the gap between research and policy (Uzochukwu et al. 2016) with communication between the

researcher and the policy makers being one of the most prominent gaps. The policy drafting principles as proposed by Keepnews (2016) were employed in developing the policy brief. The policy brief is to be submitted to the Deputy Prime Minister's office of Eswatini, which currently houses the department of social welfare as a way of communicating the findings and recommendations from the study. The policy brief will also be published as a journal article. The Policy Brief is presented in Table 30.

Table 30: Access to healthcare for persons with disabilities in Eswatini-A Policy Brief for Policy Makers

Aspect	Description
Executive Summary	<p>Persons with disabilities account for 16.8% of the population of Eswatini (Central Statistics Office, 2010), with 86% of them residing in rural areas (Eide & Jele, 2011). Adequate access to basic healthcare for persons with disabilities is an essential human right which needs to be achieved by all states. The Constitution of the Kingdom of Eswatini has provided for the rights of persons with disabilities, including their rights to access to healthcare. The state went further to ratify the United Nations Convention of the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) in 2012. As a means of operationalising the CRPD, Eswatini developed the following National Disability Policy Reform documents: the National Disability Policy of Eswatini, the National Disability Plan of Action and the National Disability Bill of Rights of Eswatini.</p> <p>The study by Dlamini-Masuku (2020) therefore sought to establish the actors, context and processes of these policy reforms and its content as they pertain to the availability, acceptability, financial and geographical acceptability of persons with disabilities in Eswatini. A case study research design utilising multiple methods of data collection, namely, a document analysis; key informants' interviews and focus group discussions with three data sources (namely persons with disabilities, caregivers of persons with disabilities and healthcare professionals) were utilised.</p>

Findings indicated that although these policy reform documents have made provisions to ensure that healthcare services will be available to persons with disabilities with reasonable accommodation for them, these documents did not consider the influence of financial and geographical factors on the access to healthcare that persons with disabilities may experience. Simultaneously, the National Disability Plan of Action needs to be explicit on the plans for implementing the National Disability Policy Reform documents if they are to be successful. Access to healthcare continues to be a challenge for persons with disabilities in Eswatini as the healthcare system is not adequately equipped to accommodate these individuals. As a result, persons with disabilities still experience challenges related to the (i) availability of healthcare services; (ii) them being accepted by healthcare professionals at healthcare facilities due to their additional barriers; (iii) financial expenditures related to their health as well as (iv) the geographical location of healthcare facilities relative to their places of residence.

The said National Disability Policy Reform documents therefore need to be re-evaluated, considering the financial and geographical challenges of accessing healthcare services for persons with disabilities. Healthcare facilities in Eswatini also need to be reviewed and adapted to meet the needs of persons with disabilities. This can be achieved only through the support and commitment of the government of Eswatini.

Introduction

The Kingdom of Eswatini has an estimated population of 1 093 238 (Central Statistics Office, 2017), with about 69% of the population living below the poverty line (The United Nations Development Assistance Framework 2012). A total of 71% of the population of Eswatini who reside in rural areas are poor, compared to 45% of the population in urban areas. Even though healthcare services are made available, however 58% of persons who required healthcare could not access it as a result of challenges (Mavundla, 2015).

Eswatini ratified the CRPD in 2012 and subsequently, the state developed the National Disability Policy of Swaziland, the National Disability Plan of Action and the National Disability Bill of Rights (Deputy Prime Minister's Office, 2013; 2014; 2015) as a commitment to upholding the right to access for persons with disabilities. Despite the commitments that the country has made in the form of National Disability Policy Reform documents, these documents have not yet been successful in addressing the challenges experienced by persons with disabilities when they attempt to access healthcare services. The ineffectiveness of the National Disability Policy Reform documents can partly be attributed to: (i) the shortcomings in the content of the National Disability Policy Reform Documents (ii) the lack of clarity on the implementation process of the National Disability Plan of Action; and (iii) the lack of knowledge amongst healthcare professionals, persons with disabilities and caregivers of persons with disabilities regarding the existence of the policy and on the delay in passing the National Disability Bill of Rights as law. Ultimately, persons with disabilities still experience challenges with accessing healthcare services in Eswatini, regardless of the policy reform documents being in place.

The National Disability Policy of Eswatini and the National Disability Plan of Action have assured persons with disabilities of the availability of all healthcare services, including sexual and reproductive health services for women with disabilities, as well as assistive devices and disability support programmes from trained personnel within reasonable reach (Deputy Prime Minister's Office, 2013; 2015). The National Disability Policy of Eswatini and the National Disability Plan of Action have also promised persons with disabilities of reasonable accommodations with regards to physical access, communication access, access to health literacy information (Deputy Prime Minister's Office, 2013; 2015). Persons with disabilities have furthermore been promised a healthcare system that accommodates their disability and disability rights and that does not discriminate against them based on their disabilities and that accommodates their disability and disability rights (Deputy Prime Minister's Office, 2013; 2015).

The National Disability Policy Reform documents are, however, ambiguous in their address of financial accessibility to healthcare services for persons with disabilities. It promises free healthcare, and free assistive devices, such as hearing aids, walking aids, wheelchairs, augmentative and alternative communication devices, prosthetics and spectacles for persons with disabilities to all persons with disabilities who require them. However, these same policy documents do not mention any allocated funding for the repair or maintenance of these assistive devices. The policy reform documents also do not consider the comprehensive package of healthcare services at the different levels of care. For example, the policy reform documents promised to provide persons with disabilities access to all healthcare services, while disregarding the distance of the location of these services to persons with disabilities, which holds significant financial implications. This is especially concerning when considering that 86% of persons with disabilities in Eswatini reside in rural areas (Eide & Jele, 2011), implying that they have a distance to travel to access comprehensive healthcare facilities which are mostly located in towns. The long distances that the persons with disabilities have to travel result in them experiencing transportation and subsequent financial challenges. Transport is one of the major barriers to access to healthcare for persons with disabilities, especially those who reside in rural contexts (Goodridge et al. 2015; Masuku et al. 2018; Vergunst et al. 2017) and no transport accommodation has been made by the state to address this concern.

The National Disability Policy Reform documents also need to be made available in other language formats, such as braille, easy language and with pictorial support to enable non-literate, pre-literate persons with disabilities or those who have emerging literacy skills to access the content of the policy reform documents (Nomura, Nielsen & Tronbacke, 2010). Healthcare professionals in healthcare facilities also need to be made aware of the policy reform documents and their content as

currently, it appears as if they are not aware of the existence of the policy or of its contents.

The Current Status of Access to Healthcare for Persons with Disabilities in Eswatini

Despite the significant healthcare needs of persons with disabilities, healthcare services that specifically focus on rehabilitation are not readily available at all healthcare facilities in Eswatini as these services appear to be only available at the three referral hospitals. Similarly, assistive devices are also not made available to all persons with disabilities who require them (Eide & Jele, 2011; Matter & Eide, 2018). In 2018, the government of Eswatini provided assistive devices to only 11.5% persons with disabilities who required them (Matter & Eide, 2018). The unavailability of rehabilitation healthcare services are further compounded by the lack of knowledge of persons with disabilities regarding the available services and the shortage of rehabilitation staff in healthcare facilities. This limits persons with disabilities access to health services, information and decision-making in health matters.

Support services, such as community-based rehabilitation services, community outreach teams, disability peer support groups, and counselling services for persons with disabilities and their families are currently not available in all communities and healthcare facilities in Eswatini. This unfortunately has a negative effect on the emotional and psychological well-being of persons with disabilities and their families (Faurozan et al. 2013). Persons with disabilities, especially women with disabilities, continue to be excluded from sexual and reproductive health services and this discrimination, marginalisation, labelling and victimisation by healthcare professionals remains a reality. Currently, persons with disabilities do not have access to health promotion programmes and therefore, face the cumulative risk of marginalisation and exclusion.

Persons who are deaf and/or blind and present with communication disabilities face additional challenges. Materials related to healthcare (e.g. pamphlets and brochures) are typically not available in alternative formats (e.g. braille), nor are sign language interpreters available.

Healthcare professionals also do not receive training in alternative forms of communication besides sign language (and therefore have to rely on family members or interpreters to facilitate communication between themselves and persons with disabilities). As a result, confidentiality between patients and healthcare providers is compromised as healthcare information is relayed through a third party. The risk of persons with disabilities receiving compromised health information may be evident. Persons who are blind also expressed challenges in the way that health information specifically related to medicine is given. Because the medicine instructions are not in braille and are often not explained properly to them by the person dispensing the medication, they tend to take medication incorrectly.

Challenges in the Healthcare System

- Health policies should focus on providing more information in an understandable format, as they are currently provided in an inaccessible, unclear and unintelligible format.
- Coverage of healthcare services for persons with disabilities across of Eswatini (including rural areas) is needed.
- To achieve the goal of coverage, healthcare providers need more support from government.
- Community based rehabilitation services are needed to meet the needs of all Eswatini citizens, including persons with disabilities.
- The healthcare system currently in place is not geared towards the long-term rehabilitation needs of persons with disabilities and the system is not sufficiently prepared to deal with these changes.
- Over the past decade, the Eswatini healthcare system has given priority to the expansion of primary healthcare to address urgent health issues. While this is commendable, the rehabilitation needs of persons with disabilities should also be considered.

Conclusion and Policy Recommendations

In recent years, Eswatini has made significant progress in addressing the right to access to healthcare for persons with disabilities. These improvements have provided a stepping-stone for further research and development in this area. The study by Dlamini-Masuku (2020) indicated inequalities that exist when persons with disabilities access healthcare services in Eswatini. These inequalities between persons with and without disabilities related to healthcare, need to be addressed by the government of Eswatini as they impact on the welfare of persons with

disabilities and their families. It also impacts on Eswatini's potential of addressing the human rights of persons with disabilities and meeting the Sustainable Developmental Goals, in particular Goal 3, ensuring health and well-being, adopted by all United Nations Member States in 2015.

Based on the outcomes of the study by Dlamini-Masuku (2020), a series of tangible policy implications are proposed. It is proposed that policy makers in Eswatini and the government of the people of Eswatini consider the following:

- Refine and review the National Disability Policy Reform documents while considering financial and geographical access for persons with disabilities.
- Re-engineer healthcare systems to become more proactive in establishing programmes that facilitate access to healthcare for persons with disabilities.
- Re-consider the model of healthcare services provision to incorporate community-based rehabilitation (World Health Organisation, 2004) which could provide practical suggestions to programme managers on how to develop and strengthen community-based programmes to be inclusive of persons with disabilities and their families.
- Relook the finance model for the rehabilitation needs of persons with disabilities and to consider how the government of Eswatini will guarantee free access to healthcare (including rehabilitation) for persons with disabilities and how it will subsidise the issuing and maintenance of assistive devices.
- Provide training programmes for healthcare professionals by the Ministry of Health. Such training programmes should include:
 - Disability rights with an emphasis on health and well-being.
 - Communication strategies and methods when interacting with persons with disabilities, with an emphasis on communicating health information in an easily accessible

and understandable way (especially those with low health literacy communication disabilities).

- Strategies to establish and maintain community support groups for persons with disabilities and their families.
- Dismantling stereotypes and myths regarding disability to curb the prevailing negative attitudes that healthcare professionals harbour on persons with disabilities.

The universal coverage of the population should be pursued. On that account, the provision and maintenance of healthcare facilities in all parts of the country are essential. This implies a network of functional healthcare facilities that are reachable by the local populations with emphasis on accessibility for all population groups. This extension of the primary healthcare service has to be accompanied by an implementation of secondary healthcare to cover rehabilitation. Additionally, the number and capacity of training centres for community-based rehabilitation should also focus on the prevention and treatment of disability related impairments and consequences. Likewise, healthcare facilities should be equipped with medical supplies and expertise to inform rehabilitation needs for persons with disabilities. This implies, for instance, response training and equipment for workshops to repair wheelchairs. Also, the government expenditure on healthcare has to increase in order to improve the health status of the growing Eswatini population. This can also be an incentive for donors to increase funding.

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7.5 THE ACCESS TO HEALTHCARE GUIDELINES

The third and fourth sub-aims of the study and how data pertaining to these aims was collected, have already been alluded to in section 7.4. It transpired from the data collected from focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals that persons with disabilities were not aware of what their rights to access healthcare were. Therefore, guidelines pertaining to access to healthcare for persons with disabilities were developed to highlight these rights.

Vallabi (2016) posits that researchers should factor in the following three key principles when formulating guidelines:

- i. The guideline recommendations should be based on the best available scientific evidence;

- ii. Persons who are affected by the guidelines must be involved in decisions pertaining to the guidelines and these stakeholders may include healthcare practitioners, public members, people using services and voluntary sectors; and
- iii. Guidelines should address equality and social value judgement.

These three principles were applied when the access to healthcare guidelines for persons with disabilities in Eswatini were developed. These guidelines were also formulated, based on a combination of scientific evidence from the National Disability Policy Reform documents, key informant interviews and focus group discussions with persons with disabilities, caregivers of persons with disabilities and healthcare professionals. Findings indicated that generally, persons with disabilities were not aware of the provisions that were made for them in the relevant policy reforms and as such, they were not aware of their rights pertaining to access of healthcare services in Eswatini. A literature review which describes the research available on access to healthcare for persons with disabilities (Chapter 2 of the thesis) was conducted prior to the focus groups. This literature review indicated gaps that existed in persons with disabilities' knowledge of policy reforms and therefore, knowledge gaps about their rights and what they can request and expect when they approach a healthcare facility. This was further confirmed in the focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals. The policy reform documents provide relevant information about the reasonable accommodations and provisions that had been made for persons with disabilities when they access healthcare service.

7.5.1 Process Followed During the Development of the Access to Healthcare Guidelines

The following steps, as proposed by Shekelle, Woolf, Eccles and Grimshaw (1999), were followed during the conceptualisation and development of the access to healthcare guidelines for persons with disabilities in Eswatini, while also considering the key principles suggested by Vallabi (2016). These four steps are shown in Figure 7.

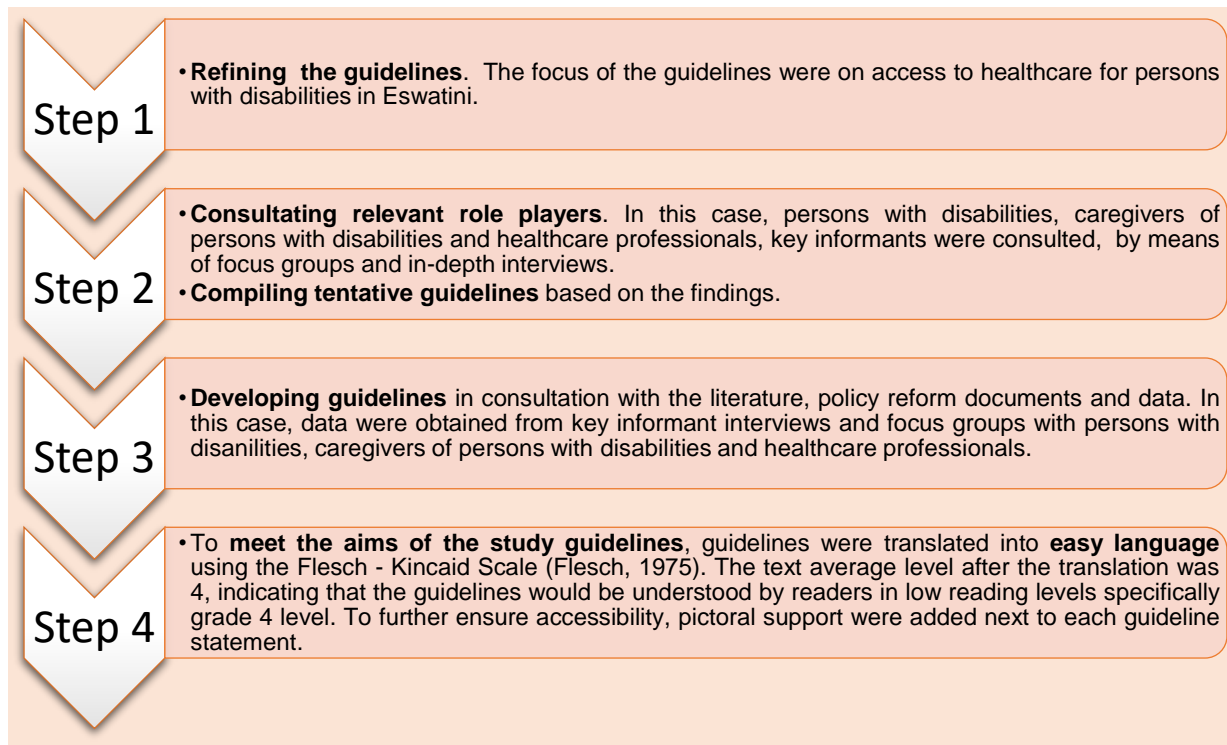


Figure 7: Four steps followed during the development of the Access to Healthcare Guidelines

The access to healthcare guidelines will be presented to the director of health so that through the director's office, these guidelines are disseminated to every healthcare facility in the country in an enlarged wall size poster formats which would be displayed in waiting areas in healthcare facilities. These guidelines could also be made available in pamphlets and booklets which could be easily translated into braille for the visual impaired. Before the dissemination of the guidelines, it is highly recommended that the guidelines undergo a process of social validation by persons with disabilities, caregivers of persons with disabilities and healthcare professionals. The process of social validation is meant to ensure that the end users (mentioned above) affirm and endorse the guidelines for the context for which they are meant for (Smith & Thelwell, 2013).

Figure 8 presents a representation of the ten access to healthcare guidelines with accompanying pictorial support. Please refer to appendix N for the SiSwati version of these guidelines.

Do you have a disability?

10 tips to access your rights to healthcare

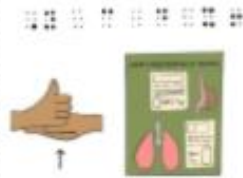


1

Go to **any hospital** when you feel sick or need therapy

6

Ask for health information in pictures, braille or sign language



2

Get your hospital treatment **for free**



7

Take part in **any** health programs



3

Tell the **staff** at the help desk about your disability and that you **need assistance**



8

Get a wheelchair, a hearing aid or a walking aid **for free**



4

Skip the queue



9

Ask hospital staff to fix your wheelchair, hearing aid or walking aid **for free**



5

Expect to be treated **respectfully**



10

Remember that hospital staff must **support** you



Dlamini-Masuku. 2020 ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI. UNPUBLISHED DOCTORAL DISSERTATION. FACULTY OF HUMANITIES. UNIVERSITY OF PRETORIA. PRETORIA, SOUTH AFRICA.

Figure 8: Access to Healthcare guidelines

7.6 CONSIDERATIONS WHEN CONDUCTING RESEARCH WITH KEY STAKEHOLDERS

7.6.1 Policy Stakeholders

Gaining access to representatives of government ministries and organisations such as the United Nations, proved to be a challenging due to gatekeepers restricting the researcher's access. This could be attributed to the fact that the subject matter of the study is sensitive as it pertains to the human rights of persons with disabilities, and also because key informants had to provide extensive and contextual knowledge on this topic. Various researchers also confirm the challenging nature of accessing research sites in similar conditions with similar expectations (Johl & Renganathan, 2010; Okumus, Altinay, & Roper, 2007; Shenton & Hayter, 2004).

It was possible to successfully access five of the seven organisations affiliated with the United Nations in Eswatini in this study, as well as one government ministry, namely the Deputy Prime Ministers' Office that houses disability matters. With regards to the organisations affiliated to the United Nations, two participants committed to the interview, but on the date of the interview they did not honour the appointment, while three cancelled closer to the interviews, stating a level of uneasiness to be involved as participants in this study with a sensitive topic. Some of the participants who honoured their commitment to participate in the study were selective with the kind of information that they were willing to share and disclose, with some information provided as "off the record", which could therefore not be reported in the study. This transpired, despite the researcher having assured them of confidentiality in the reporting of the findings of the research study.

Furthermore, these participants requested to pre-view the interview script before they committed to the interviews. This request for pre-viewing the interview script may have been due to various reasons. For example, participants might have been sceptical regarding the role of the outside researcher (Johl & Renganathan, 2010). Participants may also have been cautious about exposing any information that they

considered as potentially destructive to the individual, organisation or the state (Moroe, 2018), irrespective of the researcher having been thorough in providing participants with information related to the study.

In addition, locating actors, seven years since the inception of the National Disability Policy Reform documents was challenging as no records of actors were available. This made it difficult to track and locate some of these actors (particularly by those who represented non-governmental organisations, such as the council of churches) to participate in the present study.

Restricted access to policy actors had further implications for the study as not all organisations were represented. The implementation of the National Disability Policy of Swaziland and its supporting documents rested solely on each individual ministry with their respective National Disability Plan of Action, as is the case with many countries (Shumba & Moodley, 2018). The lack of representation of key informants, from these specific ministries, therefore created a gap regarding relevant information pertaining to the processes of planning, implementation and tracking the progress of the National Disability Policy Reforms in Eswatini. This was evident across all data sources and to a certain degree, amongst key informants that there was a lack of detail surrounding the implementation processes of the policy. When questioned about these implementation processes, limited detail was provided. Key informants only referred to the National Disability Plan of Action as the way in which the policy documents were implemented. The National Government expected each respective ministry in Eswatini to develop a National Disability Plan of Action as the process of implementing the policy. The lack of involvement of all the respective ministries in this key informant group in the current study is therefore concerning because government ministries have notoriously been viewed by disability organisations as lacking the political will and resources to implementing laws that protect persons with disabilities in Eswatini (Eide & Jele, 2011).

7.6.2 Healthcare Professionals

Access to field sites and informants is fundamental to qualitative research (Riese, 2018), as it determines the success or failure of the project, yet it is often one of the challenges when conducting research successfully (Johl & Renganathan, 2010). Numerous reasons for challenges with the recruitment of medical staff (e.g. nurses and doctors) for research studies have been documented in literature following previous research (Johl & Renganathan, 2010). These reasons include, amongst others, the long duration of focus groups, difficulties with the accommodation of the various work schedules of hospital staff, lack of familiarity between medical staff and researchers, frequent requests to participate in research, leading to them becoming reluctant to participate, low interest in the topic of discussion and misperception of the purpose of the study have (Broyles et al. 2011; Cunningham et al. 2015; Flanigan, McFarlane & Cook, 2008; Khamisa, Pelzer, Llic & Oldenburg, 2016). Similar sentiments were shared by medical healthcare professionals (e.g. medical officers) in the current study when they were approached and asked to participate in the study.

While these medical officers acknowledged the value of the study in informing and potentially facilitating positive access to healthcare outcomes for persons with disabilities, they could not participate in the focus groups due to time constraints as a result of high workloads. In realising that medical officers could not participate in a focus group, individual interviews were proposed because interviews would be scheduled around the individual schedule of that particular doctor. But this method also proved to not be feasible. Subsequently, online emailed questionnaires were proposed as a more effective option for healthcare professionals because they can complete these questionnaires at a time and place convenient for them. It is also advisable that the request to participate in the study should come from a person who is in a superior position to facilitate the process of data collection as healthcare professionals are believed to be more receptive to their peers with authority. This might be attributable to the hierarchical structure of hospitals. Cunningham et al. (2015) and Tausch and Menold (2016) agree with this recommendation as they propose that an individual of a higher rank may facilitate peer influence. The length of the

questionnaires should be considered when compiling an online email questionnaire. Questions should be open ended, and the questionnaire should be shorter (Flanigan et al. 2008). These authors posit that questions requiring less completion time are more appealing for healthcare professionals (Flanigan et al. 2008).

7.6.3 Persons with Disabilities

There is a paucity of research documenting practical considerations when conducting research with persons with disabilities. In part, this may be attributed to the fact that, for many years, research has been conducted on persons with disabilities, but not in partnership with or through meaningful engagement with persons with disabilities, who, ultimately, are the end users of the implemented policy strategies and guidelines.

When the study at hand was conceptualised, focus groups were the preferred data collection strategy, particularly because of the involvement of persons with disabilities and caregivers of persons with disabilities. In this case, focus groups encouraged participation in a discussion generated by others. Human rights for persons with disabilities is also a difficult and emotional topic. Discussions about this topic in a group setting was ideal as it facilitated mutual support in expressing common feelings. Persons with disabilities present with low literacy levels, and therefore utilising focus groups would ensure that they are not discriminated upon because they cannot read or write. Persons with disabilities and their families are vulnerable and at times, disempowered, as such, they may view themselves as having nothing worthy of contributing or be intimidated by a formal one-on-one interview (Kroll et al. 2007).

It is widely documented that persons with disabilities are amongst the poorest amongst the populations that are classified as vulnerable (United Nations, 2018; Van Rooy et.al, 2012; World Health Organisation, 2011). It is therefore imperative that financial considerations are considered and made available when researchers invite persons with disabilities to participate in research studies. These financial considerations, in the form of stipends, can be used to cover transportation costs for persons with

disabilities and their caregivers to and from research venues, as well as provisions for meals. Due to the notorious transportation challenges experienced by persons with disabilities, especially in LMICs (Barratt & Penn, 2009; Johnson et al. 2015), the importance of careful considerations of the locations of research venues are underscored. Ideally, venues should be located in places where persons with disabilities will be able to access them at the lowest possible costs and with the least inconvenience. Venues need to be physically accessible to persons with disabilities who are in wheelchairs and include lavatories that are accessible.

Researchers also need to be considerate and respectful when obtaining consent from persons with disabilities. It is of utmost importance that persons with disabilities understand the purpose and the requirements of the study. Hence, information should be clear and potential participants should be well-informed on what they are consenting to as well as the expectations, risks and benefits thereof. They should at no point feel coerced to participate in the study and researchers, therefore, need to make sure information is presented in easy reading formats with pictorial support.

When conducting research with persons who are blind, it is recommended that information letters are translated into braille. However, in a case where that is not practical, an independent observer should be present to witness and approve the process of consent. The role of the independent observer would be to ensure the appropriateness of the content of the information letter; to confirm that the participant indeed consented to participating in the proposed study, and to guide the participant to physically sign in the correct space. Alternative to physically signing, persons who are blind can orally consent to the process and have this verbal consent recorded. The above-mentioned recommendations can also be applied with persons with disabilities who have low literacy levels or who have other visual disabilities.

7.7 CONCLUSION

Chapter 7 focused on insights for the development of instrumental intervention initiatives namely; (i) the Integrated Disability Policy Analysis Framework, which served as valuable input when analysing National Disability Policy Reform documents in LMICs; (ii) the policy brief, and strategies all of which can be implemented by the government of Eswatini to improve the content and implementation processes of the currently existing National Disability Policy Reform documents and (iii) the access to healthcare guidelines for persons with disabilities in Eswatini. Finally, the researcher presented methodological and practical considerations when conducting research with policy makers, healthcare professionals and persons with disabilities.

CHAPTER 8: CONCLUSION AND RECOMMENDATIONS

8.1 INTRODUCTION

As stipulated in the first chapter, the study intended to establish the extent to which the National Disability Policy Reforms had addressed access to healthcare for persons with disabilities in Eswatini. It also strove to establish how these National Disability Policy Reform documents were developed and implemented and how they influenced access to healthcare for persons with disabilities in Eswatini. Chapter 8 presents a summary of the findings according to the three data sources used in this case study. This is followed by a description of the implications of the findings for clinical practices and policy, an evaluation of the study (strengths and limitations) and recommendations for further research.

8.2 SUMMARY OF THE FINDINGS

The summary of findings is organised according to the three different data sources of the study.

8.2.1 Data Source 1: Document Analysis

The findings of the document analysis indicated that the development of the National Disability Policy Reforms was a collaborative effort between different stakeholders inclusive of the national government ministries, the United Nations organisations, disability movement organisations, the commonwealth officer and council of churches. The National Disability Policy Reforms were developed as a need for laws that would protect the rights of persons with disabilities and facilitate their access across all entities existing in Eswatini. The premise was that introducing these laws would assist with disability mainstreaming and also enable financial support for persons with disabilities through social support by the state. The policy reforms were also developed as a United Nations mandate after the country ratified the CRPD in 2012. With regards

to the content of the National Disability Policy Reforms, it was clear that these documents had adequately addressed the availability of services and the acceptability of persons with disabilities in healthcare facilities. It was, however, evident that the financial and geographical components of access to healthcare were largely neglected. The policy reform documents were not forthcoming with information specific to the processes of implementation of the National Disability Policy Reform documents.

8.2.2 Data Source 2: Key Informants Interviews

Data Source 2 encompassed in-depth interviews with key informants who were involved in the development of the National Disability Policy Reform document. Findings from in-depth interviews corroborated findings from the document analysis with regards to the actors involved in the development of the National Disability Policy documents. Key informants confirmed that the development of the policy reforms was the result of a collaborative effort that included all government ministries, including the Deputy Prime Minister's Office, the national disability unit, disability organisations, United Nations organisations, council of churches and a commonwealth officer. The key informant interviews further indicated the specific roles that these sectors contributed in the conceptualisation, development and implementation of the National Disability Policy Reform documents. The key roles played by the sectors represented in this process contributed valuable insights that were missing from the document analysis alone. This data source was therefore supplemental and enriching.

In particular, the Deputy Prime Minister's Office is the main custodian of the National Disability Policy Reform documents and therefore, the development and implementation of these documents was initiated from that office. To facilitate the process of developing the policy reform documents, the Deputy Prime Minister's office drafted, read and edited these documents in co-operation with the Ministry of Justice. The respective ministries were then assigned the task of implementing the National Disability Policy Reform documents through developing each ministry's costed

National Disability Plan of Action. Each ministry was also entrusted with allocating a budget to fund the implementation processes of the policy reform documents.

The National Disability Unit operates under the Prime Minister's Office and its role was that of collating all the ideas contributed by stakeholders and also co-ordinating all activities concerning the development and implementation of the policy reforms. The disability organisations informed the kind of content to be included in the policy reform documents. They are also instrumental in following-up and encouraging the government to implement the policy reform documents. The United Nations organisations and the council of churches also contributed towards the content of the policy reforms. The United Nations organisations further support and lobby for disability rights issues and also provide funding for disability related initiatives in Eswatini. The commonwealth officer, who was visiting Eswatini during the period of development of the policy reforms, had an advisory role on the development and implementation of the policy reform documents.

The key informant in-depth interviews confirmed the findings of the document analysis regarding the context of the National Disability Policy Reform documents. Key informant interviews affirmed that the policy reforms were developed because there was a need for laws to protect persons with disabilities and also to operationalise the policy reform documents. The key informant interviews also attested to the findings of the document analysis that the policy reforms were mandated by the United Nations. They further supported the findings of the document analysis that the policy reforms were developed to address the need for financial support, accommodation and mainstreaming of persons with disabilities.

While key informant interviews collaborated findings from the document analysis that healthcare facilities provided for availability of assistive devices as intended by the policy reform documents, it was, however, evident that there were challenges with availability of healthcare professionals and disability specific programmes. Acceptability was also a challenge as physical access, access to augmentative and

alternative communication and health information was a challenge for persons with disabilities. These challenges were further exacerbated by the negative attitudes of some healthcare professionals.

Although the content of the policy reform documents had not mentioned geographical or financial accessibility, the findings from the key informant interviews revealed that these two factors which transpired as transportation challenges and inconsistent financial support were key drivers that negatively influenced access to healthcare for persons with disabilities.

The implementation of the National Disability Policy Reform Documents was said to be the responsibility of the government of Eswatini. Organisations of persons with disabilities have been assigned the role of following-up with government on the progress of these implementations. The development of the National Disability Plan of Action and the National Disability Bill of Rights were meant to be a practical process of implementing the policy. However, to date the National Disability Bill of Rights has not been legalised. The implementation of the policy reforms has been hindered by the lack of financial and human resource commitment from policy implementers and the lack of knowledge and skills of implementers.

8.2.3 Data Source 3: Focus Groups

Data Source 3 represented findings from focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals, as well as additional electronic questionnaires with healthcare professionals. Findings indicated that persons with disabilities still experienced challenges with accessing healthcare regardless of the development and implementation of the policy reform documents. Findings from Data Source 3 clearly highlighted that healthcare facilities were still not equipped with the necessary human and financial resources to render comprehensive services within a reasonable distance to persons with disabilities. As a result, persons with disabilities struggled with obtaining and maintaining relevant assistive devices

due to the lack of a dedicated budget for assistive devices, for rehabilitation services and also for rehabilitation staff.

Persons with disabilities had to travel long distances in mountainous terrains of Eswatini to reach healthcare facilities. This was further exacerbated by the negative attitudes of public transport drivers and the lack of social support grants to assist in covering some of the expensive costs related to public transport.

While physical access (e.g. ramps and wider passages and doors) and sign language training had been prioritised by the National Department of Health, this was not evident across all healthcare facilities. Moreover, communication accommodation in the form of braille and accessible language formats with pictorial support was still not provided. As a result, persons with disabilities were still excluded from health information programmes and their privacy and confidentiality was still compromised during consultations with healthcare professionals when interpreters were used.

Due to the lack of training on disability and the entrenched cultural and contextual stereotypes about disability, healthcare professionals still projected negative attitudes towards persons with disabilities. This was particularly evident in the case of sexual and reproductive health. Myths about disability were also evident in communities where persons with disabilities and their families reside, resulting in marginalisation and stigmatisation. As a means of protecting their relatives with disabilities, caregivers of persons with disabilities resorted to hiding persons with disabilities in their houses, an act which negatively influenced access to healthcare for them on the one hand, while leading to burnout of their caregivers on the other hand. Social support services are therefore desperately needed. Although some communities provided these services, they were not consistent across all communities.

Hence, it became evident that people at the grassroots levels, including healthcare professionals, were not familiar with the National Policy Reform documents and thus perceived it as being ineffective in facilitating access to healthcare for persons with disabilities. This finding is also a strong indicator of the gaps in policy implementation.

8.3 IMPLICATIONS OF STUDY FINDINGS FOR PRACTICE

The findings of the study highlighted the need for disability sensitisation across Eswatini. The findings indicated that there is a need for training of healthcare professionals on various disability aspects and disability rights. Training could include national anti-discrimination legislation, the CRPD, relevant ethical standards, and the principles of reasonable accommodation and universal design. Such training will assist in dismantling the stereotypes and stigma that healthcare professionals have about persons with disabilities. Ideally, persons with disabilities themselves should provide this training or be involved in facilitating the content of the training materials. In doing so, the information included will be more appropriate, relevant and influential.

Further training of healthcare professionals is necessary on the general principles concerning the manner for interactions with persons with disabilities and also on the assessment of disability and the functional consequences of specific disability conditions. This will be helpful when considering practical management of persons presenting with specific disability conditions.

Additional training on the content of the policy reform documents for persons with disabilities, caregivers of persons with disabilities and healthcare professionals, particularly those at grassroots level and those who were not involved in the drafting or implementation of these policy reform documents, is necessary as they were not aware of the actual content of the policy reforms.

The access to healthcare guidelines could be displayed as easy to read posters in healthcare facilities and used by healthcare facilities to conscientise persons with disabilities, caregivers of persons with disabilities and healthcare professionals about the rights of healthcare persons with disabilities regarding what are provided for by the National Disability Policy Reform documents.

The policy brief can be used by policy makers to revise the content of the National Disability Policy Reform documents so that it is cognisant of the paramount influence of geographical and financial accessibility to the access to healthcare for persons with disabilities in Eswatini. The policy brief may also influence policy makers to relook and address the gaps of policy implementation and the influence of these gaps for access to healthcare for persons with disabilities.

The integrated access to healthcare policy analysis framework can be applied in policy studies related to other marginalised groups and across different sectors, as access to different sectors such as education, employment to name just a few continues being a challenge for marginalised groups especially in LMIC.

8.4 EVALUATION OF THE STUDY

The section below provides an evaluation of the study by focusing on both its strengths and the limitations.

8.4.1 Strengths

A novel meticulous framework approach, the Integrated National Disability Policy Analysis Framework was developed, following the paucity of context specific disability analysis frameworks that consider all the relevant components of a policy framework pertaining to access to healthcare for persons with disabilities. The application of this framework across all the data sources in the study not only provided a rigorous way in which to analyse the data, but also provided an opportunity for the researcher to compare data from all three data sources.

The sequential steps that were followed in this research design, which entailed the researcher detailing the methods, findings and discussion for each individual data source before proceeding to the next source, ensured thorough engagement with one data source at a time while establishing the link and relevance of each data source to the data source preceding and succeeding it. This impacted positively on addressing the main research aim.

The inclusion of multiple data sources, representative of all the stakeholders who are involved in guaranteeing the success of persons with disabilities when they access healthcare, ensured that the different viewpoints and voices were represented in the study. The study succeeded in bringing forth the voice of persons with disabilities themselves, an important strength of the thesis, as these voices are often excluded from studies pertaining to disability matters. Persons with disabilities were able to bring forth their experiences and to also offer potential solutions to some of the challenges that they experience.

The collaborative coding approach using three coders during the document analysis and two coders during data analysis of in-depth interviews and focus groups, assured that a rigorous process of determining themes and sub-themes was followed.

The use of a procedural checklist for all three focus groups guaranteed a high level of focus group integrity as an overall procedural checklist adherence of 98% was achieved across all three focus groups.

As the researcher and research fieldworker were from the same cultural and linguistic background as all the participants in the study, rapport and a level of trust was quickly created and maintained between the researcher and the participants in the focus groups. The openness as a result of the fact that they could relate to the researcher allowed the researcher to capture the pure richness of their experiences, with no meaning lost or misunderstood. Language is central in all phases of qualitative

research from data collection to data analysis (van Nes et al. 2010) and it influences how meaning is understood and constructed. The translation of the access to healthcare guidelines into an easy language format accompanied by pictorial support and further translated into SiSwati ensured that the guidelines would be understood by even those persons with disabilities who present with low literacy levels.

8.4.2 Weaknesses

Despite the researcher's attempts at insuring that all stakeholder groups were represented during the key informants' interviews, the Council of Churches was unfortunately not represented. This was owing to the fact that during the drafting of the policy reforms, the Council of Churches established a task team that was assigned to present the views of the council of churches. This task team was disbanded soon after the drafting of the policy reform documents, which was seven years ago. The current incumbents of the office had no record of the names of individuals who were part of this task team.

Some of the key informants requested that certain facts could not be reported when the researcher described her findings. Out of respect for the participants' request and adhering to the ethical obligations of the study, these specific facts were omitted, even though they could have added to the richness of data obtained from these participants.

While the focus group of persons with disabilities produced rich data pertaining to the experiences of persons with disabilities when they access healthcare, this group was small. This focus group was also mostly composed of participants who were involved in disability activism and lobbying. Most of the participants had also been involved in the drafting of the policy reform documents. A few participants represented persons with disabilities that were at grassroots level.

The participants of the three focus groups resided either in an urban area or are practicing in a healthcare facility located in an urban area. The findings may therefore not reflect the experiences of persons with disabilities, caregivers of persons with disabilities and healthcare professionals residing in or working in rural contexts. This is an important factor especially considering that approximately 75.8% of the entire population of Eswatini and 86% of persons with disabilities reside in rural areas (Eide & Jele, 2011; Central Statistics Office, 2010).

Numerous attempts to attract and recruit medical and nursing professionals to participate in the study were made. In spite of these attempts, there was poor representation from the healthcare professional groups, irrespective of the method employed (focus groups or electronic questionnaires).

Even though careful consideration was applied in the phrasing of guideline statements and in the development of pictorial support to enhance these guideline statements, the Access to Healthcare Guidelines was finalised without the input of an expert panel. It is therefore possible that there may be certain pictures and wording with which those end users may disagree. Social validation of these guidelines is therefore necessary. The Access to Healthcare Guidelines also need to be translated into braille and made available as handouts because a large percentage of persons with disabilities in Eswatini is blind (Eide & Jele, 2011).

8.5 RECOMMENDATIONS FOR FUTURE RESEARCH

- Future studies could attempt to determine the appropriateness of the Access to Healthcare Guidelines for the context of disability in Eswatini through a process of social validation with the following different stakeholder groups; persons with disabilities, caregivers of persons with disabilities and healthcare professionals is recommended. Following this, the guidelines could be translated into other formats, such as braille, handouts and videos with sign language, so that they

are accessible to participants who are blind, visually impaired, hearing impaired or deaf.

- The findings of the current study reflect only the experiences of persons with disabilities, caregivers of persons with disabilities and healthcare professionals residing and practising in peri-urban and urban areas, with not much representation of participants (persons with disabilities, caregivers of persons with disabilities and healthcare professionals) residing and practising in rural areas. Considering that access to healthcare for persons with disabilities is further compounded in rural areas, it would thus be imperative to conduct a similar study in the rural context and compare these findings to those of a similar group in urban areas.
- Considering that access to healthcare is influenced by the involvement of other departments such as the department of transport, housing, social welfare and employment. It would therefore be important to interrogate policy documents from other ministerial departments to establish what it is that they have provided for access to healthcare for persons with disabilities.
- The study proposes the need for studies that interrogate policy formulation, policy implementation and policy reviews for marginalised populations, which should be conducted by researchers in partnership with policy makers.
- Healthcare professionals can receive a disability sensitivity training programme as it was evident throughout the study that they were unaware of the rights of this population. A pre-test post-test research design that focuses on knowledge, skills and attitudes can be implemented in order to evaluate the effect of training. It should also be reiterated that all possible attempts should be made to ensure that the change brought about through training should be long lasting to be sustainable.
- Although the government has made available disability reform documents that address access to healthcare for persons with disabilities in Eswatini, it was clear from the lack of awareness and knowledge about these documents that was evident in the findings of the study that the policy reform documents had

not reached all persons with disabilities, families of persons with disabilities and healthcare professionals. A training programme to disseminate the policy reform documents while also conscientising persons with disabilities, families of persons with disabilities and healthcare professionals on the available policy reform documents is proposed for future research.

- While the imperative and sole responsibility of the government of Eswatini in policy implementation is acknowledged, the study does however pose the following research question: What is the value of persons with disabilities, caregivers of persons with disabilities and healthcare professionals in the development and implementation of the disability plan of action in the Ministry of Health.

8.6 CONCLUSION

Chapter 8 presented the significant findings from the study. The implications of the findings of the study for the training of healthcare professionals was discussed. Additional implications of the access to healthcare guidelines for the rights to healthcare for persons with disabilities were deliberated on and further implications of the policy brief for the improvement of the policy reform documents were addressed. The strengths and limitations of the study were highlighted in an attempt to evaluate the study. Finally, recommendations for further studies were suggested.

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APPENDICES

APPENDIX A: Ethics Approval University of Pretoria



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

19 April 2018

Dear Ms Dlamini

Project: Experiences of people with disabilities when accessing health services in Swaziland
Researcher: KP Dlamini
Supervisors: Dr E Johnson and Prof J Bornman
Department: Centre for Augmentative and Alternative Communication
Reference number: (GW20160721HS)

Thank you for your response to the Committee's letter of 8 August 2016.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 19 April 2018. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

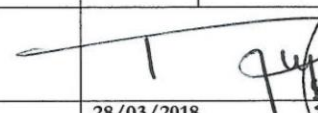
cc: Dr E Johnson (Supervisor)
Prof J Bornman (HoD)

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Dr L Blokland; Dr K Booyens; Dr A-M de Beer; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder; Dr E Johnson; Dr W Kelleher; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

APPENDIX B: Permission from Swaziland Health Ethics Committee

Research Protocol clearance certificate



Type of review	Expedited	<input checked="" type="checkbox"/>		Full Board		
Name of Organization	Khetsiwe Masuku					
Title of study	Experiences of Persons with a disability when they access healthcare services in Swaziland					
Protocol version	1.0					
Nature of protocol	New	<input checked="" type="checkbox"/>		Amendment		
List of study sites	The National Disability Unit at the Deputy Prime Minister's Office, The Federation Organisations of the Disabled People in Swaziland (FODSWA) and The Ministry of Health.					
Name of Principal Investigator	Khetsiwe Masuku					
Names of Co- Investigators	N/A					
Names of steering committee members in the case of clinical trials	N/A					
Names of Data and Safety Committee members in the case of clinical trials	N/A					
Level of risk (Tick appropriate box)	Minimal			High		
	<input checked="" type="checkbox"/>					
Clearance status (Tick appropriate box)	Approved	<input checked="" type="checkbox"/>		Disapproved		
Clearance validity period	Start date	28/03/2017		End	28/03/2019	
Signature of Chairperson						
Date of signing	28/03/2018					
Secretariat Contact Details	Name of contact officers					
	Simangele Masitela					
	Email address					
	Telephone no.					



Approval Conditions

1	Implementation of approved version of protocol	✓				
2	Reporting of adverse events within 5 days of occurrence	✓				
3	Submission of progress reporting for multi-year studies	Yr 1	Yr 2	Yr 3	Yr 4	Yr 5
		N/A	N/A	N/A	N/A	N/A
4	Submission of end of project report (Hard copy)	✓				
5	Submission of end of project report (Soft copy)	✓				
6	Submission of data sets	✓				

List of reviewed documents

Ref.	Documents	Reviewed documents (tick appropriate box)
1	Completed application form	✓
2	Cover letter	✓
3	Evidence of administrative permission to conduct the research by involved institutions/sites (where applicable)	✓
4	Detailed current resume or curriculum vitae of Principal Investigator/s including Principal investigators declaration	✓
5	Summary resume or biography for other investigator(s)	✓
6	Evidence of approval/rejection by other Ethics Committees, including comments and requested alterations to the protocol, where appropriate.	
7	Research protocol (see outline in Annex 1)	✓
8	Questionnaires and interview guides (with back-translated versions where applicable)	✓
9	Case report forms (CRFs), abstraction forms and other data collection tools	✓
10	Participant/subjects Information Statement(s) (where applicable)	✓
11	Informed consent form(s) including photographic and electronic media consent statements.	
12	Advertisements relevant to the study (where applicable)	
13	Source of funding and detailed budget breakdown including material and incentives to participants if applicable	
14	Notification form for adverse effects/events.	
15	Proof of payment	✓
16	Proof of insurance cover for research subjects in clinical trials or where applicable	
17	Any other special requirements should be stated, if applicable	None

R. C.

APPENDIX C: Permission from the Federation for Disability Organisations



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

The Federation of Organizations of the Disabled People in Swaziland

Faculty of Humanities

Reply slip: Permission letter (FODSWA)

I hereby grant permission to Khetsiwe Masuku to conduct research with the title:

"Experiences of people with disabilities when accessing health services in Swaziland"
by accessing the database of the Federation of the Disabled persons in Swaziland.

President of Federation of the Disabled Persons in Swaziland



P.O. Box 2052
Mbabane H1100
Swaziland

Member of Southern Africa Federation of the Disabled (SAFOD)
Also of Disabled People International (DPI)

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617-0524

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotheo

APPENDIX D: Permission from Superintendent of the public tertiary state hospital



Telephone: (+268 404 2431)
Fax: (+268 404 2092)

MINISTRY OF HEALTH
P.O. BOX 5
MBABANE
SWAZILAND

THE KINGDOM OF SWAZILAND

14th May 2018

To: SMO, Matron, Sister-in-Charge

Dear Sir/Madam

RE: PERMISSION TO CONDUCT RESEARCH ON DISABILITY SERVICES

This letter serves to inform you that permission has been granted to Ms Khetsiwe Masuku nee Dlamini to collect data for her research on “Experiences of Persons with Disability When Accessing Health Services in Swaziland”. Ms Khetsiwe Masuku is a PhD student at the University of Pretoria and would like to conduct the research at the Mbabane Government Hospital and Lobamba Clinic and Satellite Clinic.

Ms Masuku will be conducting focus group discussions with clients and health workers on a voluntary basis. It is our hope that the results of her research will inform the health sector strategy going forward in terms of being ready to service people living with disabilities in the country.

Please assist her in any way possible to make her research a success.

Yours Sincerely

A handwritten signature in blue ink, appearing to be 'B.M.' or similar initials.

[Redacted signature box]

Deputy Director of Health Services



MEMORANDUM

TO: ALL HOSPITAL STAFF
MBABANE GOVERNMENT HOSPITAL

FROM: SENIOR MEDICAL OFFICER
MBABANE GOVERNMENT HOSPITAL

DATE: 16TH MAY, 2018

**RE: EXPERIENCES OF PERSONS WITH DISABILITY WHEN ACCESSING HEALTH SERVICES IN
MBABANE GOVERNMENT HOSPITAL**

I kindly write this letter to inform you that the management of Mbabane Government Hospital has granted **Khetsiwe Masuku** permission to continue with the above topic.

We would very much appreciate if the findings and recommendations of the study can be communicated back to the facility (**electronic and hard copy**).




SENIOR MEDICAL OFFICER



APPENDIX E: Poster Presentation of the Study

Provisions of The National Disability Policy of Swaziland for Access to Healthcare for Persons With Disabilities: A Policy Analysis

Khetsiwe Masuku (PHD candidate); Ensa Johnson (PHD); Juan Bornman (PHD)
Centre for AAC at the University of Pretoria, South Africa (www.caas.up.ac.za)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Centre for Access to Care
University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Introduction

- The United Nations (UN) declared **health as a basic human right**,
- BUT persons with disabilities (PWD) continue experiencing **worse access to healthcare** than their counterparts without disabilities
- Human rights are a contentious subject in Swaziland
- The **rights of PWD** arguably being amongst the **least addressed** in the country = PWD are still **vulnerable to stigma, marginalisation and exclusion**.
- The **National Disability Policy of Swaziland (NDPS)** was enacted in 2013 as pressure mounted from international bodies and local disability organisations for Swaziland to produce a National Disability Policy after she ratified the CRPD in 2012.
- The NDPS is the **only currently available comprehensive document** that made **provisions, regulates and addresses access** to equal opportunities for PWD, including access to healthcare.

Aims

- To describe the provisions of the NDPS and its supporting documents for access to healthcare for PWD and to further describe the actors, context and processes of the NDPS.

Methods

Design

- **Document analysis** (part of a bigger study that explored access to healthcare for PWD in Swaziland)
- **Case study research design** combining the *Wait and Gilson policy analysis framework* and the *Peters et al., (2008)'s access to healthcare framework*, using **multiple data sources**.
- A document review of the NDPS and other documents associated with it along with in-depth interviews with key informants were utilised to establish the provisions for access to healthcare and the actors, context and processes of the NDPS.

Participants

- ✓ Purposive sampling (N=8)
- ✓ Expert Reviewers (n=2); One male and one female
- ✓ Key Informants (n=6); Two were females and three were males., between the ages of 25 and 35 years.

Setting: In-depth interviews were conducted in Mbabane, Swaziland

Results

Content

- Availability**
Provisions of:
 - effective healthcare services
 - sexual and reproductive health
 - rehabilitation facilities
 - Counselling
 - Available trained personnel
- Acceptability**
 - Communication needs of PWD
 - Personnel trained on disability; braille; sign language
 - Health information and in different formats
 - Non-discrimination, inclusiveness, equal access
 - Physical Accessibility
- Geographical Accessibility**
 - Mobilisation of communities on the awareness and health promotion to prevent disabilities
- Financial Accessibility**
 - Free subsidised, affordable health services

Processes

- Practice Barriers**
 - Lack of Leadership
 - Lack of Funding
 - Lack of political commitment
 - Lack of disability personnel
- Policy Barriers**
 - Government not passing the National Disability Bill of Rights
 - The National Disability Plan as the blueprint of implementation
- Knowledge and Skills Barriers**
 - Lack of knowledge on disability and disability rights in government structures
 - Lack of management skills
- Attitudes**
 - Negative Stereotypes from those responsible form implementation

Context

- Practice Barriers**
 - Lack of disability co-ordination
 - Lack of political commitment
- Policy Barriers**
 - Lack of Legislation
 - Pressure from local and international structures
- Knowledge and Skills Barriers**
 - Lack of Knowledge on disability and disability rights
- Attitude Barriers**
 - Stigma towards persons with disabilities
 - Negative attitudes towards persons with disabilities
 - Lack of Inclusion of Persons with disabilities

Actors

- Disability Organisations
- Non-Governmental Organisations
- All Government Ministries
- The National Disability Unit
- Council of Churches

Discussion

- The NDPS was developed to address human rights for persons with disabilities in Swaziland as a mandate from the constitution of the Kingdom of Swaziland and the CRPD.
- There was adequate representation of the different governmental and non-governmental organisations during the drafting phase of the policy
- However this was not the case during the implementation of the policy, as implementation was left solely to the government
- There is therefore evidence of gaps in terms of implementation
- While the policy has provided for PWD in terms of the pillars of availability and acceptability, gaps are apparent in the pillars of financial and geographical accessibility

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Theoretical Framework

Figure 1. Adapted Framework for Policy Analysis based Wait & Gilson (1994) and Peters et al. (2005)

APPENDIX F: Biographical Questionnaire for Key Informants

ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI KEY INFORMANTS' DEMOGRAPHIC QUESTIONNAIRE

Dear Participant

Please complete all questions.

Demographic Questionnaire	
1. What is your gender?	
2. What language (s) do you speak?	
3. What is your professional background?	
4. What was your job title during the drafting and implementation of the National Disability Policy Reform Documents of Swaziland?	
5. What was your institution of employment during the drafting and implementation period of the National Disability Policy Reform Documents of Swaziland?	
6. What was your department of employment during the drafting and implementation of the National Disability Policy Reform Documents of Swaziland?	
7. For what period of time had you been employed in that institution?	
8. Describe your involvement in the development of the National Disability Policy Reform Documents of Swaziland?	
9. Describe your involvement in the implementation of the National Disability Policy Reform Documents of Swaziland?	

APPENDIX G: Key Informant Interview Script in English

ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI

SECTION A: QUESTION ON THE ACTORS INVOLVED IN THE NATIONAL DISABILITY POLICY REFORM DOCUMENTS OF SWAZILAND

Question on actors
<p>Which actors, bodies and organisations were involved in the formulation of the National Disability Policy Reform Documents of Eswatini</p> <ul style="list-style-type: none"> • Probe for those actors or bodies involved in the development of the policy • Probe for those actors or bodies involved in the implementation of the policy
<p>What was the selection criteria for the actors involved in the development and implementation of the National Disability Policy Reform Documents of Eswatini?</p> <ul style="list-style-type: none"> • How was it decided that certain people should be part of the policy development processes? • How was it decided that certain people should be part of the policy implementation processes?
<p>Who was involved in the development and implementation of the National Disability Policy Reform Documents of Eswatini?</p>

SECTION B: QUESTIONS ON THE CONTEXTUAL INFLUENCE OF NATIONAL DISABILITY POLICY REFORM DOCUMENTS OF SWAZILAND

Question on context
<p>Can you tell me about the reasons why the National Disability Policy Reform Documents of Eswatini was initiated?</p> <ul style="list-style-type: none"> • Probe what was the situation before the implementation of the National Disability Policy Reform Documents of Eswatini
<p>What would you say are the contextual factors that have influenced the implementation of the National Disability Policy Reform Documents of Eswatini?</p> <ul style="list-style-type: none"> • What are the situational factors? See definitions at the bottom of the interview questions. • What are the structural factors? See definitions at the bottom of the interview questions. • What are the cultural factors? See definitions at the bottom of the interview questions. • What are the international factors? See definitions at the bottom of the interview questions.
<p>What would you say are the contextual factors that have influenced the implementation of the National Disability Policy Reform Documents of Eswatini in the health sector?</p>

- What are the situational factors? See definitions at the bottom of the interview questions.
- What are the structural factors? See definitions at the bottom of the interview questions.
- What are the cultural factors? See definitions at the bottom of the interview questions.
- What are the international factors? See definitions at the bottom of the interview questions.

SECTION C: QUESTIONS ON THE PROCESS OF IMPLEMENTATION OF THE NATIONAL DISABILITY POLICY REFORM DOCUMENTS OF SWAZILAND

Question on implementation

Describe the steps that were followed during the implementation process of the National Disability Policy Reform Documents of Eswatini?

- Explore the steps that were followed during the implementation of the National Disability Policy Reform Documents of Eswatini?
- What were the successes and challenges in the implementation of the National Disability Policy Reform Documents of Eswatini?
- What were the challenges in the implementation of the National Disability Policy Reform Documents of Eswatini?
- What do you think could be done to improve the implementation of the National Disability Policy Reform Documents of Eswatini?

Describe the steps that were followed during the implementation of the National Disability Policy Reform Documents of Eswatini in the department of health.

Explore the steps followed during the implementation of the National Disability Policy Reform Documents of Eswatini

- What was the situation before the implementation of the National Disability Policy Reform Documents of Eswatini in the department of health?
- Explore the measures taken by the department of health to support implementation of the National Disability Policy Reform Documents of Eswatini
- What were the successes and challenges in the implementation of the National Disability Policy Reform Documents of Eswatini in the department of health?
- What do you think could be done to improve the implementation of the National Disability Policy Reform Documents of Eswatini in the healthcare context?

DEFINITIONS:

- **Situational factors:** (the specific conditions of a moment in history that influence on the policy change intended).
- **Structural factors:** the relatively unchanged circumstances of the society and the policy such as the structure of the economy and the political system.
- **Cultural factors:** the values and commitments of society and groups
- **International factors:** the events and values outside of any one country or system

APPENDIX H: Informed Consent Letter for Key Informant and Focus Group Participants



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Participant Information and Informed Consent Letter

Dear Participant

Invitation to participate in a research study

My name is Khetsiwe Masuku (nee' Dlamini) and I am a PhD student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am requested to conduct a research project. I would therefore greatly appreciate your participation in my research study.

Research Topic: *Access to healthcare for persons with disabilities in Swaziland (Eswatini)*

Rationale for the study: Persons with disabilities experience more often than people who do not have a disability challenges when accessing the health services even though they have more healthcare needs. The access to healthcare challenges are further exacerbated in low to middle income countries such as Swaziland (Eswatini) despite the country having provided for access to healthcare in the National Disability Policy of Swaziland (Eswatini).

Objectives of the study: The main objective of the study was to explore the experiences of persons with disabilities when accessing health services in Swaziland (Eswatini). This will be done in three stages, namely stage 1 which encompassed first analysing the National Disability Policy of Swaziland (Eswatini) and its supporting documents, specifically for its provisions for access to healthcare for persons with disabilities; stage 2, conducting in depth interviews with stakeholders who were involved in the policy development to establish the actors, context and processes that were involved and followed during the developing and implementation of the policy; and stage 3 conducting focus group discussions with persons with disabilities, caregivers of persons with disabilities and health service providers to establish the actual experience of persons with disabilities when they access healthcare services in Swaziland (Eswatini).

Why have you been invited to participate in this study? You are invited to participate in this study because you are either stakeholder who was involved in the development and implementation of the national disability policy of Swaziland; a person with disability, a caregiver of a person with a disability or a healthcare professional who works with persons with disabilities. You therefore have the necessary knowledge and experience on the following: the development of the national disability policy and on the experiences of persons with disabilities when they access to healthcare services in Swaziland (Eswatini). Due to your knowledge and experience, you will be in a better position to give contributions to the discussions on the above-mentioned topics.

What is expected of you as participate of the study?

Key stakeholders: You will be expected to participate in a one on one indepth interview with the researcher. You will be responding to questions on the development and implementation of the National disability policy of Swaziland and its supporting documents. All interviews will be audio recorded.

Persons with disabilities, caregivers of persons with disabilities and healthcare professionals: You will be expected to participate in groups discussion on the experiences of persons with disabilities when they access healthcare facilities. All focus groups will be audio recorded.

The following ethical considerations are addressed:

Risks and benefits of participants: By participating in this project, you will enable the researchers to share your experiences of accessing health services in Swaziland (Eswatini). Participation in this project is voluntary and you will not receive any incentive to participate. You may withdraw at any time without any negative consequences. Furthermore, information obtained will be handled with confidentiality and used for research purposes, writing of a PhD thesis; journal articles, and conference presentations only. Your identity will not be revealed. There are no risks associated with the study and all information will be kept confidential. As part of the University of Pretoria's policy, all electronic as well as hardcopy data will be securely stored for a minimum of 15 years. The researchers will not obtain any personal, societal or financial gain from the study. Ethics approval will be obtained from Ethics Committee at the Faculty of Humanities before the study will commence. If you wish to receive a copy of the results of the study, you may contact the principal researcher at the telephone number given below.

Your participation in this study will be greatly appreciated. If you agree to participate, kindly sign the included consent form and return to the researcher via the email provided on the reply slip. Thank you for your time and consideration in this matter.

If you have any questions concerning the research study, please call me at [REDACTED] or e-mail me at [REDACTED]

Yours sincerely,

Ms. Khetsiwe Masuku
(PHD Student)

Dr. Ensa Johnson
(Supervisor)

Prof. Juan Bornman
(Co-supervisor)

Reply Slip: Informed consent

INFORMED CONSENT FORM: Individual interviews and focus groups

<u>Name and number of Participant:</u>			
<u>Project title:</u>	Experiences of persons with disabilities when accessing health services in Swaziland		
<u>Researcher:</u>	Khetsiwe Dlamini (Masuku) [REDACTED]@gmail.com [REDACTED]	<u>Supervisors:</u>	Dr Ensa Johnson ensa.johnson@up.ac.za [REDACTED] Prof Juan Bornman Juan.bornman@up.ac.za [REDACTED]

I, _____, (full names and surname) hereby:

- Provide consent to participate in the study as outlined above
- Provide consent to be audio recorded for the purpose of the study.
- Understand that I will at no stage during the research process be exposed to any harmful situations;
- Agree that I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation and without any negative consequences;
- Understand that the content of the data will be handled with confidentiality and used for research purposes, report to Faculty; conference presentations, journal articles only;
- Understand that the data will be stored for a period of 15 years in a safe place at the CAAC, University Pretoria for archival purposes;
- Understand that information will be treated confidentially.

(Please tick appropriate block)

I give consent	<input type="checkbox"/>	I do not give consent	<input type="checkbox"/>
----------------	--------------------------	-----------------------	--------------------------

Signature of participant

Date

APPENDIX I1: Biographical Questionnaire for Participants

ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI

Experiences of persons with disabilities when they access healthcare services in Eswatini from the perspective of persons with disabilities, caregivers of persons with disabilities and healthcare personnels

PARTICIPANTS' OF FOCUS GROUPS' DEMOGRAPHIC QUESTIONNAIRE

Please complete ALL questions

- If you are person with disability, please complete section 1 only
- If you are a caregiver of a person with disability, please complete section 2 only
- If you are a healthcare professional, please complete section 3 only

Section 1: Demographic Questions for persons with disabilities				
1. What is your gender?	Male		Female	
2. What language (s) do you speak?	SiSwati	English	Both	
3. What is your age?				
4. Where do you reside?				
5. What type of disability do you present with?				
6. How long have you been living with a disability?				
7. How often do you access healthcare services?	Weekly	Monthly	Every 2 months	Every 3 months
	Every 4 months	Every 6 months	Other:	
Section 2: Demographic Questions for caregivers of persons with disabilities				
8. What is your gender?	Male		Female	
9. What is your age?				
10. Where do you and the person with disability you are caring for reside?				
11. What type of disability does the person you are caring for present with?				
12. How long has the person with disability that you are caring for lived with a disability				
13. How often do you accompany the person with disability that you care for to a healthcare facility	Weekly	Monthly	Every 2 Months	Every 3 Months
	Every 4 Months	Every 6 Months	Other:	
Section 3: Demographic Questions for healthcare professionals				
14. What is your gender?	Male		Female	
15. What is your age?				
16. Where do you currently work?				
17. What is your profession?				

18. What is the highest level of education that you have?	
19. How many years have you been practicing in your profession?	
20. How many years have you been working with persons with disabilities?	
21. How often do you provide healthcare services to persons with disabilities?	

APPENDIX I2: Biographical Questionnaire for Participants in SiSwati

KUTFOLA TEMPHILO KWEBANTFU LABAKHUBATEKILE ESWATINIbantfu Labakhubatekile uma benta taba tekutfola temphilo Eswatini –imibono yebantfu labakhubatekile, bantfu labanakekela bantfu labakhubatekile kanye netisebenti tetemphilo.

Phendvula Yonkhe Imibuto

- Uma ungumuntu Lokhubatekile, gcwabisa, uphendvule sigamu sekucala kuphela.
- Uma unguuntu lonakekela umontfu lokhubatekile, gcwabisa, uphendvule sigamu sesibili kuphela
- Uma ungumuntu losebenta etiko letemphilo, gcwabisa, uphendvule sigamu sesitsatfu.

Sigamu 1: Imibuto yebantfu labakhubatekile				
1. Yini Bulili bakho?	Umdvuna		Umsikati	
2. Nguluphi Lulwimi Lolukhulumako?	SiSwati	Singisi	Kokubili	
3. Mingaki imnyaka wakho?				
4. Ngukuphi lapho uhlala khona?				
5. Ukhubateke ngayiphi indlela?				
6. Sowuphile sikhatsi lesingakanani ukhubatekile?				
7. Uya kangakhi emtfolamphilo ngemunyaka?	Kanye ngeliviki?	Kanye ngenyanga?	Emva Kwetinyanga letimbili?	Emva kwetinyanga letintsatfu?
	Emva kwetinyanga letine?	Emva kwetinyanga letisitfupha?	Lokunye?	
Sigamu 2: Imibuto yebantfu labanakekela bantfu labakhubatekile				
8. Yini Bulili bakho?	Umdvuna		Umsikati	
9. Mingaki imnyaka wakho?				
10. Ngukuphi lapho uhlala khona?				
11. Ukhubateke ngayiphi indlela umuntu lomunakekelako?				
12. Sekusikhatsi lesinganani unakekela umuntu lokhubatekile?				
13. Uya kangakhi emtfolamphilo ngemunyaka umuntu lomunakekelako?	Kanye ngeliviki?	Kanye ngenyanga?	Emva Kwetinyanga letimbili?	Emva kwetinyanga letintsatfu?
	Emva kwetinyanga letine?	Emva kwetinyanga letisitfupha?	Lokunye?	
Sigamu 3: Imibuto yetisebenti telitiko letemphilo				
14. Yini bulili bakho?	Umdvuna		Umsikati	

15. Mingakhi iminyaka yakho?	
16. Usebentaphi?	
17. Usebentaphi?	
18. Ufundze kanganani?	
19. Sowusebente sikhatsi lesingakanani?	
20. Sowunesikhatsi lesinganani usebenta nebantfu labakhubatekile?	
21. Ubalapha kangakhi bantfu labakhubatekile?	

APPENDIX J: Information Letter for Focus Group Participants



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Focus Groups Participant Information Letter

Dear Participant

Invitation to participate in a research study

My name is Khetsiwe Masuku (nee' Dlamini) and I am a PhD student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am requested to conduct a research project. I would therefore greatly appreciate your participation in my research study.

Research Topic: *Access to healthcare for persons with disabilities in ESwatini*

Rationale for the study: Persons with disabilities experience more often than people who do not have a disability challenges when accessing the health services even though they have more healthcare needs. The access to healthcare challenges are further exacerbated in low to middle income countries such as ESwatini despite the country having provided for access to healthcare in the National Disability Policy Reform Documents of ESwatini.

Objectives of the study: The main objective of the study is to explore the experiences of persons with disabilities when they access health services in ESwatini. The study is in 3 steps. The first step is the analysis of the National Disability Policy Reform Documents of Eswatini with specific reference to its provisions for accessibility to healthcare for persons with a disability. The second step encompasses conducting in-depth interviews with key informants who were involved in the development and implementation of the National Disability Policy Reform Documents about the actors, context, processes and content of the National Disability Policy Reform Documents. The final step involves focus group discussions with persons with disabilities, caregivers of persons with disabilities and health service providers who work with persons with disabilities on the experiences of persons with disabilities when they access healthcare in Eswatini.

Why have you been invited to participate in this study? You are invited to participate in this study because you are either a person with disability, a caregiver of a person with a disability or a healthcare professional who works with persons with disabilities and you therefore have knowledge on the experiences of persons with disabilities when they access healthcare services in Eswatini. Due to your knowledge and experience, you will be in a better position to provide relevant input on the experiences of persons with disabilities when they access healthcare services in Eswatini and potentially on the National Disability Policy Reform Documents for persons with disabilities.

The procedure of the focus group discussion: You will be given an information letter with a consent letter attached to it. You will be assisted to complete the consent letter before commencing with the focus group discussion. You will be placed in a group with other persons with disabilities, caregivers of persons with disabilities and healthcare professionals. You will be expected to make a contribution to the discussion of access to healthcare for persons with disabilities by responding to questions that will be asked by the researcher.

The following ethical considerations are addressed:

Risks and benefits of participants: By participating in this project, you will enable the researchers to share your experiences of accessing health services in Eswatini. Participation in this project is voluntary and you will not receive any incentive to participate. Participants of the persons with disabilities and caregivers of disabilities' focus groups will be given E200.00 to cover their transportation costs and to cater for their lunch packs. Participants of the healthcare professional group will be provided with lunch. You may withdraw at any time without any negative consequences. Furthermore, information obtained will be handled with confidentiality and used for research purposes, writing of a PhD thesis; journal articles, and conference presentations only. Your identity will not be revealed. There are no risks associated with the study and all information will be kept confidential. As part of the University of Pretoria's policy, all electronic as well as hardcopy data will be securely stored for a minimum of 15 years. The researchers will not obtain any personal, societal or financial gain from the study. Ethics approval will be obtained from Ethics Committee at the Faculty of Humanities before the study will commence. If you wish to receive a copy of the results of the study, you may contact the principal researcher at the telephone number given below.

Your participation in this study will be greatly appreciated. If you agree to participate, kindly sign the included consent form and return to the researcher via the email provided on the reply slip. Thank you for your time and consideration in this matter.

If you have any questions concerning the research study, please call me at (011) 550 1111 or e-mail me at k.masuku@up.ac.za.

Yours sincerely,

Ms. Khetsiwe Masuku
(PHD Student)

Dr. Ensa Johnson
(Supervisor)

Prof. Juan Bornman
(Co-supervisor)

APPENDIX K: Focus Group Script

ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI

FOCUS GROUP DISCUSSIONS WITH PERSONS WITH DISABILITIES; CAREGIVERS OF PERSONS WITH DISABILITIES AND HEALTHCARE PROFESSIONS

FOCUS GROUP SCRIPT

Focus Group Question	Theoretical Justification
<p>1. Could you tell me what you know about the National Disability Policy Reform Documents of Eswatini?</p> <p>Probes:</p> <ul style="list-style-type: none"> • How were you made aware of the national disability policy reform documents? • What changes have you seen in terms of access to healthcare for persons with disabilities since the development and implementation of the national disability policy reform documents? • What other disability programs (services) have been implemented in the department of health for the benefit of persons with disabilities as a result of the development and implementation of the national disability policy reform documents? 	<p>It is important for all those that a policy in intended for to be aware of the existence and the contents of the policy so that they benefit from the policy</p>
<p>2. What are the experiences of persons with disabilities when they access healthcare services in Eswatini?</p> <p>Probes:</p> <ul style="list-style-type: none"> • What are the difficulties that are experienced by persons with disabilities when they access healthcare services in Eswatini? • What actions could be put in place to facilitate access to healthcare for persons with disabilities in Eswatini? • What support services are available in healthcare for persons with disabilities in Eswatini? • What support services should be available in healthcare for persons with disabilities in Eswatini? <p>3. Is there anything else you would like to add?</p>	<p>It is important to establish the actual experiences of persons with disabilities when they access healthcare services as it is the ultimate goal of the study</p>

APPENDIX L: Procedural Checklist

ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI

Procedural Checklist for focus groups with persons with disabilities, caregivers of persons with disabilities and healthcare professionals

Step	Procedure	Completed Yes/No	For Office use only
1.	The room was set with chairs in a circle with a microphone at the centre.		
2.	Upon arrival participants completed a consent form and a demographic questionnaire		
3.	Participants were issued with name tags and given an option to use a pseudonym.		
4.	The researcher welcomed participants and introduced herself and the research fieldworker. Participants were then also asked to introduce themselves.		
5.	The researcher gave a detailed background of the study and explained the purpose of the focus groups.		
6.	The rules of the discussion were outlined and agreed upon by all participants.		
7.	The researcher used the focus script, asking one question at a time. Each participant had an opportunity to respond. Persons who are blind were called by their names so that they knew when to respond.		
8.	The research fieldworker used a project chart to highlight the key points as the discussion progressed.		
9.	After the discussion of each question, the researcher captured and summarised the main points, and asked participants to confirm the correctness of their responses (member checking).		
10.	After all the questions had been completed, the researcher thanked all participants for their time and constructive participation.		
11.	Transport stipends were given to participants (excluding Healthcare Professionals).		
12.	The researcher and research fieldworker offered participants refreshments		

APPENDIX M: Questionnaire for online questions with healthcare professional.

ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI

ONLINE QUESTIONNAIRE WITH HEALTHCARE PROFESSIONALS

Please Complete All the Questions on this Questionnaire

- 1. What do you know about the National Disability reform documents of Eswatini?**

- 2. How were you made aware of the National Disability policy reform documents?**

- 3. What changes have you seen in terms of access to healthcare for persons with disabilities since the development and implementation of the National Disability policy reform documents?**

- 4. What other disability programs (services) have been implemented in the department of health for the benefit of persons with disabilities as a result of the development and implementation of the National Disability policy reform documents?**

- 5. What are the experiences of persons with disabilities when they access healthcare services in Eswatini?**

- 6. What are the difficulties that are experienced by persons with disabilities when they access healthcare services in Eswatini?**

- 7. What actions could be put in place to facilitate access to healthcare for persons with disabilities in Eswatini?**

- 8. What support services are available in healthcare for persons with disabilities in Eswatini?**

9. What support services should be available in healthcare for persons with disabilities in Eswatini?

10. Is there anything else you would like to add?

APPENDIX N: Access to healthcare guidelines in SiSwati

Do you have a disability?

10 tips to access your rights to healthcare



1



Go to **any hospital** when you feel sick or need therapy

6



Ask for health information in pictures, braille or sign language

2



Get your hospital treatment **for free**

7



Take part in **any** health programs

3



Tell the **staff** at the help desk about your disability and that you **need assistance**

8



Get a wheelchair, a hearing aid or a walking aid **for free**

4



Skip the **queue**

9



Ask hospital staff to fix your wheelchair, hearing aid or walking aid **for free**

5



Expect to be treated **respectfully**

10



Remember that hospital staff must **support** you

Dlamini-Masuku, 2020. ACCESS TO HEALTHCARE FOR PERSONS WITH DISABILITIES IN ESWATINI. UNPUBLISHED DOCTORAL DISSERTATION. FACULTY OF HUMANITIES. UNIVERSITY OF PRETORIA, PRETORIA, SOUTH AFRICA.

APPENDIX O: Code Book

Segments from the National Disability Policy Reform Documents	Integrated Disability Policy Analysis Framework						
	Actors	Context	Content				Processes
			Availability	Acceptability	Geographical	Accessibility	Financial
1. Build and strengthen partnerships with relevant government, non-governmental, private sector agencies and organisations of persons with disabilities.	✓	✓		✓			✓
2. Ensure support services including provision of assistive devices and resettlement.			✓				
3. Harmonising and strengthening of partnerships between Disability Persons' Organisations, and relevant government, non-governmental organisations and private agencies to ensure inclusion of persons with disabilities in all services planned to benefit them.	✓	✓		✓			
4. Facilitate community awareness and community mobilisation on health promotion to prevent disability.		✓		✓	✓		
5. Ensure provision of effective medical intervention for the prevention, early detection, diagnosis and treatment of disability and disabling conditions.			✓				
6. Provide rehabilitation and necessary referrals and counselling for individuals who have disability and their family members.			✓	✓			
7. Ensure human resource development to ensure adequate trained personnel at all levels of health service delivery and rehabilitation.			✓				

	Integrated Disability Policy Analysis Framework						
8. Ensure access to health information for all persons with disabilities.			✓				
9. Provide training of health workers in relevant communication skills such as braille and sign language.			✓				
10. Hospitals and healthcare facilities to be disability friendly/compliant.			✓	✓			
11. Hospitals and healthcare facilities to include free and affordable health care services.		✓				✓	
12. Create an enabling environment to ensure availability and accessibility of family planning information for all including persons with disabilities.			✓	✓			
13. Secure resources for the provision of comprehensive family planning services.			✓				
14. Ensure accessible to information and communication technology.			✓				
15. Provide technical guidance and tools on adolescent sexual and reproductive health issues at all levels of service provisions.			✓	✓			
16. Provide comprehensive adolescent sexual and reproductive health issues information and services to persons with disabilities.			✓	✓			

	Integrated Disability Policy Analysis Framework						
17. Secure resources including competent and skilled human resources required for management of sexually transmitted infections, HIV and AIDS.			✓				
18. Improve monitoring and evaluation systems of sexually transmitted infections HIV and AIDS intervention.			✓				
19. Increase accessibility and availability of commodities and supplies for prevention.			✓	✓			
20. Management of supplies for prevention and management of sexually transmitted infections, HIV and AIDS at all levels of service provision.			✓				
21. Provide comprehensive information and management of sexually transmitted infections, HIV and AIDS.			✓				
22. Engage communities on sexually transmitted infections, HIV and AIDS prevention and treatment activities.	✓			✓			
23. Facilitate that those who are severely disabled and vulnerable get subsidies or even free treatment at public health facilities.						✓	
24. Government will encourage local innovative, production, maintenance and distribution of assistive device services.			✓		✓	✓	
25. Private sector to make available assistive devices at affordable means.	✓					✓	
26. Government shall set standards on the distribution of assistive devices.			✓	✓	✓		

	Integrated Disability Policy Analysis Framework						
27. Government shall ensure that assistive devices are prescribed and issued by qualified and trained personnel.			✓				
28. All buildings and related structures which are public will be periodically audited for their accessibility to persons with disabilities.				✓	✓		
29. Communication needs of persons with disabilities will be met by making information services and public documents accessible.				✓			
30. Special programmes will be developed for education, employment and providing of other rehabilitation services to women, girls, boys with disabilities keeping in view their special needs.			✓	✓			
31. To promote inclusiveness and ensure that all institutions provide services to persons with disabilities in the same manner as they provide to the non-disabled except where necessary.		✓		✓			
32. Advocacy for the establishment or refurbishment of public buildings such as schools, places of worship, banks, healthcare facilities, so that they become user friendly for persons with disabilities.		✓		✓			
33. Ensure capacity building for personnel involved in all spheres catering for all age groups including para-social workers, traditional midwives, assistant nurses and other community based workers.			✓	✓			
34. To ensure that all persons with disabilities have equal access and opportunities to education and health services at all levels.	✓		✓	✓			
35. The policy is aimed at ensuring the full commitment by government towards improving the livelihoods of persons with disabilities.		✓					

	Integrated Disability Policy Analysis Framework						
36. It has been realised that a majority of persons with disabilities can lead a better quality of life if they have equal opportunities and effective access to rehabilitation measures yet they live in poverty and society tends to exclude, discriminate thus, ultimately disabling them.		✓	✓	✓			
37. The disability movement has been advocating for the formulation of a National Disability Policy of Swaziland.	✓	✓					
38. The policy is then a fundamental tool for providing both stimulus and momentum to the process of social development that will change the situation of persons with disabilities.		✓	✓				
39. It was developed to promote, protect and ensure a full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities in the country.		✓	✓				
40. Until the year 2013, Swaziland did not have a comprehensive policy, strategy or legislation for addressing the rights and needs of persons with disabilities hence the National Disability Policy of Swaziland.		✓					
41. Swaziland ratifies this convention in September 24, 2012 thus emphasising the importance of the National Disability Policy of Swaziland. The basis of the policy therefore is on the UNCRPD and all its optional protocols.		✓					
42. The National Disability Policy of Swaziland is the outcome of the contribution from numerous stakeholders and individuals such as the Deputy Prime Ministers Office; the Government Sector Ministries; Save the Children; non-governmental organisations; organisations of persons with disabilities, community based organisations and private sector companies.	✓						
43. We extend gratitude to the United Nations Population Fund for financial assistance and the Ministry of Justice and Constitutional Affairs for availing the service of Mr Francis Wilson, a legislative drafting consultant from the commonwealth secretariat.	✓						
44. This has been essentially participatory with the Deputy Prime Minister's Office seeking collaboration from other line Government Ministries non-governmental organisations, the private sector (culminating in a consultative workshop at the Happy Valley Resort at Ezulwini from the 24 th -28 th September 2012).	✓						✓

	Integrated Disability Policy Analysis Framework						
Totals number of times addressed	9	9	26	19	4	3	2