

**THE ATTITUDES OF SAKHISIZWE LOCAL SERVICE AREA
COMMUNITY TOWARDS PEOPLE WITH DISABILITIES**

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**Assignment presented in partial fulfilment of the requirements for the
degree *Masters of Philosophy majoring in Rehabilitation Studies* at the
University of Stellenbosch.**

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DATE: March 2012

DECLARATION

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ABSTRACT

A qualitative study was utilised as it was appropriate for the study of attitudes of non-disabled people of Sakhisizwe towards people with disabilities (PWDs). This case study set out to: investigate the perceptions of people with disabilities with regard to attitudes towards them; examine the nature of attitudes toward people with disabilities; determine the impact and influence of attitudes on the integration of people with disabilities; and determine facilitators and barriers with regard to the integration of people with disabilities.

This instrumental case study explored the attitudes of non-disabled people towards disabled people of Sakhisizwe Local Service Area in the Eastern Cape, South Africa. The researcher used convenience sampling to select a group of disabled participants from a meeting of the disabled structure held at one of the clinics of Sakhisizwe, to form a focus group. In the focus group of disabled people, two participants were identified as information-rich and were selected using purposive sampling for further interrogation. A convenience sample was used to select mostly three diverse groups of non-disabled participants from youth (seven participants), clergy (seven participants), community members (10 participants) and one group of disabled people consisting of six participants making a total of four groups to conduct focus groups interviews. Furthermore, three key informants (traditional healer, social worker and local councilor) from the community at large were also purposively selected.

Data was collected by means of semi-structured interviews guided by interview schedules for focus groups, disabled individuals'

interviews, as well as for the three key informants' interviews. To supplement the data, observation was done to study the behaviours of people with disabilities in the service centre towards non-disabled people, and vice versa.

Data was analysed by the process of inductive thematic analysis in which four themes emerged. These were: attitudes of non-disabled people towards people with disabilities; determinants of different disabilities; challenges facing young people with disabilities; and confidence and self-esteem of people with disabilities.

In conclusion, it is recommended that the community identify the general public education and awareness in order to change the negative attitudes that lead to social exclusion and marginalisation of people with disabilities.

ABSTRAK

Die houdings van nie-gestremde persone teenoor persone met gestremdhede in Sakhisizwe is deur middel van 'n kwalitatiewe studie ondersoek. Hierdie gevalstudie het ook nagevors hoe persone met gestremdhede hierdie houdings ervaar; die aard van die hierdie houdings; asook die impak en gevolg hiervan op die integrasie van persone met gestremdhede in die samelewing met spesifieke verwysing na fasilitators (“facilitators”) of hindernisse.

Hierdie waardevolle gevalstudie is in die Sakhisizwe Plaaslike Dienste Area in die Oos Kaap provinsie van Suid Afrika gedoen. 'n Fokusgroep is gekies deur middel van 'n gerieflikheidsteekproef (“convenience sample”) uit 'n groep persone met gestremdhede wat 'n vergadering oor gestremde bestuurstrukture by een van die plaaslike klinieke in Sakhisizwe bygewoon het. Uit die fokusgroep is twee deelnemers met ryk ervarings geïdentifiseer as doelbewuste streekproef (“purposive sampling”) vir verdere onderhoude.

Benewens die fokusgroep van 10 persone met gestremdhede, is drie verdere fokusgroepe vanuit die geledere van nie-gestremde persone gekies. Die groeperings was uiteenlopend en het deelnemers vanuit die volgende groepe ingesluit, naamlik: die jeug (sewe deelnemers), geestelike leiers (sewe deelnemers), en gemeenskapslede (10 deelnemers). 'n Verdere drie persone is doelbewus (“purposive sampling”) as sleutel informante van die groter gemeenskap gekies (tradisionele geneser, maatskaplike werker en plaaslike raadslid).

Data was deur middel van semi gestruktureerde onderhoude vir elk van die vier fokus groepe ingesamel. Hierdie data is aangevul deur die wedersydse gedrag van persone met gestremdhede en nie – gestremde persone waar te neem en te bestudeer.

Deur middel van induktiewe tematiese ontleding (“inductive thematic analysis”) van die data is vier temas geïdentifiseer. Houdings van nie – gestremde persone teenoor persone met gestremdhede; bepalende faktore van verskillende tipes gestremdheid; uitdagings wat alle persone met gestremdhede in die gesig staar; asook selfvertroue en self-beeld van persone met gestremdhede.

Ten slotte word aanbeveel dat die gemeenskap self die algemene opvoeding en bewusmaking ten opsigte van gestremde persone aanspreek sodat die negatiewe houdings wat lei tot sosiale uitsluiting en gemarginaliseerdheid (“marginalization”) aangespreek kan word.

ACKNOWLEDGEMENTS

To my wife who stood by me when I felt like giving up when she was involved in a series of motor vehicle accidents. The Almighty saved her soul in all those incidences.

To all my children who remained patient and waiting for their dad to graduate.

To Mr Eugene and Mrs Monique Oosthuizen for their technical computer support. They were never tired.

To my sister in-law, Penina, for constantly encouraging me to finish up my studies, despite the difficulties in my life.

To my colleague, Ms MN Busakwe, without whose help I would not have finished the data collection.

To my son, Hleze, for trusting and believing in me and accepting me as your mentor.

To Judy Mackenzie, without your support and assistance this study could not be a success.

To my supervisor, Siphokazi Gcaza, for your encouragement, support and perseverance towards the completion of my studies.

To the Creator, without trusting Him I would have never reached the destination.

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CHAPTER 1: INTRODUCTION

1.1 Introduction and background

In the past, society displayed a negative attitude towards people with disabilities to such an extent that people with disabilities were locked up against their will, denied access to treatment and even forced to work essentially as slaves at institutions. [1] Furthermore, people with disabilities had very limited choices with regard to employment and were often in disability stereotype jobs, such as switchboard operators. In most government facilities, such as hospitals and post offices, switchboard operators were mainly those who were visually impaired. Very often people with disabilities were required to negotiate and resolve tensions between self- and socially-constructed identities in everyday life. [2] People with disabilities had suicidal tendencies due to the lack of support from their families and communities. Even social workers had no problem solving programs. People with disabilities had to face their challenges alone. These tensions were as a result of competing individual, biomedical and social perceptions of impairment and disability.[2]

People with disabilities in Central and Eastern European countries were thought of as bad omens and were rejected or abandoned. They were frequently mocked and abused or viewed as unproductive and even useless. [3] Researchers' experiences have shown that very often men were reluctant to marry disabled women for fear that they would not be able to have children and would be called names for having married such women. However, regardless of the type of impairment, people with disabilities were seen as mentally disabled,

illiterate and half human beings. Their emotional, psychological and sexual feelings were disregarded. [4]

At schools, attitudes with regard to disabilities were more remarkable, although the perpetrators might not have been aware that they were critical or biased. For example, a child with a cognitive disability was made to write one hundred times: "I must pay attention", or might have been labelled as dumb, lazy or stupid and was made to stay in class after school. [5] These labels might then result in the child with a disability playing truant or having school phobia.

Due to the patriarchal nature of South African society, women were vulnerable. Women with disabilities faced stigma, myths and fears increasing women's social isolation. Women with disabled children also faced rejection and scorn from society. [6]

The above discussion regarding attitudes towards disabled people thus evoked some thoughts and interest within the researcher to explore the topic: "The attitudes of Sakhisizwe Local Service Area (L.S.A.) community towards people with disabilities".

1.2 Evolution of the study

In the 10 years I spent as a nurse in the maternity ward at a facility in the sub-district of Sakhisizwe, I found that many babies were born with disabilities. Often the husband and the family of the husband reacted negatively towards the mother and the disabled child. Most of the time, negative attitudes were apparent in the behaviour of husbands and in-laws. For example, husbands would verbalise non-acceptance of the disabled child. There were also accusations that

the mother of a disabled child was promiscuous or that the mother's family had a lineage of disability. This resulted in the in-laws distancing themselves from the mother and her child. Husbands and wives were inclined to blame each other, resulting in divorce on one hand and incidents of domestic violence on the other.

According to my experience, the above phenomena in respect of negative attitudes did not only occur with young disabled children but with disabled adults as well. For example, when there was a meeting in my community, a disabled person wanting to comment on issues being discussed, was ridiculed or not allowed to talk by the community. They also refused to hear his or her opinions as he or she was regarded as not being equal to other community members.

Furthermore, my experience with the local community indicated that people with disabilities were ostracized and were called names in the general belief that their parents were bewitched or had sinned. The community would also associate any kind of disability with an expression of the wrath of God, thus taking the presence of these people with disabilities as a punishment from God. Thus, disability was regarded as being sinful. On the same note, the researcher often heard people with disabilities conceding that they were isolated, neglected and stigmatized.

1.3 Problem statement

Negative attitudes were a major barrier for the inclusion and integration of disabled people and children in becoming part of the social fabric in their communities. People with disabilities were regarded as people who were socially dependent and who could not think on their own. Hence the researcher's interest in exploring how

the attitudes of the Sakhisizwe community impacted on the integration of disabled people and children in this community.

1.4 Motivation

This research interest was triggered by what the researcher had experienced while working as a nurse. The researcher was a suitable person to conduct this study. As a professional nurse, the researcher had worked in various wards with different types of disabilities such as congenital abnormality in maternity and physical disabilities in orthopaedic wards. At present, the researcher is a clinic supervisor at Sakhisizwe L. S.A.

During the time I was a student and a male midwife (Accoucheur, 1991/1992), I observed an incident involving a disabled woman. A gynaecologist became furious when a disabled pregnant woman entered the maternity ward for delivery. This doctor asked the woman who was responsible for her pregnancy and was not willing to hear the woman's story or expecting any answer. The doctor further verbalized that he was going to perform a Caesarean section and a tubal ligation, without her consent. There was no medical condition that indicated the need for a Caesarean section.

The pregnant woman had to make use of callipers as a result of her disability caused by Polio. She was not married and was a gravida 2 (pregnant for the second time), having delivered the first baby normally. However, she was not given the opportunity to try for normal delivery the second time around. On his own accord, the doctor ordered the Caesarean section and tubal ligation immediately. At that time, if an unmarried woman was over 18 years

of age, she could sign consent for a tubal ligation but it had to be witnessed by the medical superintendent.

The attending doctor at the time was a senior at the hospital; he signed the consent form for a Caesarean section and tubal ligation for the woman. Eventually, a Caesarean section and tubal ligation were performed on the woman. The incident indicated that health professionals during that time displayed negative attitudes towards women with disabilities who fell pregnant. These attitudes demonstrated that people with disabilities were deprived of their autonomy with regard to sexual feelings and procreation. [4]

As a result of what has been shared above, the researcher was motivated to conduct a study on the attitudes that Sakhisizwe community have towards people with disabilities. In addition to this, the researcher had a certain amount of insider-awareness into the world of physical disabilities as the researcher's own mother and cousin (sister) have mobility impairment which resulted from polio.

1.5 Aim

The main aim of this research was to describe the attitudes held by the Sakhisizwe L.S.A. community towards people with disabilities and how these attitudes contributed or influenced their integration within this community.

1.6 Objectives

The specific objectives were:

1. To examine the nature of attitudes held by Sakhisizwe L.S.A. community toward people with disabilities.
2. To investigate the perceptions of persons with disabilities with regard to attitudes held by the Sakhisizwe L.S.A. community towards them.
3. To determine the influence of the attitudes of the Sakhisizwe L.S.A community on the integration of people with disabilities within this community.
4. To determine facilitators and barriers with regards to the integration of people with disabilities within the L.S.A. community.
5. To make recommendations with regard to the attitudes and integration of people with disabilities within the Sakhisizwe L.S.A. community.

1.7 Significance of the study

This study was significant since pervasive social and cultural norms, standards and expectations often led to the creation of negative attitudes towards the disabled population. [7] The significance and scientific relevance of the study would be that people with disabilities could gain in self-confidence through interaction with other people. Their self-esteem might be uplifted during such relationships.

Health workers could work towards changing their attitude from being negative to being positive, as envisaged in certain studies. [8]

The attitudes of health care professionals are very important in the rehabilitation of disabled people. Such negative attitudes could influence a disabled person's response to treatment and development or maintenance of self-acceptance. [7]

Paris [9] indicated that physicians with negative attitudes are more likely to withhold treatment from, or provide inferior treatment to, the chronically ill or disabled patient than are physicians with neutral or positive attitudes. Negative attitudes of healthcare professionals is considered to have such potentially devastating results that it has been suggested that people with negative attitudes should be excluded from professions that require or emphasize interaction with people with physical disabilities.

The forced subscription of all healthcare professionals to regulatory bodies (Health Professions Council of South Africa—HPCSA; Nursing Council—SANC) has actually regulated attitudes and paved the way for expulsion of healthcare professionals who display negative attitudes toward people with disabilities. Context was better represented as part of an interactive process (person-environment fit) influencing one's achievements in a society. Thus the environment in which the study was taking place could make it possible for people with disabilities to influence one's achievement in society. [10]

The community at large would thus benefit from the results of this study. Also, the findings of this study would assist in making recommendations with regard to raising awareness within Sakhisizwe L.S.A.

In South Africa, nurses are mini-doctors within the Primary Health Care (PHC) setting. Primary Health Care nurses use interdependent (can refer) and independent (can take decisions) roles as most of the time there are no doctors at the clinics. Among their functions they have a referral function to the doctors and other healthcare professionals. They are often put in charge of the facility or clinic, hence according to the new organogram are called clinic managers or operational managers. However, an understanding of disability issues by PHC nurses is very critical.

A nurse is the first line health professional and as such should display a positive, caring attitude and have a thorough knowledge of the different types of disabilities. This caring attitude and knowledge should be transferred to the family, community and society as a whole, through health education and provision of referral sources for special cases.

1.8 Conclusion

The background, evolution, problem statement and motivation of the study have been discussed. Aims and objectives were listed as they pointed to the focus of the study. It was also necessary for the researcher to describe the significance of the study. In the next chapter the researcher will be reviewing the literature with regard to attitudes displayed towards disabled people and how these attitudes influence their inclusion and integration in the respective communities.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In this chapter, the concepts related to the study are explained. They are: disability models and definitions; attitudes; attitudes and disability; and integration. An overview of the literature pertaining to attitudes also relates to attitudes within families of disabled people, attitudes of the broader community towards people with disabilities and attitudes toward sexuality and gender issues. Lastly, the researcher presents an argumentative, critical and integrated understanding of different literature and sources.

2.2 Disability concept (models and definitions of disability)

The Department of Health [11] defines disability as “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (for example, difficulty in speaking, hearing or walking)”. Popovich *et al.* [12] define disability “as any physical or mental condition that substantially limits one or more major life activities”. Both of these explanations or definitions emphasize restriction, limitation and lack of ability of the individual to perform their daily functions.

The researcher viewed these explanations or definitions as only focusing on a biomedical model (individual or disability). Hence, the study considered that explaining or defining disability just on a biomedical model is not enough. The surrounding context cannot be ignored as a major factor that contributes to explaining the functional and social consequences of disease and trauma on community living (social model of disability). [10]

Oliver[13] argued that disability research was not representative of disabled peoples' experiences and knowledge. This author associated this with the fact that non-disabled researchers conducted research. People with disabilities were seen as being poor, unable to learn at neither school nor work and as such were perceived as people who could not make their own decisions.

Studies [14] view the first model (medical model) as a problem of the individual. The disability is thus the direct result of disease, trauma or other health condition and requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at a cure or at the individual's adjustment and behaviour change. This model is viewed as the main issue, and at the political level the main response is that of modifying or reforming health care policy.

WHO (September 2001) [14] on the other hand, sees the second model (social model), as dealing with a socially-created problem, and basically as a matter of the full integration of individuals into society. WHO argued that a social model is a collection of conditions, many of which are created by the social environment. The management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is thus an attitudinal one requiring social change. At the political level it becomes a question of human rights.

Disabled People of South Africa (DPSA) [15] argued that within the medical model a person is regarded as having a disability if she or

he has a physical or mental impairment which has a substantial and long term effect on her or his ability to carry out normal day to day activities. This impairment would affect one or more of the following: mobility, manual dexterity, physical coordination, continence, ability to lift or carry or otherwise move everyday objects, speech, hearing, eyesight (unless correctable by spectacles), memory or ability to concentrate or learn or understand and perception of the risk of danger.

DPSA suggests that the social model is not limited to such a narrow description of activities as the medical model. DPSA can show that limitation of activity is not caused by impairments but is a result of social organization. In other words, the social model argues that a person is disabled if the world at large will not take into account the physical or mental differences.

2.3 Attitudes

Here the focus is on literature related to the study of attitudes which is the focus of this study. McCaughey and Strohmer [16] suggested that attitudes reflect a predisposition to behave in a stereotypical and predictable way toward or in the presence of members of a group. On the other hand, Longoria and Marini [17] suggested that attitudes have a cognitive, behavioural and affective component, which may not necessarily be congruent with one another.

Antonak and Livneh [18] argued that there are two dimensions to be considered when defining attitudes. The first dimension of abstractness is whereby attitudes are defined as descriptive concepts, which are inferred from observation and are therefore not directly observable or measurable. The second dimension provides

the basis for conceptualizing the content of attitude in a categorical structure or components such as cognitive, affective and behavioural or conative components. In other words, they indicated that in the dimension of abstractness, attitudes are not directly measurable or observable whereas in the dimension of conceptualization, attitudes can be measured and observed.

Other writers like Thara and Srinivasan [19] associate attitudes with stigma and define stigma as the “social devaluation of a person because of personal attributes leading to an experience or sense of shame, disgrace and social isolation”. Phemister and Crewe [20] define stigma as “a socially constructed phenomenon that may serve as a constant reminder to persons with visible disabilities that society views them as “different” and devalues them as a result”.

Antonak and Livneh [18] also cite Katz (1960) in their description of four functions relevant to the study of attitudes. Firstly, they indicated that attitudes perform an adjustive or utilitarian (emphasizes preventive measures rather than curative) function. Attitudes dispose the individual toward reinforcing objects and, at the same time satisfying one’s needs by attaining valued goals.

Secondly, attitudes serve as an ego-defence function. Attitudes, therefore, protect the self from acknowledging certain painful truisms such as inner conflicts, objectionable wishes and unacceptable impulses. Thirdly, attitudes facilitate value expressions. Expressing attitudes appears to involve gratification of the affective domain thus individuals gain social recognition within the community at large. Fourthly, attitudes satisfy knowledge or understanding functions. Attitudes therefore provide clarity and

consistency by setting the standards or frame of reference for organizing and understanding one's environment.

Experience has shown that, when meeting others, people tend to make assumptions that subsequently lead to attitudes. [21] This could be an emotional reaction; a defence mechanism; or a biased opinion or labelling that takes place. There are discussions around the definition of the term "attitude" by various authors. Wilson & Kneisl [21] define attitudes as feelings held over a period of time. Other authors, White and Olson [22] define the concept as reflections of deep-seated values and a pervasive force driving how people choose to act and respond to others. Plotnik [23] however, defines an attitude as "any belief or opinion that includes a positive or negative evaluation of some target (an object, person, or event) and that predisposes us to act in a certain way toward the target".

2.3.1 Attitudes within families of disabled people

Once one is born with a disability, the family is affected too. Floyd and Zimch [24] argued that negative feelings or stress may be increased in parents of disabled children and these feelings may result in depression. The results of the study by Hartley *et al.* [24] describe the challenges faced by families and by children with disabilities. Furthermore, Hartley *et al.* [25] argued that the main problem encountered by people with disabilities, as acknowledged by their caregivers, were negative attitudes.

In the paper presented by McDonald Rod [26] of the Deaf-Blind organization, it is argued that as a rule, deaf-blind people cannot participate in family decisions as children. Thus, they do not learn to

make decisions in childhood. This is also a norm in African culture that children do not participate in family decision-making.

According to the researcher's experience, people with disabilities were not afforded the opportunity to participate in family discussions and decisions. The Constitution of South Africa provides every citizen of South Africa an opportunity to participate in discussions and the decisions of family and community.

Hartley *et al.* [25]cite Porter and McKenzie (2000) in suggesting that the way in which families develop attitudes and the way they cope with disability depends on internal and external resources. They stated that internal resources include personality characteristics, energy and self-determination. These researchers also cited Maes, Leventhal and de Riddler (1996) as saying external resources include support from the extended family, community and government programmes. Therefore, it is important to understand that the family is the first point of call when it comes to supporting a disabled person.

2.3.2 Attitudes of the broader community towards people with disability

A team of physiotherapists [27] in their book 'Cerebral Palsy...ga se boloi...is not witchcraft' acknowledge the attitudes displayed by the individuals and community towards people with disabilities (PWDs). Positively, they indicate that PWDs are complete people with normal feelings and needs. They further state that having a physical disability does not mean that one has a mental disability and also that such a disability is not infectious.

These physiotherapists heard negative stories related by parents of children with disabilities that the dead had somehow possessed children with cerebral palsy or that children were bewitched. This team argued that many problems arose from cultural beliefs. For example, male domination manifestation in oppression makes the woman feel responsible if she has given birth to a disabled child. Women declared that the men usually argued that there were no disabled persons in their family; therefore the mother has to perform a range of things to rectify her mistakes. According to the researcher's experience, the woman is sent or requested to go home (maiden home) so that rituals can be made for her. Such rituals are '*ukunxityiswa ubulunga*' which is the wearing of a necklace made up of a cow's tail hair. The belief is that when a ritual of wearing necklace has been done to a woman, possibilities of giving birth to a child with disability are reduced or none at all.

Longmore [28] highlights that negative attitudes towards disabilities are apparent in many countries around the world. For example, the author indicated that a blind couple (Jacobson couple) was arrested for refusing to move from seats in the emergency exit row of a United Airline flight on which they were to leave Louisville, after attending the National Federation of the Blind convention. Paris [9] also agreed that social attitudes towards people with disabilities are often negative. However, the author argued that in general, healthcare professionals hold more negative attitudes than might be expected. Paris [9] further suggests that physicians with negative attitudes are more likely to withhold treatment from, or provide inferior treatment to, the chronically ill or disabled patient than are physicians with neutral or positive attitudes.

Lyons [29] suggests that the nature of negative attitudes can vary considerably. The author argued that the PWDs might be viewed as sick, pitiful or a social menace. This however, resulted in extreme measures being taken against PWDs such as incarceration in institutions, deprivation of many civil rights such as freedom of choice regarding accommodation, work and relationships. The author referred to this as “devaluation of PWDs”. Thara and Srinivasan [19] support the concept of devaluation though they define it as being a form of “stigma” and define it as “social devaluation of a person because of personal attributes leading to an experience of sense of shame, disgrace and social isolation”.

Goffman [30] went on to define stigma as a term that highlights a deeply discrediting personal attribute that leads to assumptions about the person’s character and abilities and often presents in various forms of discrimination. Goffman further identified three types of stigma: “abomination of the body (e.g. physical deformity); blemishes of individual character (e.g. mental disorders, unemployment); and tribal stigma or tribal identities (e.g. race, religion)”. Hahn and Belt [31] also highlighted that at one stage, the visible indications of a disability were so heavily stigmatized that persons bearing these traits simply remained indoors or in “back bedrooms” to avoid the humiliation of appearing in public.

Vash [32] looked at attitudes displayed by religions and stressed that the very institutions that we invented to guard and promulgate what we believed was the best in us...religions... have excluded and derogated PWDs for thousands of years. She also highlighted that in the West disability is used as a symbol for sin and portrayed as a punishment for it in this life, whereas in the East, disability is

assumed to reflect punishment for wickedness in a previous incarnation.

Also, Jacobs [33] stated that refusing to acknowledge or understand the experiences of stigmatization is a form of passive aggression. The author argued that, in terms of lifestyle, the stigmatized are not expected to develop emotionally, to have ambitions or be successful, and are presumed to have reduced, if any, life chances. Jacobs also concludes by saying that some stigmatized people can “become dependent, passive, helpless, and childlike because that is what is expected of them”. According to the researcher’s experience, mothers of disabled people tend to be overprotective of their disabled children thus leading to these individuals with disabilities becoming dependent and childlike.

In The World Book Encyclopedia [34] it is suggested that PWDs can lead complete lives in spite of their impairments. It is further suggested that PWDs are not as dependent as one may think, especially in terms of decision-making and sex choices or partners.

2.3.3 Attitudes towards sexuality of people with disabilities and gender issues

Low [35] argues that one of the biggest problems is how people view PWDs and their sexuality.

“...because I am disabled I am supposed to be asexual...the girl was saying ‘I have this friend with Spina Bifida and she has just had a baby, is it not that great...one of the guys said ‘I could never have sex with someone like that’.” (Low:242)

That is a negative response. With reference to sexuality, Bartlett [36] argued that young women are under pressure to form

heterosexual relationships, to marry and have children whilst these expectations are not applied so readily to PWDs. According to Bartlett, the PWDs are viewed as asexual. Yet, Chen *et al.* [37] admit that little has been published in the social context of dating and marriage in terms of PWDs.

2.3.4 Barriers excluding people with disabilities

Exclusion of PWDs from society in Africa is a common phenomenon that is also practiced worldwide. In the African context, PWDs do not have the right to vote and political information is not given to them. This is unlike in South Africa after 1994 where everybody has the right to vote and political information is given to everybody. These rights are included in the Constitution of South Africa and they are enforced. The existence of the high court (Constitutional Court) is evidence that when a PWD is not happy about the way she or he is treated, the matter can be referred to the Constitutional Court. (Bill of Rights) [38] Negative attitudes, the physical environment and lack of information and services also prevent PWDs from being included in society. BBC World Service Education [3] cite negative attitudes toward PWDs as being responsible for exclusion, lack of information as well as a physical environment which is not disabled user-friendly. In addition, many African PWDs are denied the use of services that can provide them the opportunity to participate fully in society. The researcher fully agrees with BBC World Service Education with regard to the exclusion of PWDs from the society. On a positive note the South African Constitution is trying to address such exclusion by adopting inclusion criteria of PWDs in all spheres of life in society, that is, all government and private sectors and NGOs.

On a negative note, the concept of inclusion criteria of PWDs is there in the Constitution of South Africa but its implementation is rather slow as it is in a rudimentary phase. There is still a gap between the Constitution and everyday reality for PWDs. For example, if one looks at the Department of Education buildings, especially schools, these still have stairs that lead to classrooms - impacting negatively on PWDs especially those who are physically disabled. [39]

2.4 Conclusion

The literature reviewed revealed a relationship between attitudes and stigma. In other words attitudes may result in stigma and vice versa. The list of gaps in terms of the application of inclusion criteria goes on. In the next chapter the researcher looked at the selected methodology relevant for the study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

In this chapter, the researcher includes a discussion of the aim and specific objectives. In addition, the ethical considerations that were taken into account are also deliberated upon in this chapter. Further, the researcher describes the study design, study population and sampling, selection of participants, eligibility criteria, sampling methods and size and data collection. The researcher had conducted a pilot study during which the research instrument was tested for relevance. Thereafter, the researcher made an amendment to the research instrument which was finally used for data collection.

3.2 Aim

The main aim of this research was to describe the attitudes held by the Sakhisizwe community towards people with disabilities and how these attitudes contributed to their integration within this community.

3.3 Objectives

The researcher worked according to these objectives:

1. To examine the nature of attitudes held by Sakhisizwe L.S.A. community toward people with disabilities.
2. To investigate the perceptions of persons with disabilities with regard to attitudes held by the Sakhisizwe L.S.A. community towards them.
3. To determine the impact of the attitudes of the Sakhisizwe L.S.A community on the integration of people with disabilities within this community.
4. To determine facilitators and barriers with regards to the integration of people with disabilities within the L.S.A. community.

5. To make recommendations with regards to the attitudes and integration of people with disabilities within the Sakhisizwe L.S.A. community.

3.4 Research design

The researcher used a qualitative approach. In this way, the researcher studied individuals in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people brought to them. [40] Holloway and Wheeler [41] state that the researcher takes a holistic view, looking at people in their natural environment, whereby the researcher-informant relationship is based on trust and openness. The researcher dealt with perceived data and focused more on lived experiences, for example, “What do you think or what do others think or feel about...?” The meanings and interactions that underlie human behaviour were investigated by the researcher. [42] Thus, this qualitative approach was used with the intention of developing an in-depth understanding of the phenomenon.

DePoy and Gitlin [43] explain various qualitative research paradigms such as grounded theory, ethnography, life history research, case study, phenomenology, critical theory and participation action research. The researcher used a case study as a method of choice for this study. Yin [44] defines case study as “an empirical inquiry that investigates a contemporary phenomenon within its real life context especially when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used”. Yin argued that there are different kinds of case studies but they all have a common definition. Stake [45] uses three terms to describe case studies: intrinsic, instrumental and collective. Stake further explains these terms indicating that if the researcher

is intending to gain insight and understanding of a particular situation or phenomenon, an instrumental case study is the method of choice. Thus, the researcher focused on the instrumental case study since the instrumental case study plays a supportive role in facilitating an understanding of something, as Stake asserted.

The researcher used the Sakhisizwe community as a case study in order to understand and to describe the perceived attitudes held towards people with disabilities in this community. The researcher also used the case of Sakhisizwe because of its potential to increase the researcher's understanding of attitudes of the Sakhisizwe community towards PWDs. As a result, the instrumental case study was particularly useful as the researcher wanted to get a detailed contextual view of an individual's life or of a particular phenomenon. In other words, phenomena were explored in the context or natural environment. Merriam [46] suggests that a case study is an entity that is studied as a single unit and that it has clear boundaries that define the limits of the inquiry.

The researcher interviewed people on their past and present experiences and expectations for the future. DePoy and Gitlin [43] cites this as a primary data collection strategy whereby the participants tell of their biographical stories emphasizing experiences that relate to time, body and space, as well as other persons. It explores the structures of consciousness in human experiences. For example, with an open-ended invitation, the researcher would prompt the participant: "Tell me about your experience of how the attitudes of people of Sakhisizwe affect your social integration or participation into this community's activities". Thereafter, the researcher used semi-structured interviews to all the participants.

3.5 Study population

The population of this study consisted of the community members of Sakhisizwe, including disabled people.

3.6 Study setting

The study site was in the Eastern Cape, in Chris Hani district municipality, at Sakhisizwe Local Service Area (L.S.A.). Sakhisizwe is made up of two local municipalities, Cala and Elliot, with a population of 54026 [47]. This area is approximately 2256 square kilometers in size. Out of the above population figure, 4 092 (7.5%) are PWDs of various categories of disabilities such as sight 2.31%, hearing 0.9%, communication 0.25%, physical 2.34%, intellectual 0.7%, emotional 1.2% and multiple 0.85%. This is shown by Statistics South Africa. It has a population density of 22.19 and it is rural in nature with very bad roads that are not accessible to PWDs. This information is shown in Statistical Survey for Chris Hani District 2002) [47] It has two hospitals, seven fixed provincial clinics, three municipal clinics and three mobile clinics serving six wards. Public transport is mainly made of 80% unregistered taxis, and buses. Socio-economic features shows that 4.6% of this population have access to electricity though meter boxes are high and therefore not disabled user-friendly, 10.3% have access to telephones, 18.6% have access to safe and clean water though 30% is using potentially unhealthy water. It also shows that 15% of this population has proper sanitation. 53% of this population is unemployed and 92% is living below poverty line. This is the area where the research was taking place.

3.7 Sampling and selection of participants

People with disabilities were the main target of the study. The researcher used convenience samples to select a group of disabled participants from a meeting of the disabled structure held at one of the clinics of Sakhisizwe. Six participants volunteered to participate and this group was used as a focus group.

A convenience sample was also used to select mostly diverse groups of non-disabled participants of youth from one of the high school's Grade 12 classes. Seven participants volunteered to participate with the permission of the principal of the school. Seven members from clergy, including the chairperson, participated in the interview. After presentation of the study to the communal meeting and with the permission of the local chief, ten participants, including the chief, volunteered to participate. Four focus group interviews were thus conducted.

Out of the focus group of disabled people, two participants were identified as information-rich and were selected using purposive sampling for further interrogation. Purposeful sampling was also used to select key informants. The key informants were regarded as knowledgeable figures in the community.

The researcher purposely selected the chairperson of the Council of Churches and the chief as key informants, but both declined to be interviewed alone. The chairperson of the Council of Churches preferred to be interviewed with the entire executive and gave assurance that he was going to invite the executive. The Chief opted to invite the researcher to a routine communal meeting that was

pending. This ended up being focus groups of clergy and community and as such convenience samples were conducted.

However, three other key informants were selected using purposive sampling which included a traditional healer, social worker and local councillor.

3.7.1 Gaining entry

The necessary permission to conduct interviews with participants from Local Government and Social Development was requested from the head of the structure or Department. Thereafter participants were approached individually as permission was granted. The traditional healer was approached by the researcher and gave the researcher an appointment date which was honoured.

A group of people with disabilities happened to have a meeting in one of the clinics. For a focus group of people with disabilities and considering inclusion and exclusion criteria, the researcher, through the chairperson of the structure, requested volunteers to participate in the interviews.

For the youth group, the researcher requested permission from the principal of the school and permission was granted.

Initially, the researcher wanted to use the local chief as a key informant but chief preferred to be interviewed with his people. Thus, the chief invited the researcher to a meeting that was held at '*Ikomkhulu*' (the chief's residence). The researcher attended the meeting and was given an opportunity to conduct the interviews. After presentation of the study to the communal meeting and with

the permission of the chief, ten participants, including the chief, volunteered to participate. This ended up being a focus group for the community.

The researcher also went to the home of the chairperson of the Council of Churches to request the chairperson to participate as a key informant. The chairperson suggested he be interviewed with the entire executive. The chairperson of the Council of Churches organized a meeting of the executive and invited the researcher to come and conduct interviews. This ended up being a second focus group of non-disabled people.

The researcher had interviews with two individual disabled people. One person with disability was approached at home and the other one in a work environment. Both people with disabilities gave the researcher appointments dates.

3.8 Other sampling methods

3.8.1 Disabled people

Polkinghorne [48] states that the logic and power of purposive sampling lies in selecting information-rich cases for the in-depth study. The selection of participants was based on certain predefined criteria. However, the researcher used purposeful sampling to select two individuals with a wide range of disabilities, that is, physical/medical, hearing impairment and sensory impairment, to participate in the study. The researcher also used this sampling strategy so that PWDs could share with the researcher and among themselves, their experiences related to the attitudes held by the community members of Sakhisizwe L.S.A..

3.8.2 Inclusion criteria

The inclusion criteria were that the participants were:

- Residents of Sakhisizwe L.S.A.
- Disabled for more than 12 months
- Disabled and have a disability which falls within any of the three broad categories of impairments (i.e. physical/medical, sensory and intellectual/mental impairments) or a combination of any of the three
- Both females and males, disabled
- Able to speak isiXhosa
- 18 years of age and above
- Willing to participate in the study

3.8.3 Exclusion criteria

The exclusion criteria were that the participants were: -

- Seventeen years of age and below
- Not residents of Sakhisizwe
- Disabled for less than 12 months
- Not willing to participate in the study

3.8.4 Key Informants

Purposeful sampling was used to select three key informants (one from Local Government, one from Social Development and one a traditional healer) as they were regarded as knowledgeable figures in the community.

The researcher continued sampling until data saturation occurred. Thus the sample size was determined by reaching the point of saturation during data collection.

3.9 Data collection

In all the interviews, the researcher used semi-structured interviews as the primary method of data collection. Armstrong and Grace [49] refer to semi-structured interviews as interviews falling midway between unstructured and structured interviews. They further explained that in semi-structured interviews, the interview schedule is well structured but unstructured responses are allowed.

Hancock and Algozzine [50] state that semi-structured interviews are particularly well suited for case study research. They went on to say that the researcher asked predetermined but flexibly-worded questions and asked follow-up questions to probe more deeply issues of interests to interviewees. It was found that this method invited participants to express themselves openly and freely and to define the world from their own perspectives, not solely from the perspective of the researcher. The researcher was empathetic about the way participants express themselves and considered himself part of the process. Multiple sources of information were considered as the researcher wanted to understand the multiplicity of factors that lead to positive and negative attitudes. In other words, the researcher wanted to understand these attitudes from different perspectives and as such gathered data from disabled people, non-disabled people, key informants (traditional healer, Social Development and Local Government and youth). The whole process however, is known as triangulation. Thus, the process ensured that the trustworthiness of the tools used during data collection was

maintained. The researcher validated findings by examining whether different sources used provided the same information.

3.9.1 Interviews

Two individual interviews with persons with disabilities took place - one at home lasted for one hour and one in the work environment lasted for one and half hours. Individual interviews took the general form of discussions between the interviewer and interviewees about the attitudes of Sakhisizwe L.S.A. community towards people with disabilities. This method was used because the researcher wanted detailed information from the individuals. Also, this method did not follow any sequence but the researcher used the interview schedule to facilitate the discussion. The researcher allowed participants to talk and cover areas on their own terms and from their own perspectives. [45]

3.9.2 Focus groups

Focus group interviews for persons with disabilities took place at the clinic as the disability structure was holding a meeting there and the interview lasted for one hour and forty-five minutes. This took a little longer because two participants were deaf and unable to speak spoken language from birth. They were using sign language for communication with other people and amongst themselves.

One of the participants who happened to be their neighbour was able to communicate with these two participants using sign language. The researcher therefore used this participant as a translator for the group, translating sign language to spoken language and vice versa using isiXhosa as they were all comfortable with isiXhosa. This participant (translator) volunteered to translate for the group. All the other focus groups lasted for one and half hours and were conducted

in isiXhosa for all the participants were comfortable with the language. Katzenellenbogen *et al.* [51] explains that a focus group is a structure that involves a number of people meeting in a group in which the participants talked to one another under the guidance of the facilitator. The aim of having the focus group was to provide insights into the attitudes of Sakhisizwe L.S.A community towards PWDs.

One focus group was interviewed consisting of community members at the chief's home following a communal meeting that was held there. Another focus group of clergy took place at the home of the chairperson of the Council of Churches and the last one took place with youth from one of the high schools at Sakhisizwe in the board room of Sakhisizwe L. S. A. office as the classrooms were busy during the time of interview. The researcher conducted four focus group interviews.

Two key informants were interviewed at home (traditional healer and participant from Social Development); one interviewed on the site of the organization (Local Government) and all interviews lasted for one hour. These key informants preferred the interviews to be conducted in isiXhosa. During the interviews, the researcher used interview checklists asking the participants the same questions. Since the questions were open-ended they permitted everyone to respond in different ways in terms of content and form. Additional probes were allowed or even encouraged thus allowing the interviewer to clarify the questions to help the participants to provide more information.

The researcher used a tape recorder to record all the interviews as permitted by the interviewees. Tape-recorded interviews were

administered by the researcher who is isiXhosa-speaking. Oral speaking tradition rather than writing method is the natural way of Sakhisizwe L.S.A. when there are communal meetings. However, the researcher used the oral tradition of interviews which is the traditional way of conducting meetings which involves more listening than writing. The other forms involve more writing and less listening. After completion of the interviews, the recorded tapes were kept by the researcher. Within a few hours the researcher transcribed the recorded interviews verbatim in the language that was used during the interviews, in this case in isiXhosa. Thereafter it is translated into English. The qualitative approach facilitated the process of gathering data on numerous aspects of the research situation and to construct a complete picture of the social dynamic of the particular situation or setting.

The researcher continued to collect interview data up to the point of saturation or when the gathered information could not provide additional insights or new understanding to attitudes of the Sakhisizwe community towards PWDs. In other words, when the researcher could not find, or participants could not add, any new information. The transcriptions of all the interviews conducted were available to the researcher.

3.9.3 Observations

The researcher conducted observations in order to provide additional information about the attitudes of Sakhisizwe community towards people with disabilities. The purpose was to understand the people's responses towards a disabled person and how the disabled person reacted to these responses. The researcher visited the service point for South African Security Service Agency (SASSA) and requested permission from the head of the service centre to

conduct observation from arrival to departure when a PWD-client was receiving service on renewal of the disability grant. After receiving verbal permission, the researcher requested permission from the parents of one of the PWDs to observe how a PWD was being handled at the service centre by the staff and by other patients. The researcher used 'unstructured' observation because the researcher did not want to intrude. [48] Asking questions might have caused the participant to change certain behaviour. The researcher started on a blank slate entitled 'field notes' and recorded relevant items such as actions, emotions and even body language with regard to this observed patient. The researcher also had notes on challenges and lessons learnt during observation. After the observation procedure, the participant or parents of the participants were thanked and informed of how the data was going to be used.

3.10 Trustworthiness and rigour

3.10.1 Confirmability

An audit trail was kept throughout the research process. The steps of the research process as well as the process of data management were recorded via the tape recorder and as such each transcription is starting by explaining the process to be followed before, during and after the interviews.

3.10.2 Authenticity

Authenticity was considered and verified as the researcher sought the same data from various sources. [43]

3.10.3 Reliability

The researcher developed a protocol before the actual interviews took place, with the following sections: an overview of the project with aim and objectives to be investigated; and field procedures with sources of information and gaining access to sites and specific questions that the researcher had to keep in mind during data collection. This is stated by Yin, 1994 as cited by Tellis. [44] Also, the researcher requested one of the colleagues to assist in observation of one of these participants. By so doing the researcher wanted to ensure stability of the findings.

3.10.4 Member checking

The researcher checked data with the supervisor. This was done verbally by the presentation of transcripts and interpreted transcriptions.

3.11 Ethical considerations

Ethical approval was gained from the Research Ethics Committee at the University of Stellenbosch. The project number of this study from the Ethics Committee is NO7/03/067.

After ethical approval was granted by the university, the researcher wrote a letter to the Government of the Eastern Cape (Department of Health: Research Unit) as this was a requirement for all the studies that are conducted in the Eastern Cape. The Department gave the go-ahead after reading the researcher's proposal. (Appendix D). For management or administrative purposes, letters were also written to the District Manager and Immediate Supervisor (L.S.A. Manager) of the researcher. (Appendix E and Appendix F) The researcher received permission to continue with the research from all stated levels, in writing. After the researcher had received these letters,

the researcher visited the key stakeholders such as the chiefs, disability structures, Council of Churches, Local Government, Social Development, and Department of Education to negotiate permission for entry into their structures or facilities. Permission was granted verbally. The key informants and individual persons with disabilities were approached by the researcher to inform them of the intended research study.

Before any interview could start, the participants were requested to sign consent after the procedure had been explained. All the participants signed the consent before the interviews started. (Written consent protects both participants and the researcher). The explanation of the procedures revolved around privacy (desirable to gain the confidence and cooperation of the interviewee); anonymity (their real names could not be revealed); confidentiality (they were assured that whatever information was discussed in the research would be kept secret); voluntary participation (freedom to participate and withdraw at anytime); destroying of tapes after transcription, translation, analysis of data; and publishing (dissemination of findings) of the results.

3.11.1 Reimbursement of participants

The researcher visited all participants either at their homes or areas of work. The focus group comprising of Grade 12 youth was transported by the researcher from the school to the office and from the office to their homes. Thus, the entire group of participants did not have any financial expenses during the course of the study.

3.11.2 Referral to appropriate services

The researcher left contact details should any of the participants need support with this in future. Otherwise there was no need to

refer any of the participants to other services like rehabilitation, counselling and support health workers or non-governmental organizations (NGOs).

3.12 Data analysis

Data analysis was done in the form of content analysis, which entails categorizing, ordering, manipulating and summarizing the data and describing it in meaningful terms. The researcher analyzed the content of the collected data, explored the common themes, and examined the communication messages that were transcribed verbatim in isiXhosa and thereafter interpreted in English. Katzenellenbogen *et al.* [51] cited that content analysis basically means that the data is explored in detail for common themes and these are then established into units of meaning or codes. The researcher used an inductive approach to analyze the data. This approach provides for the truth to be revealed or uncovered based on the perceptions of participants. [43] The data was coded, recorded on a computer and then categorized according to patterns. The categorized data was closely examined; compared for similarities and differences; and thus themes were developed. During this process, questions were constantly asked by the researcher about the phenomena as reflected in the data. The process of coding helped the researcher filter out motives and unresolved personal issues or fears from collected data.

The researcher explained this analysis on three levels:

Level 1 analysis: This involved a within-case analysis. [45] Coding was used to break data down into meaningful phrases or codes. Colour coding was used to highlight meaningful pieces of data or codes. Developed categories were supported by quotes from participants and traced by line number(s). Interpretation of the

meaning of the themes was presented and discussed verbally with the supervisor.

Level 2 analysis: The researcher looked for similar categories within the case. These categories were collapsed/grouped into themes. Assertions were made and interpretations formed about what the data was telling the researcher.

Level 3 analysis: The researcher was able to look objectively at the process of data analysis as well as at how the themes had been developed. This stage thus required the researcher to restructure the data back into a meaningful whole.

3.12.1 Reliability of coding

During the process of coding the researcher continuously monitored how the research topic was related to the issue highlighted by coding. However, discussion with the supervisor was equally important in facilitating this process.

3.13 Conclusion

Special care was taken to ensure trustworthiness, rigor and ethical consideration. The semi-structured interviews were used for the participants to express themselves openly and freely and to define the world from their own perspectives and it was analysed as per category interviewed. To sift out the dominant categories and themes of the research findings, the body of the data was examined at three levels of analysis and this discussion is presented in Chapter 4.

CHAPTER 4: FINDINGS

Chapter 4 are the findings that emerged from the process of data analysis of four focus groups, two disabled individuals interviews, three key informants interviews and observations. Four themes emerged out of this data analysis and are presented below:

Theme 1: Attitudes of non-disabled people towards people with disabilities

Theme 2: Determinants of different disabilities

Theme 3: Challenges facing young people with disabilities

Theme 4: Confidence and self-esteem of people with disabilities

The themes reflected the following: facilitators and barriers with regard to integration of people with disabilities; the influence of attitudes on the integration of people with disabilities; the perceptions of persons with disabilities; and the nature of attitudes towards people with disabilities within the community of Sakhisizwe.

Each theme was sub-divided into categories. Transcripts were translated to English and used as supporting quotes of categories. The themes and categories were tabulated and are presented in the table below:

4.1 Theme 1: Attitudes of non-disabled people towards people with disabilities

Theme	Categories
Attitudes of non-disabled people towards people with disabilities	Disability terminology
	People with disabilities are objects of pity
	Burden to others

	Lower expectations of people with disabilities by others
	Attitudes of people with disabilities towards inclusion

This theme focuses on the influence of attitudes on the integration of people with disabilities. Attitudes displayed by non-disabled people have impacted upon the integration of people with disabilities. Most of these attitudes were negative and discriminatory in nature. The consequence of these attitudes towards disabled people meant that they had a tendency to accept the use of unacceptable language and words towards them. These opinions subject people with disabilities to being objects of pity and burdens to others. Also, these attitudes resulted in others having lower expectations of people with disabilities.

4.1.1 Disability terminology

People with disabilities were reduced to objects. They were deprived of their real names and acquired new names. They were called by names that referred to the types of disabilities they had. The most common and frequently used words or language for PWDs, as cited by PWDs, were:

'You become that object who uses sticks, that man who uses wheelchair. It is easy on us (people with disabilities) for a person to throw words no matter how you feel and say 'limping person' (isiqhwala), 'hunchback' (isifombo), 'cripple' (isidalwa) or that' blind person' (laa mfama).'

Other people with disabilities actively disliked the use of certain words when people referred to them. They associated the use of

these terms as a means of killing them spiritually. One disabled individual participant said:

'I hate very much the word 'shame'. You must know that you have killed me spiritually. Do not use shame as 'if boils have just erupted over my body' (ndithe putyu amathumba emzimbeni). No this is a 'cripple' (sisidalwa); this is 'Mrs So and so's cripple' (isidalwa sikaMabani).'

The traditional healer refers to the use of unacceptable language or words that are prohibited. Prohibition literally means not allowed. In this case, people were not allowed to call a disabled person by names that referred to his or her disability. Name-calling was sometimes accompanied by forms of punishment. However, use of prohibited words could result in the perpetrator being beaten or sued. The traditional healer had this to say:

'When you are angry you say this 'one eyed' (le nyhori). One man would stand up and hit the one who called that name with a stick on the head. Speak with your mouth; do not call him with disability. If you fight, fight, do not name by his disability.'

It was also noticed that people who worked for stakeholders like government, business, associations and non-governmental organizations (NGOs) also used unacceptable words without considering how disabled people might feel. Disabled people however, would let non-disabled people use that language or words if they deemed the language or word would benefit them (people with disabilities). There is an isiXhosa saying '*Isithuko asikhuphi siphaku*' meaning 'calling names does not leave mark'. The participant from key informants (social worker) cited this:

'Do you see the games like 'Amakrokrokro' yes, but those people have their terms now. But you can see that really

negative attitudes are there. They do not want to accept people with disabilities.'

4.1.2 People with disabilities are objects of pity

It was a common phenomenon that people with disabilities were seen as objects of pity. Non-disabled people used some gestures - body as well as verbal language - when referring to people with disabilities. The two individual disabled participants interviewed revealed these by:

'When people see me they see somebody to be pitied for. You look to the person the way he looks at you. You see this person is saying something inside and has sympathy'.

'I hate very much the word "shame"'.

Findings revealed that people with disabilities had a tendency to develop self-pity. This was reflected by one disabled individual participant in the following:

'In life you must not be sympathetic to yourself. The minute you become sympathetic to yourself, people will always be sympathetic to you'.

Results reflected that other non-disabled people developed pity according to the type of disability that a person had and crimes that might be committed by a person with a disability. One of the participants from the clergy group had this to say:

'Pity of his condition. You even think how those who stay with him treat him. Maybe at home he is treated like an egg sometimes.'

'When a PWD has committed a crime...it becomes pitiful if you know this person he was not like this'.

Findings of the research illustrated that mothers were more sympathetic than fathers. This was confirmed by the participants with reference to the unique type of pain encountered by mothers during pregnancy, delivery and after delivery. The participant from the non-disabled group reflected this:

'I do not know the cause of this pity, we use to attach 'maternal feeling of empathy of the mother' (inimba) and be protective to our children'.

It appeared to be common practice that people with disabilities are afforded fast lane status (people with disabilities do not queue) in the public services. The Department of Health, for example, has a policy stating that people with disabilities should be afforded fast lane service. Also, results of the research revealed that non-disabled people requested that people with disabilities be put in the fast lanes. The participant from the group of clergy put it this way:

'Maybe he is in the Post Office he is in the queue, offers first place in the queue, in many things even in the pay queues. When they are on the queue, they must sympathize with him/her'.

One of the participants gave an example of a member of the congregation who was injured and had then become disabled. The whole congregation became sympathetic to this member to an extent that the member felt uneasy. The participant from the clergy group reflected this:

'To an extent it becomes painful to him. Because he is disabled he is going to say 'yoo they will do this thing...they will lift me'.

4.1.3 Burden to others

There is a perception that people with disabilities are dependent on non-disabled people in every aspect of life. The rough and uneven terrain in between homesteads requires that people using wheelchairs be assisted to move around. This has now brought about the perception that people with disabilities are inconveniences to others. One of the individual participants mentioned witnessing this:

'Other person sees a person who cannot do anything for himself.'

At the same time, people with disabilities were seen as burdens to the government. The participant from PWDs group supports this statement by saying:

'...who is supposed to be a burden of the social worker or doctor? Wish that social workers could take a role or do something about you'.

In the past, people with disabilities were institutionalized. For example, children with gross mental retardation were the first group to be considered. These places were provided for by the government. Also the participant from PWDs group highlighted this by:

'Government should have a place where people with disabilities could be kept. They see us as burden to the government'.

The infrastructure at the places of work did not seem to cater for people with disabilities. Accesses to entrances were not PWD user-friendly. Thus, these accesses acted as barriers to employment opportunities and resulted in the economic burden of people with disabilities. Such a situation then brought about a problem when a

person with a disability was competing for employment or already employed. This was discussed by the individual disabled participant:

'I am solely dependent to somebody. I need to call this mother I am working with 'help me mother to put this book there'.

The huge backlog of wheelchair applications in the Eastern Cape Department of Health has resulted in the already-allocated wheelchairs being in such a state of disrepair that these need to be replaced. For an applicant to receive the wheelchair took a minimum of a year. This then resulted in the disabled person becoming a burden to the family or others because of a broken wheelchair. One of the participants from the clergy group asserted this:

'For instance, the one I am talking about had a problem of wheelchair that sometime it would be worn out. It usually take some time for his wheelchair to be replaced and needed for him to get his pension. A car would be hired though he could be able to use his wheelchair'.

4.1.4 Lower expectations of people with disabilities by others

There was a perception among the non-disabled people that people with disabilities had only specific skills and that they expected to get hand-outs. These hand-outs were expected from the government. It was a norm that a disabled person ought to have a specific skill that represented a lower status. The two disabled individual participants revealed this by:

'Finding other people asking you 'do you get disability grant; do you know handwork, are you able to do it?'

4.1.5 Attitudes of people with disabilities towards inclusion

Certain attributes possessed by people with disabilities can impact positively towards inclusion within the community. When a disabled person accepted a disability this made it easier for integration into the community. The participant PWDs group illustrated this by:

'We need to accept it (disability), you see. It was necessary that I accept the place where I am. So that my friends can accept it, especially my family. The family managed to accept and friends managed to accept. They (friends) still visit me even today and ... my family for my disability'.

People with disabilities are human beings. Human beings have belief systems. For people to be integrated within their community they needed to believe in something. Christianity is the most dominant belief system at Sakhisizwe community. Thus, most people believed in Christianity while very few believe in the African Religion. If a person believed in any of these belief systems it facilitated integration into the community. Data analysis as discussed by a disabled individual and a traditional healer consecutively revealed:

'I will quote sometimes, it is said 'God created us to be like Himself' (Genesis 1:27). This does not mean when you are disabled you are not created by Him.'

'The ancestor is punishing you, we believe that there is presence of ancestors, I am in traditional service called 'Qamata', I am also a Christian.'

People with disabilities who used humility and humour to cope found it simple to be included in the community activities. Non-disabled people could see that a person with a disability did not have self-pity. This sense of humour was apparent in the remark by this disabled individual participant:

'For these people to understand me, I must be humble myself. When you stay with people who are not disabled you must have a sense of humour about your disability.'

4.2 Theme 2: Perceptions with regards to causes and determinants of disability

Theme	Categories
Perceptions with regards to causes and determinants of disability	Causes and onset of disability
	Cultural beliefs associated with disability
	Socio-economic determinants of disability

4.2.1 Causes and onset of disability

Data analysis illustrated that there were various causes for disabilities in people. It revealed that a child could be born with a disability or one can acquire a disability later in life as an adult. Other people became disabled through diseases and others through accidents. These causes were reflected by PWDs and disabled individual participants as:

'I was born disabled.'

'I heard from my parents that the thing that caused me to be disabled was Polio.'

'I was not born disabled.'

'I was stabbed at the back of the neck.'

4.2.2 Cultural beliefs associated with disability

It was found in the analysis of data that other disabilities were the result of cultural beliefs. If a person had been involved in immoral actions within a family, it was believed that that person was likely to give birth to a disabled child. Also, if the non-disabled person laughed at a disabled person, that person was likely to give birth to a disabled child. The traditional healer as participant supported this by:

'We take them as children who are incorrectly brought and hated by ancestors.'

'When this child is delivered and he has seizures. It is believed that the mother come across close to a person with seizures and has transmitted this wind (spirit) to the unborn during pregnancy.'

'...was thinking that if you laughed an albino you will give birth to an albino.'

4.2.3 Socio-economic determinants of disability

The researcher's awareness about the attitudes towards disability within the researched community was reflected in the data analysis. The childhood diseases that could have been prevented earlier were not prevented. Poor literacy levels of parents also contributed to disabilities apparent in this community. This is what the disabled individual participant revealed:

'A newborn baby must be taken to the clinic to get first immunization.'

'My parents were not enlightened about immunizations.'

Lifestyles within this community resulted in the occurrence of different types of disabilities. This was exposed during the data analysis by two participants from PWDs group:

'I was hit by a car.'

'I was shot.'

4.3 Theme 3: Challenges facing young people with disabilities

Theme	Categories
Challenges facing people with disabilities	Wishing for a barrier-free community (including neighbours)
	Poor access to schools equals poor education
	Disabled people with sensory impairments are facing discrimination in their community

This is the most important and common theme with regard to people with disabilities. This theme emphasizes important facilitators as well as barriers within the community. Facilitators refer to the enabling factors that can make people with disabilities receptive in the community. Barriers, on the other hand, refer to factors that can inhibit people with disabilities from participating in the activities of social living. Participants found these challenges such as physical access within the community, poor access to schools as well as absence of teachers for learners with sensory impairments at public schools. Thus participants wished for a barrier-free community.

4.3.1 Wishing for a barrier free community

People with disabilities were unable to attend activities in their community. The rough terrain between the homesteads made it difficult for people with physical disabilities to move from one homestead to the other. One of the disabled individuals had this to say:

'Neighbour must know that he has a neighbour who is disabled and who, on one day needs to find him at his (neighbour) home. If I (neighbour) do not cater for these, a person with disability will not come to my home.'

Attending community gatherings and rituals became a challenge for those with this type of disability. The desire for a barrier-free community was also displayed by one of the disabled individual participants:

'So that when I enter his (neighbour) home, there must be no step.'

A barrier-free community will bring along independence and self-reliance to people with disabilities as indicated below by one of the disabled individual participants:

'Step that will need me (person with disability) to be lifted.'

4.3.2 Poor access to schools equals poor education

Bad roads leading to the schools around Sakhisizwe contributed to the fact that children with disabilities - especially the physically-disabled ones - did not attend schools. The infrastructure of mainstream schools did not cater for children with disabilities because the stairs leading to the classrooms were, in reality,

barriers to their learning. This made it difficult for disabled children to attend schools. The participants from PWDs reflected this:

'People with disabilities must not be discriminated by steps to enter the school. It is difficult to get in schools. It is rare to see people with disabilities having standard 10.'

One of the disabled participants who had the means to go to an institution of higher learning found the physical access challenging in that institution. The participant had this to say:

'At ...university I found residential area having steps when you enter. In the olden days when structures were built, it was not anticipated that there could be people with disabilities who could study up to tertiary level.'

This participant also highlighted the lack of support for students with disabilities who were doing university courses. This often resulted in their failing the first year at university. The participant's remark below indicates this:

'It was difficult for me such that in my first year I did very badly. But I ended up repeating at this university. Lecturers do not understand what kind of a person am I.'

Mainstream schools in Sakhisizwe were not equipped to teach those with sensory impairments such as hearing as well as speech impairments. None of the teachers had been trained to teach people with these disabilities. The participant with a hearing impairment reflected by saying:

'I grew up old, thereafter I saw that hey I want to go to school. Then I went to school. I found myself stupid, not able to do anything. I gave up and stayed at home. I was that type of a person.'

Children with speech impairments are not even accepted by mainstream schools as there are no professionals to deal with them. It is assumed that these children cannot learn. The mainstream schools lacked resources like hearing aids for people with hearing impairments as well as teachers with skills to teach these children. Their parents, with the help of social workers, took such children to the nearest school for children with hearing impairment. At this school these children were taught skills like carpentry and beadwork.

‘And took him to special school for the deaf called Efata in Mthatha.’

4.3.3 Disabled people with sensory impairments are facing discrimination in their community

Non-disabled people were inclined to discriminate against people with sensory impairment such as hearing and speech impairments. The assumption was that they were disabled and as such they were not able to make decisions and could not own property. One of the participants from the PWDs showed this by:

‘When he (her husband) died all property was taken away by the in-laws, even those cattle. I realize that I do not have a say and gave up. Eh, when they were taking this property they were saying they are eating the sweat and efforts of their child(batya ukubila namandla omntwana wabo).’

4.4 Theme 4: Confidence and self-esteem of people with disabilities

Theme	Categories
Confidence and self-esteem of people with disabilities	People with disabilities put under one definition

	Self-determination
	Education equals pride
	People with disabilities are knowledgeable

This theme had a direct impact on perceptions of people with disabilities with regard to attitudes towards them.

4.4.1 People with disabilities put under one definition

People with disabilities were seen as mentally ill people regardless of whatever disability they had. Such a generalization did not deter people with disabilities; instead it gave them power to acknowledge differences in disabilities. The disabled individual participants discussed this attitude by stating that:

‘As people we are different in the community. Maybe your (person with disability) idea is more important and can build the nation because you are not disabled mentally.’

4.4.2 Self-determination

Data analysis reflected the unbelievable determination of people with disabilities once they were given opportunities. This was demonstrated by one of the disabled individual participants as:

‘If I want to live a better life, I need to study. I am not going to be able to do washing for the people. Know what you want in life... You must follow your instincts if you want something.’

4.4.3 Education equals pride

A wise African person once said *‘Ndingafundanga nje ndiza kubafundisa rhoqo abantwana bam’* (although I am not

learned/educated I will always educate my children). This saying referred to any child, disabled or non-disabled. Some disabled children did not let down their parents; they studied up to tertiary level. Results indicated that one disabled individual did not let herself or her parents down:

'But I (person with disability) ended up being a graduate (emphasizes), you see. So my parents are proud of me.'

4.4.4. People with disabilities are knowledgeable

As indicated earlier, people with disabilities are not mentally ill; therefore given the chance, they display knowledge like any other person. This was put succinctly by one disabled individual participant as:

'When being asked about some information, express yourself (person with disability) giving full explanation.'

'They (non-disabled people) are going to be surprised and see that you (non-disabled person) can get some information to this person.'

4.5 Conclusion

As a result of the data analysis, four themes were identified and developed in an attempt to determine facilitators and barriers as well as the impact of attitudes with regard to the integration of people with disabilities within Sakhisizwe community. Thereafter categories that had direct impact on the developed themes were identified. The themes were presented individually so that interconnections could be discerned. In the next chapter there is a theme-by-theme discussion of the research findings.

CHAPTER 5: DISCUSSION OF FINDINGS

5.1 Overview of findings

This chapter deliberates on the four themes that emerged from the findings of the research in Sakhisizwe. The study considered four aspects, issues or categories as reflected in the objectives: the perceptions of persons with disabilities with regard to attitudes towards them; the nature of attitudes towards people with disabilities; the impact of attitudes on the integration of people with disabilities; and facilitators and barriers with regard to the integration of people with disabilities.

The researcher will discuss the themes that emerged from the findings. These themes are also linked to the objectives as follows:

1. Challenges facing young people with disabilities focused on facilitators and barriers with regard to integration of people with disabilities (poor access to school equals poor education; disabled people with sensory impairments are facing discrimination in their community)
2. Attitudes of non-disabled people towards people with disabilities looked at the impact of attitudes on the integration of people with disabilities (disability terminology, people with disabilities being objects of pity)
3. Confidence and self-esteem of people with disabilities focused on perceptions of PWDs with regard to attitudes towards them (people with disabilities are knowledgeable, self-determination)
4. Perceptions with regards to causes and determinants of disability looked at causes and determinants of different

disabilities (causes and onset of disabilities, cultural beliefs associated with disability)

5.1.1 Theme 1: Challenges facing people with disabilities

People with disabilities faced social challenges that affected the family, community and themselves. It was assumed that families with disabled children tend to break up. This perceived disruption of family was caused by the addition of a disabled child in the family. [52]

There was a general desire within the disabled community for households to be disabled-user-friendly as people with disabilities would love to visit their neighbours. People with disabilities were keen to participate in community activities but they experienced physical barriers. Participation however, is defined by the International Classification of Functioning, Disability and Health (ICF) [14] 'as involvement in life situations and environmental factors as social, attitudinal and physical environments in which people live'. Thus, when these factors have a positive influence on the participation of a person with a disability, they are referred to as facilitators, and when having a negative influence, they are called barriers.

Barriers to participation within the community included the existence of uneven surfaces in the physical environment, increased dependence on adult supervision within the social environment and bullying in the attitudinal environment. Also, the absence of sign language facilities indicates a form of institutional attitude. [53] Social models of disability strongly suggest that the environment, not the disabled person, must change or be changed to enable participation. In the community setting, people with disabilities often

experience limited employment opportunities, challenging lifestyles, fluctuating health status and questionable financial status. [54] Several reasons for this have been identified, such as: the lack of appropriate skills or education of people with disabilities; and social or physical barriers in the work environment. Children with disabilities from the mainstream often have limited social relationships brought about by both personal and environmental factors. Such factors include the vital role of negative attitudes of peers. [55]

It transpired in the interviews that inclusivity of people with disabilities in community activities and in education was really necessary. The community of Sakhisizwe believed that people with disabilities should be included in community meetings so that they could participate to their maximum potential. Also, this community felt that children with disabilities should attend mainstream schools. This was aligned to the concept of inclusive education which started about forty years ago in countries like the United States. Hence, the term inclusive education indicates that the school has the responsibility to modify its environment to meet the needs of children with developmental disabilities or special educational needs. [56] Inclusive education offers benefits for the children with special needs and opportunities for the other children to discover disabled children as their peers and as friends.

Sensory impairments, especially hearing loss, posed speech, socio-emotional, educational and vocational consequences. The problem did not only affect individuals with sensory impairments, but also had long term societal costs. [57] Thus, the most effective way was to reduce these consequences through the implementation of early hearing detection and intervention programmes.

5.1.2 Theme 2: Attitudes of non-disabled people towards people with disabilities

This theme focuses on the impact of attitudes on the integration of people with disabilities. Attitudes displayed by non-disabled people have impacted on the integration of people with disabilities. Most of these attitudes were negative and discriminatory in nature. These attitudes subjected people with disabilities becoming objects of pity and burdens to others. Also, these attitudes resulted in others lowering their expectations of people with disabilities. Some of these attitudes resulted in the use of unacceptable language and words to refer to people with disabilities.

Townley *et al.* [58] asserted that a lack of engagement in meaningful activities could be a barrier to community integration and as such could lead to isolation of people with disabilities. These researchers further suggest that community integration had traditionally been perceived as physical presence in the community. They argued that physical integration comprised of participation in activities of daily living in the broader community; social integration looks on social contact with non-disabled neighbours and other community members; and psychological integration can be perceived as an individual's sense of community and belonging.

With regard to physical disabilities, new problems arise in the period of transition from childhood to adolescence and adulthood. Such changes include independent and dependent living; work; social relationships; partnership; and child wish. [63] These researchers asserted that chances for living independently, attending regular education and having a regular job were minimal and were dependent on the level of disability. The level of education of people

with disabilities was lower at Sakhisizwe and the unemployment rate was at 53%. [60]

Becker *et al.* [61] suggested that participation in community recreation programmes supported the development of peer relationships, enhanced self-esteem, improved general health, and reduced stress and anxiety in adults and children. Such participation might increase opportunities to establish social networks and develop communication skills. As a result, international games called 'Paralympics Games' were established to cater for people with disabilities. One of the participants from key informants (social worker) had asserted this by:

'South Africa has established a national team called 'Amakrokrokro' which is doing well in the Paralympics Games.'

On a smaller scale, learners from Khanyisa Special School located at Sakhisizwe had been participating in these games up to international level and brought back medals. In addition, government departments like The Department of Social Development have introduced games called 'Golden Games' that allowed older persons to participate at local, sub-district, district, provincial, national as well as international levels. Older persons of Sakhisizwe have participated in these games up to national level and won medals.

5.1.3 Theme 3: Confidence and self-esteem of people with disabilities

This theme had a direct focus on the perceptions of people with disabilities with regard to attitudes towards them. The data analysis revealed different categories that included: people with disabilities

are put under one definition; self-determination; education equals pride; and people with disabilities are knowledgeable.

Negative attitudes toward people with disabilities were a product not only of individual beliefs but also of societal and organizational practices. [62] These attitudes resulted in the lack of confidence and lowered self-esteem of people with disabilities. Thus, attitudes, beliefs and misconceptions of society towards disability constituted major barriers for person with disabilities. Statistic South Africa 2001 revealed that the population of Sakhisizwe had 7, 5% of people with disabilities. [47] These researchers however, argued that there is a serious lack of reliable information on the nature and prevalence of disability in South Africa.

People with disabilities are generally put into one bag in terms of definition. It did not matter what type of disability there was; a person who was less disabled would be regarded as disabled. For example, a person using one crutch (less disabled) and a person with severe disability were regarded as the same although their level of functioning was different. All persons with a disability of any type were regarded as persons who could not think, thus causing negative attitudes that led to the social exclusion and marginalization of people with disabilities. [62] These attitudes toward individuals with disability were thus often charged with prejudice including false cognition, negative effects and behavioural ignorance –all posing barriers restricting their degree of active participation in community life. [63]

5.1.4 Theme 4: Perceptions with regards to causes and determinants of disability

Studies have shown that disabilities are caused by many factors. [63]They revealed that, for example, Spina bifida is a health condition that is caused by a congenital neural tube disorder. [59] In other words, a child may be born with this condition. Other disabilities were acquired during life processes as a result of traumatic causes. These traumatic causes were due to road motor vehicle accidents. Others were due to chronic conditions like Diabetes Mellitus and, most recently, debilitating conditions like HIV and AIDS.

Socio-economic levels at Sakhisizwe as revealed by the Statistical Survey for Chris Hani District 2002 [47] showed these features:

4.6% of this population had access to electricity though meter boxes were too high for PWDs to reach and therefore not disabled-user-friendly; 10.3% had access to telephones; 18.6% had access to safe and clean water though 30% were using potentially unhealthy water. It also revealed that 15% of this population had proper sanitation, 53% of this population was unemployed and 92% living below the poverty line. Hence, socio-economic factors also contributed to the causation of disability in disadvantaged areas like the Eastern Cape.

5.2 Conclusion

In Chapter 1 on the evolution of the study, the researcher indicated that many babies were born with disabilities at maternity wards where the researcher spent most of the time. The researcher also indicated that there was a high incidence of negative attitudes in the behaviour of husbands and in-laws. Irrespective of what caused the disability, negative attitudes would be displayed by non-disabled people towards PWDs. This resulted in PWDs mostly being under

one definition, regardless of functional ability. There is a need for professional healthcare workers to conduct awareness campaigns in the community on issues of disabilities. These findings led the researcher to make several conclusions, which will be presented in the next chapter.

CHAPTER 6: CONCLUSION

The findings of this research demonstrated how people with disabilities were denied their basic rights and roles to be mothers, fathers, wives, husbands and children. Experiences shared in this study suggested that people with disabilities have needs to be met.

Most of the public facilities were difficult bridges to cross for people with disabilities. These had steps to the entrances and no ramps. It was difficult for people with disabilities to do even simple shopping as shops had steps to the entrances with narrow passages inside. This made it difficult for disabled people who used wheelchairs to move around freely.

People with disabilities need to be protected from abuse within the family and the community. They also need protection from attitudinal discrimination within their homes and communities. This protection is important in terms of self-worth, self-confidence and self-actualization of people with disabilities.

People with disabilities often experience social isolation as there is no formal and informal support network available at Sakhisizwe. In South Africa, there are several policies as well as a number of mechanisms to challenge legislature, but participants in this study do not participate in policymaking decisions due to their level of education and inaccessibility of relevant resources.

The experiences shared in this study show that people with disabilities at Sakhisizwe are still marginalized. To be marginalized is to be ignored or not taken into account and this lead to a failure to achieve potential in both the individual and society. The effect can

be unintentional (non-disabled people displaying attitudes to people with disabilities) and due to a lack of understanding of how attitude affects people with disabilities. [64] The findings showed that the historical and current context in which people with disabilities live greatly hindered their full participation in health-promoting activities.

Opportunities for quality education were non-existent as the public schools were not built to accommodate people with disabilities. All the schools around Sakhisizwe have flights of stairs thus making it difficult for physically-disabled people to access the classrooms. At all the schools around Sakhisizwe, the teachers were not trained to teach children with sensory impairments such as people with hearing impairment and those with speech impairments. As a result, there were financial implications for the parents or families of these children as they had to take their children outside Sakhisizwe for basic education. The only special school at Sakhisizwe also catered for intellectually-impaired children with no physical disability at all.

6.1 Limitations of the study

The researcher was familiar with most of the participants. This might have influenced their responses and elicited response biases. In spite of all this, the researcher had to maintain an objective attitude all the times.

During the research data collection process, the participants might have responded in a favourable manner to the researcher so as not to represent themselves in a bad manner to the researcher. To this effect the researcher worked on establishing and maintaining a good rapport in which they could respond freely without feelings of intimidation. During the interviews the researcher acknowledged what the participants said in a non-judgemental manner.

During the first selection of key informants as participants, the researcher had limitations. The researcher wanted to have a key informant from the religious fraternity through the Council of Churches. When the chairman of the Council of Churches was approached he preferred to be interviewed with the executive of the council and this ended up being a group interview.

The researcher also wanted to interview the Chief of Sakhisizwe as a key informant but the proposal was denied by the Chief saying that his community needed to be involved in the interviews as he believed in democracy. The researcher had to abide by these requests.

6.2 Recommendations

As teachers lacked skills in teaching children with sensory impairments and parents lacked communication skills, for example, such as with those who were hard-of-hearing or deaf or those who had speech impairments, the researcher recommended that:

- Disability awareness days be organized so that people are informed of disability issues and disability policies. These policies and programmes need to be communicated through community meetings.
- All people of the community, regardless of any disability, must attend communal meetings.
- Admission of children with disabilities in the mainstream school must be enhanced so that children with disabilities can socialize with non-disabled children.
- The community should organize '*ilima*' (pro-activeness of one or more of the community members to invite or organize other community members to come and assist in a project that needs

immediate results) to construct roads to schools and other public facilities so that people with disabilities can get an education and participate in decision-making.

- Several content areas ought to be added to professional preparation programmes for educators of the hard-of-hearing and child development theories. [65]. This should be organized at institutions of higher learning as this is not applicable at Sakhisizwe L.S.A.
- Creation of awareness about people with disabilities should start at Grade R so that the child grows knowing that a disabled child is a human being like anybody else.
- Avoid the use of unacceptable language towards people with disabilities at an early stage.
- Non-disabled people must avoid being sympathetic towards people with disabilities.
- Sakhisizwe community need to have support networks, whether formal or informal.
- Health professionals should try and adopt positive attitudes for the positive results of PWDs.

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APPENDICES

APPENDIX A1: Interview schedule/questions

Faculty of Health Sciences
MPhil Rehabilitation
University of Stellenbosch

The aim of this interview is to **determine how the non-disabled community perceives people with disability at Sakhisizwe**. The information is confidential and the interviewee can stay anonymous if he or she so wishes.

1. Tell me about People with Disabilities (PWDs) you came across whether at home or in a community setting.
2. What were your reactions and feelings when you met the disabled person or child?
3. In your opinion, what does disability symbolize or reflect to you?
4. In your own opinion, do you think people with disabilities should be part of the community or society? In what way?
5. In your own opinion, what do you think about the way society addresses or refers to people with disabilities?
6. In your own opinion, what do you think are the attitudes that assist people with disabilities to be integrated to this community?
7. In your own opinion do you think people with disabilities have the same rights and convictions as non-disabled people in this community?

Thank you for your time and consideration.

Udliwano-ndlebe nabantu abangakhubazekanga malunga nolwamkelo lwabantu abakhubazekileyo eSakhisizwe.

Injongo zoludliwano-ndlebe kukufuna ukuqonda ukuba ingaba abantu abangakhubazekanga bababona njani abantu abakhubazekileyo eSakhisizwe. Ulwazi oluya kufumaneka luyakuhlala luyimfihlo kwaye lowo uthe wathatha inxaxheba uya kuhlala engaziwa ukuba unqwenela oko.

1. Kha undibalisele ngabantu abakhubazekileyo owakhe wadibana nabo ekhaya okanye ekuhlaleni.
2. Waziva njani xa udibana okanye uhlangana nomntwana okanye umntu okhubazekileyo?
3. Ngokwee ngcinga zakho ingaba ukukhubazeka oku kuthetha ntoni okanye kubonisa ntoni?
4. Ngokwe ngcinga zakho ingaba abantu abakhubazekileyo bangayinxalenye yabantu ekuhlaleni na? Ngaluphi uhlobo?
5. Ingaba ucinga ni ngendlela uluntu olungakhubazekanga oluthetha ngayo kuluntu olukhubazekileyo?
6. Ngokombono wakho ucinga ukuba zintoni izinto ezingancedisa abantu abakhubazekileyo ukuba baqukwe kuluntu lwalendawo?
7. Ngokucinga kwakho ingaba abantu abakhubazekileyo banawo amalungelo nezigwebo njengabantu abangakhubazekanga kulendawo?

Enkosi ngexesha lakho nengqwalasela.

APPENDIX A2: Interview schedule/questions

Faculty of Health Sciences
MPhil Rehabilitation
University of Stellenbosch

The aim of this interview is to determine **how PWDs at Sakhisizwe perceive their own disabilities**. The information is confidential and the interviewee can stay anonymous if he or she so wishes.

1. When did you realize something was wrong with your body?
2. In your opinion, what was the cause of your disability?
3. How does the community react when they see you and how do these reactions affect you?
4. In your opinion, what does disability symbolize or reflect to you?
5. In your own opinion, do you think people with disabilities should be part of the community or society? In what way?
6. In your own opinion, what do you think about the way society addresses or refers to people with disabilities?
7. In your own opinion, do you think people with disabilities have the same rights and convictions as non-disabled people in this community?

Thank you for your time and consideration.

Udliwano-ndlebe nabantu abakhubazekileyo malunga nolwamnceleko lwabo eSakhisizwe.

Injongo zoludliwano-ndlebe kukufuna ukuqonda ukuba ingaba abantu abakhubazekileyo bakubona njani ukukhubazeka kwabo. Ulwazi oluya kufumaneka luyakuhlala luyimfihlo kwaye lowo uthe wathatha inxaxheba uya kuhlala engaziwa ukuba unqwenela oko.

1. Waziqonda nini ukuba ikho into engalunganga malunga nomzimba wakho?
2. Ngokucinga kwakho yintoni eyabangela ukuba ukhubazeke?
3. Xa abantu bekubona bathini, kwaye oluhlobo bakubona ngalo lukuphatha njani?
4. Ngokwee ngcinga zakho ingaba ukukhubazeka oku kuthetha ntoni okanye kubonisa ntoni?
5. Ngokwee ngcinga zakho ingaba abantu abakhubazekileyo bangayinxalenye yabantu ekuhlaleni na? Ngaluphi uhlobo?
6. Ingaba ucinga ni ngendlela uluntu olungakhubazekanga oluthetha ngayo kuluntu olukhubazekileyo?
7. Ngokucinga kwakho ingaba abantu abakhubazekileyo banawo amalungelo nezigwebo njengabantu abangakhubazekanga kulendawo?

Enkosi ngexesha lakho nengqwalasela.

APPENDIX A3: Interview schedule/questions

Interview schedule for key informants

1. What are the causes of disabilities in this community?
2. What does disability mean to you or the community as traditional healer?
3. What are the reactions of non-disabled people when they meet or see a person with disability?
4. What services are available for people with disabilities in this community? What do the available services do when a person with disability does not get the needed service?
5. In your own opinion, what do you think are the attitudes that assist people with disabilities to be integrated to this community?
6. In your own opinion, what do you think about the way the community addresses or refers to people with disabilities?

Udliwano ndlebe nabantu abanexaxheba ephambili abantwini

1. Zinto zini ezibangela ukukhubazeka kule ngingqi?
2. Ingaba ukukhubazeka oku kuthetha ntoni apha kuwe okanye kule ngingqi njenge gqirha?
3. Baziva njani abantu abangakhubazekanga xa bedibana okanye bebona umntu okhubazekileyo?
4. Ziziphi iinkonzo ezikhoyo zabantu abakhubazekileyo kule ngingqi? Ziye zenze njani inkonzo ezikhoyo xa umntu okhubazekileyo engakulufumani uncedo aludingayo?
5. Ngokombono wakho ucinga ukuba zintoni izinto ezingancedisa abantu abakhubazekileyo ukuba baqukwe kuluntu lwale ndawo?
6. Ingaba ucinga ni ngendlela uluntu olungakhubazekanga oluthetha ngayo kuluntu olukhubazekileyo?

APPENDIX B: Letter to Department of Health Eastern Cape

No.16 School Street
ELLIOT
5460
28 January 2009

The Head of Department
Department of Health
Private Bag X0038
BHISHO
5200

Dear Sir/Madam

RE-PERMISSION TO CONDUCT RESEARCH

I am a student at the University of Stellenbosch pursuing a programme of a Masters Degree in Rehabilitation.

I am expected to undertake a research project in partial fulfilment of this programme. The title of my topic is “The attitudes of Sakhisizwe Local Service Area (L.S.A.) community towards people with disabilities”.

The project number of my study from the Ethics Committee is “NO7/03/067”.

I hereby request permission to conduct the research at the Sakhisizwe Local Service Area. The objectives of the study are:

- To examine the nature of attitudes held by Sakhisizwe L .S. A. community toward people with disabilities.

- To determine the perceptions of people with disabilities with regards to the attitudes held by the Sakhisizwe L. S. A. community towards them.
- To determine the impact of the attitudes of the Sakhisizwe L. S. A. community on the integration of people with disabilities within this community.
- To determine the facilitators and barriers with regards to the integration of people with disabilities within Sakhisizwe L. S. A. community.
- To make recommendations with regards to the attitudes and integration of people with disabilities within the Sakhisizwe L.S.A.

The findings of this study will assist the department in reviewing the attitudes of community towards people with disabilities.

Thanking you in anticipation

J. NTENDA (MR)

APPENDIX C (1) Consent form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:THE ATTITUDES OF SAKHISIZWE LOCAL SERVICE AREA COMMUNITY TOWARDS PEOPLE WITH DISABILITIES

REFERENCE NUMBER: NO7/03/067

PRINCIPAL INVESTIGATOR: Joseph Ntenda

ADDRESS: No. 16 School Street
ELLIOT
5460

CONTACT NUMBER: 078 796 8089 (cell)/ 047 877 0931 (w)/ 045 931 2071 (h)

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

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

What is this research study all about?

- Where will the study be conducted; are there other sites; total number of participants to be recruited at your site and altogether.
- Explain in participant friendly language what your project aims to do and why you are doing it?
- Explain all procedures.
- Explain any randomization process that may occur.
- Explain the use of any medication, if applicable.

Why have you been invited to participate?

- Explain this question clearly.

What will your responsibilities be?

- Explain this question clearly.

Will you benefit from taking part in this research?

- Explain all benefits objectively. If there are no personal benefits then indicate who is likely to benefit from this research e.g. future patients.

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

- Identify any risks objectively.

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

- Clearly indicate in broad terms what alternative treatment is available and where it can be accessed, if applicable.

Who will have access to your medical records?

- Explain that the information collected will be treated as confidential and protected. If it is used in a publication or thesis, the identity of the participant will remain anonymous. Clearly indicate who will have access to the information.

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

- Clarify issues related to insurance cover if applicable. If any pharmaceutical agents are involved will compensation be according to ABPI guidelines? (Association of British Pharmaceutical Industry compensation guidelines for research related injuries which are regarded as the international gold standard). If yes, please include the details here. If no, then explain what compensation will be available and under what conditions.

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

No, you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You should inform your family practitioner or usual doctor that you are taking part in a research study. (Include if applicable)
- You should also inform your medical insurance company that you are participating in a research study. (Include if applicable)
- You can contact Mr. Joseph Ntenda at tel. 078 796 8089 (cell)/ 047 877 0931 (w)/ 045 931 2071 (h) if you have any further queries or encounter any problems.
- You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled **“The attitudes of Sakhisizwe local service area community towards people with disabilities”**.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.

- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) on (date) 2010.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I, Joseph Ntenda declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (place) on (date) 2010.

.....

Signature of investigator

.....

Signature of witness

Declaration by interpreter

I (name) declare that:

- I assisted the investigator (name) to explain the information in this document to (name of participant) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) on (date) 2010.

.....

Signature of interpreter

.....

Signature of witness

APPENDIX C (2): Consent form

INCWADANA ENGOLWAZI NGOMTHATHI-NXAXHEBA KUNYE
NEFOMU YEMVUMELWANO

ISIHLOKO SEPROJEKTHI YOPHANDO:

THE ATTITUDES OF SAKHISIZWE LOCAL SERVICE AREA
COMMUNITY TOWARDS PEOPLE WITH DISABILITIES

INOMBOLO YONXULUMANO: NO7/03/067

UMPHANDI OYINTLOKO: Joseph Ntenda

IDILESI: No 16 School Street
ELLIOT
5460

INOMBOLO YOQHAGAMSHELWANO: 078 796 8089 (nomyayi)/
047 877 0931 (w)/ 045 931 2071 (h)

Uyamenywa ukuba uthathe inxaxheba kwiprojekthi yophando. You are being invited to take part in a research project. Nceda thatha ixesha lokufunda ulwazi oluvezwe apha, oluzakuthi luchaze iinkcukacha zale projekthi. Nceda buza nayiphina imibuzo emalunga nayiphina indawo ongayiqondiyo ngokupheleleyo kubasebenzi besi sifundo okanye kugqirha. Kubaluleke kakhulu ukuba waneliseke ngokupheleleyo yinto yokuba ucacelwe kakuhle ukuba yintoni ebangwa sesi sifundo kwaye ungabandakanyeka njani. Kwakhona,

ukuthatha kwakho inxaxheba kungentando yakho ngokupheleleyo kwaye ukhululekile ukuba ungarhoxa ekuthatheni inxaxheba. Ukuba uthi hayi, oku akusayi kuchaphazela ukungavumi kwakho nangayiphina indlela. Ukwakhululekile ukuba uyeke kwesi sifundo naninina, nkqu nokokuba uyavuma ukuthatha inxaxheba ekuqaleni.

Olu phando luvunywe ziinkqubo ezisesikwenizeKomiti yoPhando Lomntu kwiYunivesithi yaseStellenbosch kwaye luzakwenziwa ngokwemigaqo esesikweni lo phando elamkelekileyo kwiSaziso seHlabathi sika-Helsinki, iMigaqo eLungileyo yoMzantsi Afrika yokuSebenza eKliniki kunye neBhunga lezoPhando ngamaYeza (MRC) iMigaqo yeNkqubo yezoPhando.

Simalunga nantoni esi sifundo sophando?

- Luza kwenziwa phi uphando; ingaba zikhona ezinye iindawo; bangaphi bebonke abathathi-nxaxheba abazakugaywa.
- Cacisa ngolwimi oluwiwa ngumthathi-nxaxheba ukuba iprojekthi yakho ijonge ukwenza ntoni kwaye kutheni uyenza?
- Cacisa zonke iinkqubo.
- Cacisa nayiphina inkqubo engakhethiyo enokuthi ibekho.
- Cacisa ukusetyenziswa kwalo naliphina iyeza, ukuba likhona.

Kutheni umenyiwe ukuba uthathe inxaxheba?

- Cacisa lo mbuzo kakuhle.

Luyakuba yintoni uxanduva lwakho?

- Cacisa lo mbuzo kakuhle.

Ingaba uza kuzuza ekuthatheni inxaxheba kolu phando?

- Cacisa yonke inzuzo ngokungaqhutywa luluvo. Ukuba akukho inzuzo bonisa ke ukuba ngubani onokuthi azuze kolu phando umz. Abazali bangomso.

Ingaba zikho iingozi ezibandakanyekayo ekuthatheni kwakho inxaxheba kolu phando?

- Chaza naziphina iingozi ngokungaqhutywa luluvo.

Ukuba awuvumi ukuthatha inxaxheba, loluphi olunye unyango onalo?

- Bonisa ngokucacileyo ngokubanzi loluphi olunye unyango alokhoyo kwaye lungafunyanwa phi, ukuba lukhona.

Ngubani oza kufumana ingxelo yakho yamayeza?

- Cacisa ukuba ulwazi oluqokelelweyo luza kuba yimfihlelo kwaye luza kukhuselwe. Ukuba lusetyenziswe ekupapashweni okanye kwithesisi, umthathi-nxaxheba akasayi kwaziswa. Cacisa kakuhle ukuba ngubani oza kukwazi ukufumana ulwazi.

Kuza kwenzeka ntoni kwimeko yesiganeko esingalindekanga sokwenzakala ngenxa yokuthatha kwakho inxaxheba kwesi sifundo sophando?

- Cacisa imiba enxulumene nentlawulo ye-inshorensi ukuba ikhona. Ukuba kukho iindawo ezibandakanyekayo ezithengisa amayeza ingaba intuthuzelo izakuhamba ngokwemigaqo ye-ABPI? (Imigaqo yentuthuzelo enxulumene nokwenzakala kuphando lweManyano yaseBrithane yezoRhwebo lwamaYeza ethathwa njengekwizinga lehlabathi legolide). Ukuba ewe, nceda bandakanya iinkcukacha apha. Ukuba hayi, cacisa ke ukuba yeyiphi intuthuzelo eyakubakhona kwaye phantsi kweziphi iimeko.

Ingaba uza kuhlalulwa ngokuthatha inxaxheba kwesi sifundo kwaye ingaba kukho iindleko ezibandakanyekayo?

- Hayi awusayi kuhlalulwa ngokuthatha inxaxheba kwesi sifundo kodwa isithuthi sakho neendleko zokutya ziza kuhlalulelwa kundwendwelo ngalunye lwesifundo. Akusayi kubakho zindleko ezibandakanyelwa wena, ukuba uthatha inxaxheba.

Ingaba ikho enye into ekumele uyazi okanye uyenze?

- Kumele wazise ugqirha wosapho okanye ugqirha oqhelekileyo nje ukuba uthatha inxaxheba kwisifundo sophando. (sibandakanye ukuba sikhona)

Isifungo somthathi-nxaxheba

Ngokutyikitya ngezantsi, Mna ndiyavuma ukuthatha inxaxheba kwisifundo sophando semfuzo esibizwa ngokuba: "The attitudes of Sakhisizwe local service area community towards people with disabilities".

Ndazisa ukuba:

- Ndilufundile okanye ndalufunda olu lwazi kunye nefomu yemvumelwano kwaye ibhalwe ngolwimi endiliciko nendikhululekileyo kulo
- Bendinalo ithuba lokuba ndibuze imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyakuqonda ukuba ukuthatha inxaxheba kolu phando kube kukuzithandela kwam kwaye andikhange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukusishiya isifundo naninina kwaye andisayi kohlwaywa okanye ndigwetywe nangayiphi indlela.

Mna (igama) ndazisa ukuba:

- Ndincede umphandi uJoseph Ntenda ekucaciseni ulwazi olu lapha kweli xwebhu ku-(igama lomthathi-nxaxheba) ndisebenzisa ulwimi lwesi Afrikaans/IwesiXhosa.
- Simkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndimxelele eyona nto iyiyo malunga nokunxulumene nam.
- Ndiyaneliseka kukuba umthathinkxaxheba ukuqonda ngokupheleleyo okuqulathwe loluxwebhu lwemvumelwano eyazisiweyo kwaye nemibuzo yakhe yonke iphendulwe ngokwanelisayo.

Kutyikitywe e-(indawo) ngo-(usuku) 2010.

.....
Umtyikityo wetoliki

.....
Umtyikityo wengqina

APPENDIX D

Letter from Research Ethics Committee unit for The Department of Health: Eastern Cape.



Eastern Cape Department of Health

Enquiries: Zonwabele Merile
Date: 23rd June 2009
e-mail address: zonwabele.merile@impilo.ecprov.gov.za

Tel No: 040 608 0830
Fax No: 043 642 1409

Dear Mr Joseph Ntenda

Re: The attitudes of Sakhisizwe Local Service Area community towards people with disabilities

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants. You will not impose or force individuals or possible research participants to participate in you study. Research participants have a right to withdraw anytime they want to. However, you shall be responsible in dealing with any adverse effects following the research treatment provided in your study.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

APPENDIX E

Letter to the District Office and Local Service Area.

No. 16 School Street
ELLIOT
5460
11 August 2008

The District Manager
Chris Hani District Office
P. O. Box 1661
QUEENSTOWN

Dear Sir/Madam

RE-PERMISSION TO CONDUCT RESEARCH.

I am a student at the University of Stellenbosch pursuing a program of a Masters' Degree in Rehabilitation.
I am expected to undertake a research project in partial fulfilment of this program.
The title of my topic is "**The attitudes of Sakhisizwe Local Service Area community towards people with disabilities**".
The project number of my study from the Ethics Committee is "**NO7/03/067**".

I hereby request permission to conduct the research at the Sakhisizwe Local Service Area. The objectives of the study are: -

- To examine the nature of attitudes held by Sakhisizwe L. S. A. community toward people with disabilities.
- To determine the perceptions of people with disabilities with regards to the attitudes held by the Sakhisizwe L. S. A. community towards them.
- To determine the impact of the attitudes of the Sakhisizwe L. S. A. community on the integration of people with disabilities within this community.
- To determine the facilitators and barriers with regards to the integration of people with disabilities within Sakhisizwe L. S. A. community.
- To make recommendations with regards to the attitudes and integration of people with disabilities within the Sakhisizwe L.S.A.

The findings of this study will assist the department in reviewing the attitudes of community towards people with disabilities.

Thanking you in anticipation


J. NTENDA (MR)

APPENDIX F

Letter from the District Office and Local Service Area.

humboro
.....
SUB-DISTRICT MANAGER Date *18.09.08*

Comments:
Recommended/Not Recommended Date *19.09.08*

[Signature]
.....
DD HRM&D

Comments Date *22/09/08*
Recommended/Not Recommended

[Signature]
.....
CSC MANAGER

Comments Date.....
Approved/Not Approved

M. Nkomo
.....
DISTRICT MANAGER Date *22/09/08*

provided the following are observed

- Maintenance of confidentiality
- Use of own resources to conduct the research eg. transport, time, etc.
- That a report on completion of the research will be submitted to this office.

M. Nkomo