A Social History of the Experiences of Africans with

Physical Disabilities who were Associated with the Cripple

Care Association (renamed the Association for the

Physically Challenged) in KwaZulu-Natal, 1970s to 2000s.

 \mathbf{BY}

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COLLEGE OF HUMANITIES

DECLARATION - PLAGIARISM

I Siyabonga Nxumalo declare that:

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- 2. This thesis has not been submitted for any degree or examination at any other university.
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ABSTRACT

This thesis provides an analysis of the social experiences of people with disabilities who belonged to the Cripple Care Association (CCA), which was later, renamed the Association for the Physically Challenged (APC). The experiences of people living with disabilities during apartheid and post-apartheid are different from one person to another. During apartheid race, class and gender influenced the lives of people with disabilities in what would become the province of KwaZulu-Natal especially in accessing resources. During the apartheid period, the state played a limited role in assisting and caring for the needs of people with impairments in South Africa. This compelled families to take an active role in caring for the needs of such persons. After 1994, the democratic government in South Africa produced a variety of policies for the betterment of people living with disabilities. This research also considers the experiences of people with disabilities who have lived in the post-apartheid period and looks at whether the lives of people with physical impairments has changed for the better.

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ABREVIATIONS

ABET - Adult Basic Education

AIDS - Acquired Immune Deficiency Syndrome

ANC - African National Congress

APC - Association for the Physically Challenged

AGM - Annual General Meeting

BEE - Black Economic Empowerment

CCA - Cripple Care Association

DPSA - Disabled People of South Africa

HIV - Human Immunodeficiency Virus

INDS - Integrated National Disability Strategy

NCCA - Natal Cripple Care Association

NGOs - Non-Governmental Organizations

TB - Tuberculosis

CHAPTER ONE: INTRODUCTION

South Africa has a long history of marginalizing people. Historically, racial discrimination has been one of the primary issues in this country. However, in this thesis I want to understand the history of another type of marginalization in South Africa; that which was experienced by people with disabilities. As indicated by the United Nations, disability is an umbrella concept covering impairments, movement confinements and participation limitations.¹

Statistics South Africa highlights that there are significant numbers of South Africans who live with disabilities. Statistics gathered for the 2011 Census highlighted that there was a national disability prevalence rate of 7.5%, with disability being more dominant amongst females (8.3%) than males (6.5%). Furthermore, the number of South Africans living with disabilities increased with age (53% of persons reported having a disability aged 85 and older). The statistics also highlight different types of disability: "The prevalence of a specific type of disability shows that 11% of persons aged five years and older had seeing difficulties, 4,2% had cognitive difficulties (remembering/concentrating), 3,6% had hearing difficulties, and about 2% had communication, self-care and walking difficulties". Finally, John Ataguba, James Akazili and Di McIntyre claim that the "burden" of ill health and disability are more prominent amongst lower socio-economic groups in South Africa.

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¹ United Nations (UN) (2006) 'Some facts about persons with disabilities' [Online] Available:

<www.un.org/disabilities/convention/facts.html> [2009, May 19] (Accessed on the 24 October 2016).

² Statistics SA. Profile of Persons with disabilities in South Africa, Census 2011 http:///www.statssa.gov.za/?p=3180 (accessed 7 August 2017).

³ John Ataguba, James Akazili and Di McIntyre. "Socioeconomic-related health inequality in South Africa: evidence from General Household Surveys." *International journal for equity in health* 10 (2011): 48.

It is vital to bear in mind that over time, different terms have been used to refer to disability. Historically, common terms used in English-speaking countries have been "handicapped" in the seventeenth century, "crippled" in the nineteenth century, and "disabled" in the twenty-first century. Sam Smith argues that the term "handicapped" first developed around 1653. It was associated with a type of lottery game called "hand-in-cap" where two players "negotiated a series of exchanges of items and forfeit[ed] money". By the late 1700s, the term was used in the field of horseracing, where horses were assigned "handicaps" by referees, which meant adding extra weight to horses more likely to win, to even the playing field. By the late 1800s, its meaning shifted again to mean "impediment or impairment", and by the 1950s, this meaning was applied to all persons with disabilities, and was used commonly in government documents. During this period, official labelling of someone as "handicapped" meant recognising that someone had a mental or physical disadvantage and needed assistance to equalise things, e.g. providing that person with a special parking space closer to an entrance to enable easier access to a building for a person who could not walk, or could not walk far.

Another commonly used term was "crippled" which means a person with a physical disability, predominantly one who is incapable of walking because of an injury or sickness. This term is no longer used in the contemporary period because it is regarded as insensitive to persons with disabilities. "Disabled" is a recent concept, which is considered politically correct. However, some still consider it to be insensitive as it still focuses on a person's limitations.⁵

⁴ Sam Smith. On 'Handicapped,' Disability Euphemisms, and False Etymologies. Posted on 23 July 2011 http://meloukhia.net/2013/07/on handicapped disability euphemisms and false etymologies/ (Accessed 17 August 2017). For more on the politically charged nature of labels, also see Ben O'Neill. "A critique of politically correct language." *The independent review* 16 (2011): 279-291.

⁵ Liz Crow. "Helen Keller: Rethinking the Problematic Icon", *Disability and Society*, 15 (2000): 6.

Another key issue to interrogate at the start of this dissertation is the simplistic linkage of disability with illness or diseases. Michael Oliver, a disability rights activist in Britain, claims that ablebodied people often identify people living with disabilities with their conditions including sickness and injury, thus neglecting the fact that they are also human beings. Another significant mistaken presumption which is regularly made by some people is that individuals living with disabilities suffer from their disability which is not always the case. In fact, Karen Stone argues that suffering only happens when a person experiences pain. To suffer is a verb, which means to undergo pain. To use disability in this way is deceiving because having a disability does not mean that a person always suffers from it.

Oliver regards "unaccomodatable environments" as the main cause of disability, rather than the focus on an individual's impairments.⁸ By "unaccomodatable environments", he means that in many instances, unsupportive environments play a crucial role in limiting and causing inabilities in people's lives. Furthermore, competing definitions of disability can lead to confusions. For example, it is difficult in South Africa to teach a culture of inclusion because some people do not regard themselves as disabled.

There are many variations amongst people living with disabilities. Davis Lennard claims that there are two variations for disability: disabilities that are visible and those that are invisible. People with visible disabilities are often made to accept the belief that they are different and inferior to able-bodied persons, whereas people with invisible disabilities tend to deal with their disabilities

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⁶ Michael Oliver. The Politics of Disablement. (United Kingdom: Palgrave: Macmillan, 1990): page number?

⁷ Karen Stone. Awakening to Disability: Nothing about us without us. (United States: Volcano Press, 1997): 9.

⁸ Michael Oliver. *Understanding Disability: From Theory to Practice*. (New York: St Martin's Press, 1996): 23.

unaided, and with arguably greater costs involved because of the stress of not wanting to tell anyone about their disabilities.⁹

Thus, defining disability is a highly complex and contested issue. I think the best working definition is that suggested by Disabled People's International, which advocates that disability "is a loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers." This definition is significant as it focuses on how societies have failed to accommodate people living with disabilities on an equal basis with those who are able-bodied.

My interest in this research topic began when I attended a workshop for students at the University of KwaZulu-Natal's Denison residence on the theme of disability and I was interested to hear about everyday hardships that people experienced living with disabilities. I learned a great deal in the workshop about the injustices and marginalization experienced by students living with disabilities on a daily basis. As a result, I was intrigued to study more about this topic. I was also influenced by the experiences of two male students I knew, who had told me about the negative ways in which some able-bodied people had treated them.

When thinking about a topic for my dissertation, I visited the Association for the Physically Challenged in Pietermaritzburg. I wanted to investigate this Association to see if I could get permission to conduct a research project on the history of this organization, which has been serving physically disabled people for more than 70 years. This dissertation was largely borne out of my

⁹ Merrill Susan. "Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions (review)." *Literature and Medicine* 22 (2003): 116-119.

¹⁰ Diane Driedger. *The last civil rights movement: Disabled Peoples' International*. (London: Hurst & Company, 1989): 39.

desire to try to comprehend the experiences of individuals living with physical impairments, particularly their social experiences during apartheid and through to the contemporary period.

This thesis investigates the lives of individuals who lived with physical disabilities in the regions of Natal and KwaZulu (which today makes up the province of KwaZulu-Natal). My access point to understanding this history was the Association for the Physically Challenged, which was formally known as the Cripple Care Association (CCA). The Natal branch of this Association was formed in 1939 as a private association in Pietermaritzburg. Overtime, this Association expanded its reach to various provinces and was aided by the government who paid for the services of social workers.

Initially, the CCA was formed to help a mainly white clientele with physical (mobility) disabilities to access social services, such as government grants, access to schools, and skills training. In 1964, its concern shifted to provide assistance to Africans too, which resulted in the development of a partnership with the Umlazi Mission Hospital; while from 1970 it included Ematupeni and Zimele (a former police station) Centres, both of which were in KwaMashu. At these facilities, skills training workshops were established, which taught cane working, and leather working skills. In 1993, on the eve of the transition to democracy, the name of this organization was changed to the Association for the Physically Challenged (APC), with the larger city of Durban becoming this organization's provincial head office.¹¹

The aim of this thesis is twofold. Firstly, it analyses the historical development of the CCA/APC as an organization. Secondly, it considers the experiences of people who lived with physical

¹¹ Association for the Physically Challenged Archives (hereafter APC Archives) Durban Provincial Office (hereafter Durban), APC Organizational Pamphlet: Thumb Nail History: Association for the Physically Challenged, 2001.

disabilities, who were members of the CCA/APC. I am particularly interested to analyse the challenges faced by Africans. It will consider their experiences in terms of access to resources; additionally, it will make comparisons in terms of race, class, and gender, as well as explore cultural superstitions and stereotypes regarding disability. The thesis will focus primarily on the apartheid period, but it will also look at the contemporary policies and issues affecting people with disabilities to consider whether significant changes have occurred since the transition to democracy in 1994.

LITERATURE REVIEW

In recent years, there has been an expanded amount of knowledge production on issues of disability internationally. The thematic material analysed by researchers is amazingly wide ranging and includes scope of material on various eras as well. Scholarship has focused on matters such as mental vs. physical challenges experienced by people, birth/genetic vs. injury causes of disability, the issue of caregivers and disability, stereotypes about persons living with disabilities, medicalization of disability, unequal treatment and marginalization of persons with impairments, the representation of people living with disabilities by the media, and disability rights activism, to mention but a few.

A number of scholars from around the world have written on the relationship for some people between physical and mental/emotional challenges. For example, Carol Ryff, and Corey Keyes, researchers in Clinical Psychology in the US, claim that mental/emotional and physical wellbeing are directly related. They argue that depression, for example, can negatively impact a person's

physical health by bringing constant illnesses, and can diminish a person's capacity to take an interest in treatment and recuperation.¹²

Other scholars have done research on injury and birth causes of disability. Robert Reville and Robert Schoeni, writers on social security policy in the USA, claim that many impairments are due to accidents or injuries that are often acquired in different ways from people's work environments. They claim that accidents or injuries related to unguarded machinery, exposed moving machine parts, or exposed electrical outlets have caused disabilities of the musculoskeletal system, but also problems with the heart, as well as the circulatory and respiratory systems. Karl Raimund Popper, an Austrian-British philosopher of science, claims that an injury to the brain or a disorder of the nervous system can hugely affect the body's movements, including that of the limbs and eyes. Sometimes, especially when there is trauma to the brain, motor disabilities of this sort can also be accompanied by mental disabilities.

Many studies have also been done about health problems faced by babies born with disabilities and the difficulties experienced by their parents or caregivers. Isak Kandel and Joav Merick, researchers in psychology, argue that caregivers of children with birth disabilities encounter more noteworthy strain and a greater number of caregiving duties, which can strain parental relationships.¹⁵ These situations can also produce greater feelings of constraint in the lives of one or both parents, and can lead to "higher levels of parental hopelessness" compared to caregivers

¹² Carol Ryff and Corey Keyes. "The structure of psychological well-being revisited." *Journal of personality and Social Psychology* 69 (1995): 719.

¹³ Robert Reville and Robert F. Schoeni. "The fraction of disability caused at work." *Social Security Bulletin Washington* 65 (2004): 31.

¹⁴ Karl Raimund Popper. *Knowledge and the Body-Mind Problem: In Defense of Interaction*. (Oxford: Routledge, 2013): 105.

¹⁵ Isak Kandel and Joav Merrick. "The Birth of a Child with Disability Coping by Parents and Siblings." *The Scientific World Journal*, 5 (2003): 125 and Elaine Carty. "Disability, pregnancy and parenting". In: Alexander J, Levy V, Roch S (eds). *Aspects of Midwifery Practice*. (London: MacMillan; 1995): 48-68.

of children without disabilities.¹⁶ Furthermore, giving assistance that fails to improve the value of the disabled child's life may lead to frustration, impatience, and undesirable health results for the caregiver, whereas successful provision of help that meaningfully addresses the wishes and needs of a patient is uplifting to the caregiver and can produce positive health results.¹⁷

Beatrice Wright, a rehabilitation counselling psychologist, has written on the issue of physical disability in the USA. Wright analyses disability as a social problem where she claims that it is societies that have promoted negative stereotypes about people living with disabilities. These include stereotypes that people with disabilities are different from other people, that they are incomplete or limited people, or that they are an "other" or lesser grouping. Wright also argues that people with disabilities are seen by so-called "able-bodied" people as generally stranded and in need of support to function in their daily lives. Similarly, Sheila Riddell and Nick Watson, researchers from Scotland who work on educational inclusion and diversity, argue that persons with disabilities have often formed their identities based on the negative stereotypes created by "able-bodied people" and placed upon them historically by their societies. Many cultures and religions have also excluded persons with disabilities and have perceived them as "cursed" people. December 20

Regarding the medicalization of disability, Michael Foucault, a French historian and philosopher, traced the development of the medical profession in eighteenth century France and America.

¹⁶ Lyn Quine and Jan Pahl. "Examining the causes of stress in families with severely mentally handicapped children." *British Journal of Social Work* 16 (1985): 508.

¹⁷ Richard Schulz and Paula R. Sherwood. "Physical and mental health effects of family caregiving." *The American Journal of Nursing*. 108 (2008): 23.

¹⁸ Beatrice Wright. *Physical disability - a psychosocial approach*. (New York: Harper Collins, 1983): 179.

¹⁹ Sheila Riddell and Nick Watson. (Eds.). *Disability, culture and identity*. (London: Pearson/Prentice Hall, 2003): 10

²⁰ James Charlton. *Nothing about us without us: Disability oppression and empowerment*. (United State: University of California Press, 1998): 22.

Foucault argued that this led to the development of a strong medicalized "gaze" (like the prison's panopticon) on patients, on how the body, but also in time the mind, became something to be observed and mapped for science.²¹ He shows how doctors assumed a key part in identifying and labelling the "abnormality" of certain people. Foucault claimed that the biomedical discipline was a vital actor influencing who was allowed full engagement in society and who was sidelined.

What is more, doctors had the power to intervene in the lives of people they helped label as abnormal.²² This is captured well in the work of Sharon Synders and David Mitchell. For these authors the institutions in which people living with disabilities were deposited were "part of the modernist project of categorizing difference and disability as abnormality and then make an effort to isolate the disabled so as not to obstruct the functioning of the normal state."²³ They also claimed that disability was an instrument for classifying human body differences which arose in the nineteenth century when people came to be "differentiated by industrialized labour practices within a capitalist system".²⁴

Continuing with the medicalization theme, Lenard Davis a US scholar with an interest in disability, argues that societies that assign medical meanings to disability produce low expectations for people, which can lead to people's loss of independence in their lives.²⁵ This means that people living with disabilities are often measured by their appearance, which can create doubts and hesitation to provide meaningful opportunities for people with disabilities. Ivan Illich, an educational philosopher, also argues that the medicalization of societies has created limitations for people living with disabilities. He asserts that these societies are only concerned about the

²¹ Michel Foucault. *The birth of the clinic*. (United Kingdom: Routledge, 2012): 32.

²² Foucault. *The birth of the clinic:* 45

²³ Sharon Snyder and David T. Mitchell. Cultural locations of disability. (University of Chicago Press, 2010): 10.

²⁴ Snyder and Mitchell. Cultural Locations of disability: 23.

²⁵ Lenard J. Davis. *The Disability Studies Reader*. (London: Routledge, 2006): 9.

assumption that disabilities arise from bodily faults within a person instead of the obstructiveness of an insensitive environment or surroundings. In addition, he argues that the medicalized view of disability tends to only focus on the incapacities or restrictions of persons and is not concerned enough about adjusting the social environment to make everyone acceptable without restrictions.²⁶

Regarding scholarship on issues of unequal treatment and marginalization of people with disabilities, Simi Linton, a US scholar with an interest in disability studies, argues that the perspectives of such people have often been ignored in favour of the perspectives of able-bodied people.²⁷ She maintains that able-bodied people have viewed individuals with impairments as "unfortunate" in light of the fact that the latter have had "cramped existences".²⁸ This includes being deprived of things such as opportunities to develop as independent human beings, or to move freely.²⁹ This assumption is dominant in our societies because they confuse a person's condition with their identity. This has produced a widespread belief that people living with disabilities are incapable of helping themselves.³⁰

Thomas Earl Backer and Elizabeth Howard, US researchers in psychology, claim that homeless people in America, for example, are often at greater risk for trauma, which may either cause or aggravate mental or physical disabilities. They argue that 32 percent of homeless people in their research reported being physically attacked while destitute.³¹ People with disabilities, especially those on crutches or in wheelchairs, are particularly easy targets for criminals. In addition,

²⁶ Ivan Illich. "Medical nemesis." *Journal of Epidemiology and Community Health* 57 (2003): 919-922.

²⁷ Simi Linton. "Disability Studies/Not Disability Studies," *Disability & Society*, 4 (1998): 525-539.

²⁸ Linton. "Disability Studies/Not Disability Studies": 527.

²⁹ Linton. "Disability Studies/Not Disability Studies": 532.

³⁰ Wright. *Physical Disability:* 162.

³¹ Thomas Earl Backer and Elizabeth Howard. "Cognitive Impairments and the Prevention of Homelessness: Research and Practice Review." *The Journal of Primary Prevention* 28 (2007): 375-388.

substance abuse or mental illness may increase their exposure to trauma and interfere with their treatment of coexisting illnesses.³²

Danette Crawford and Joan Ostrove, as well as Collin Barnes, all research experts on the issue of gender and disability have focused on the stigmatizing representation of people, especially women with disabilities in the media in United States. They show that the media has historically limited understanding of serious issues affecting disabled individuals. This has meant that people living with disabilities, when presented in the popular media, have often been presented as socially inferior people, not as people with a disability who also have their own identities.³³ Barnes also claims that disability is a marginalized position to occupy in contemporary society, and that persons with disabilities are often described in negative and offensive language. ³⁴

What is worse, racial inequalities have also produced inequalities. Researchers Gerard Goggin and Christopher Newell, who work on media and disability in Australia, have shown how aboriginal Australians have received less media coverage and support in terms of resource distribution historically by Australian governments than Australians with European ancestry.³⁵

Other international research has focused on rights activism for people with disabilities. J.V Switzer, a US- based political scientist has explored the exclusion of people with disabilities, which led to the formation, at the time of the broader Civil Rights Movement, of the Disability Rights Movement in the USA from the 1960s. During this period, disability advocates saw a

³² Backer and Howard. "Cognitive Impairments and the Prevention of Homelessness": 302.

³³ Danette Crawford and Joan Ostrove. "Representations of disability and the interpersonal relationships of women with disabilities." *Women & Therapy* 26 (2003): 182.

³⁴ Collin Barnes. "Media guidelines". *In*: A. Pointon and C. Davies. (eds.) (1997) *Framed: Interrogating Disability in the Media*. (London: British Film industry, 1999): 66 and Paul Darke. "The changing face of representations of disability in the media." *Disabling Barriers-Enabling Environments* 12 (2004): 100-105.

³⁵ Gerard Goggin and Christopher Newell. *Disability in Australia: Exposing a Social Apartheid*. (Australia: UNSW Press, 2005).

chance to assemble with other minority groups, to call for equal rights, opportunity and freedom of choice for persons with disabilities.³⁶

Andrea Califano, a researcher on disabilities in the USA has also examined important shifts in US history with the promulgation of the Education of All Handicapped Children's Act of 1975.³⁷ This sought to produce a greater degree of educational opportunities for disabled children and was widely celebrated as a pivotal expansion of the rights of Americans living with disabilities.³⁸ Anna Lawson and Caroline Gooding, experts on issues of disability equality and human rights in Europe, argue that in Europe, organizations for disabled people, such as the European Disability Forum, and the Confederation of Persons with Disabilities have played vital roles in championing and advocating for legislative transformation and development of policies to improve the lives of people living with disabilities.³⁹

Julie Livingston, a medical historian, explores African understandings of disability in which she discusses the cultural superstitions and stereotypes that have been generated around disability in Africa. She also dwells on "how historical forces and cultural contexts have produced disability as a constantly shifting and socially constructed concept." ⁴⁰ For example, she explains that disability, in Southern Botswana is measured not in relation to "body normality" but by the

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³⁶ Jacqueline Vaughn Switzer. *Disabled Rights: American Disability Policy and the Fight for Equality*. (Washington, D.C.: Georgetown University Press, 2003): 42.

³⁷ Hahn Harlan. "Disability and Rehabilitation Policy: Is Paternalistic Neglect Really Benign?" *Public Administrative Review* 73 (July-August, 1982): 385-389.

³⁸ Andrea Califano. *Governing America: An Insider's Report from the White House and the Cabinet* (New York: Simon and Schuster, 1981): 65.

³⁹ Anna Lawson. "The EU rights based approach to disability: Strategies for shaping an inclusive society." *International Journal of Discrimination and the Law* 6 (2005): 272.

⁴⁰ Julie Livingston. "Insights from an African History of Disability," *Radical History Review*, Special Issue on Disability and History 94 (2006): 118.

number of friends and community members that a person has. ⁴¹ Persons with disabilities were sidelined because they found it difficult to make friends with people in their communities. ⁴²

In addition, cultural anthropologists, such as Jane Hubert, have focused on the issue of inclusion and exclusion of individuals with mental and physical impairments in various societies in Africa. Hubert has argued that the "disabled are not inevitably excluded since different cultures interpret different phenomena as abnormal, different or dangerous." In Zulu culture, disability is commonly regarded as a result of punishment by ancestors. He This means that Zulu culture has influenced people to exclude persons with disabilities. Similarly, Theresa Abang, an academic in the Faculty of Education in Nigeria, found that in Nigeria the causes of disability were widely believed to be supernatural in origin. This meant that persons with disabilities and their families consulted "traditional healers" or diviners because it was believed that their mental or physical disabilities were the result of "witchcraft." These scholars show that in Africa cultural superstitions have contributed extensively to the isolation of people with disabilities.

In recent years, various academic works have been composed on disability in South Africa as well. Oral history experts have contributed a great deal. For example, Radikobo Ntsimane, an oral history practitioner, has looked at the importance of oral history in understanding the experiences of people living with disabilities in South Africa.⁴⁶ Philippe Denis, another oral history specialist

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⁴¹ Livingston. "Insights from an African History of Disability": 114.

⁴² Livingston. "Insights from an African History of Disability": 120.

⁴³ Jane Hubert (ed). *Madness, disability and social exclusion: The Archaeology and Anthropology of difference*. (London: Routledge, 2013): 198.

⁴⁴ Tanya Crawford and Maurice Lipsedge. "Seeking help for psychological distress: The interface of Zulu traditional healing and Western biomedicine." *Mental Health, Religion & Culture* 7 (2004): 139.

⁴⁵ Theresa B. Abang. "Disablement, disability and the Nigerian society." *Disability, Handicap & Society.* 3 (1988): 73.

⁴⁶ Radikobo Ntsimane. *Do stories of people with disabilities matter? Exploration of a method to acknowledge the stories of people with disabilities as valuable oral sources in the writing of social history.* (Pietermaritzburg: University of KwaZulu Press, 2012).

and religion scholar, concurs. He argues that oral history experts have been crucial, as "they have brought the voices of the ordinary working men and women to the centre," and have engaged in "awareness campaigns to know and interact with people with disabilities."

Other South Africans have also contributed to the disability literature. A particular interest has been the gap in terms of resource distribution amongst people living with disabilities. Scholars such as Brian Watermeyer have argued that black South Africans living with disabilities during the end of 1990s experienced the worst service delivery compared to whites living with disabilities. Furthermore, Jacqui Couper has analysed how the lack of access to health and welfare has contributed largely to difficulties experienced by disabled African children in rural KwaZulu-Natal. 49

Concerning employment opportunities in South Africa, Andrew Dube, a legal expert with an interest in disability, argues that people with disabilities continue to find themselves at the lowest level of employment. For this circumstance to change, Dube argues that there is a need for greater monitoring and greater attention to empowerment strategies, to guarantee that such individuals are promoted into positions that are more senior.⁵⁰

Julie Parle, a medical historian in South Africa, analyses the role of asylums by the Natal colonial government in controlling those suffering from mental impairments and other mental health issues. Parle suggests that the asylum was the last resort for most people in colonial Natal during

⁴⁷ Philippe Denis. "Introduction" in P. Denis (ed.), *Orality, memory and the past: listening to the voices of black clergy under colonialism and apartheid.* (Pietermaritzburg: Cluster Publications, 2000): 22.

⁴⁸ Brian Watermeyer. *Disability and social change: A South African agenda*. (Pretoria: HSRC Press, 2006).

⁴⁹ Jacqui Couper. "Prevalence of childhood disability in rural KwaZulu-Natal." *South African Medical Journal* 93 (2002): 547-549.

⁵⁰ Andrew K. Dube. *The role and effectiveness of disability legislation in South Africa*. (East London: Samaita Consultancy and Programme Design, 2005): 33.

the 1800s, because of the warehouse or jail type of connotations that these institution conjured up for people trying to find help and care for their loved ones. Thus, a wide range of various cures, for example, natural mixtures, "traditional" therapies, home remedies, and nursing, to name just a few, were tried over the years as a means to provide relief and/or to heal persons living with mental impairments.⁵¹

Other scholars, such as Peter Rule and Toadi Ruth Modipa, adult education researchers, have also contributed to the literature on South Africa. They conducted a study on learners living with physical disabilities in KwaZulu-Natal in 2008. In their study, they examined the issue of dropout rates in schools and found that some parents hide their disabled children at home because they felt ashamed of them.⁵² They argued that stereotypes in South Africa have led to the confinement of children with disabilities and denied them quality education.

Building on this rich and diverse international and South African scholarship, my research will explore the social experiences of people who lived with disabilities during the apartheid period, but with a focus on those who belonged to the Cripple Care Association (CCA). Although a few scholars mentioned in the previous paragraphs have focused on South Africa or the KwaZulu-Natal area, they have not focused specifically on the experiences of people associated with the CCA, nor elaborated extensively on the delivery of services to people living with disabilities from the period of the 1970s to the era of the democratic government. By using the archival records of this Association, as well as oral histories of people who worked and belonged to this Association, I will explore what experiences people who lived with physical impairments had in the province

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⁵¹ Julie Parle. *States of Mind: Searching for Mental Health in Natal and Zululand, 1868-1918.* (Pietermaritzburg: University of KwaZulu-Natal Press, 2007): 115.

⁵² Peter Rule and Taadi Ruth Modipa. "We Must Believe in Ourselves" Attitudes and Experiences of Adult Learners with Disabilities in KwaZulu-Natal, South Africa." *Adult Education Quarterly* 62 (2012): 142.

of Natal and in the KwaZulu Bantustan during the apartheid years, as well as the renamed and merged province of KwaZulu-Natal in the post-apartheid period.

THEORETICAL FRAMEWORK

The writing of history before the 1960s was noticeably dominated by the events of elites, as well as political and military matters. Leftist leaning popular struggles in the 1950s and 1960s led to the transformation in the minds of academics. With the emergence of social history in this era, there was much eagerness to study socio-economic affairs, as well as the lives of ordinary people and those side-lined who were usually disregarded in terms of playing an active role in history.

Thus this study is guided by the broader framework of social history. The main reason for choosing this theory is to help me analyse the experiences of less well-known people, especially those who were socially marginalized, such as people living with disabilities. British Marxist social historian, E.P. Thompson, examined society at a more extensive level moving the concentration away from elites.⁵³ To attain these voices, Thompson used a wide assortment of unofficial sources, for example, letters, journal entries, poetry, songs, and so on to expand his source base. According to Jim Sharpe, who has summarized key scholarly trends in social history, "history from below" is the model that tries to examine the history of people which were not viewed by prior leading scholars as important in historical writings.⁵⁴ Another key social historian, Miles Fairburn describes social history as the "history of the people", where scholars try to accommodate them as "agents" of historical change."⁵⁵ Geoff Eley has argued that social historians were disgruntled

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⁵³ Edward Palmer Thompson. *The Making of the English Working Class*. (Harmondsworth, Penguin, 1968).

⁵⁴ James Sharpe. "History from Below", in Peter Burke (ed.) *New Perspectives on Historical Writing*, (Cambridge: Polity Press, 1991): 63.

⁵⁵ Miles Fairburn. Social History: Problems, Strategies and Methods. (Basingstoke: Macmillan, 1999): 109.

with the concern with large structural determinants on their subjects' lives and took the initiative to write history from the ordinary person's point of view. This enabled these scholars to highlight ordinary people's struggles but also achievements, and to depict them as agents making their own history. ⁵⁶ Similarly, this study looks at the experiences of a marginalized group of people; those who have lived with and continue to live with physical disabilities.

This thesis will draw on major race theorists too. I am particularly interested to explore the experiences of African people with physical disabilities because, like able-bodied Africans in South Africa, they did not have equal opportunities or access to the same kind of resources compared to whites during apartheid.⁵⁷ International race theorists, such as Frank Dikötter and David Roediger, help us see that classifying people based on their physical characteristics, such as "race" has no scientific footing yet this imagining has real effects. Furthermore, race cannot be separated from identity and class.⁵⁸

Key race theorists, such as Deborah Posel, Dan O'Meara, Merle Lipton and Saul Dubow have written about South African history. They hold that apartheid laws in South Africa were the result of active efforts made by the state to restructure the country on the basis of race and class which assumed a vital role in distributing resources unequally between its black and white citizens. Indeed, in the South African context, they have argued that race has overlapped with class in pivotal ways, which has been a determining factor of inequalities.⁵⁹ Irrespective of their variable

⁵⁶ Geoff Eley. A Crooked Line: From Cultural History to the History of Society. (Ann Arbor: University of Michigan Press, 2005): 91.

⁵⁷ Aran MacKinnon. "Africans and the myth of rural retirement in South Africa, ca 1900–1950." *Journal of cross Cultural Gerontology* 23 (2008): 169.

⁵⁸ Frank Dikötter. *The Discourse of Race in Modern China*. (California: Stanford University Press, 1992): 44 and David Roediger. *The Wages of Whiteness: Race and the Making of the American Working Class*. (Tennessee: Verso, 1999): 23.

⁵⁹ Deborah Posel. "Rethinking the 'Race-Class Debate 'in South African Historiography." *Social Dynamics* 9 (1983): 66.

class upbringings, racial inequalities routinely determined the positions of black South Africans as second-class citizens in the country of their birth, obstructed their efforts to better themselves through equal opportunities, and provided unequal access to resources.⁶⁰ In South Africa during apartheid, Africans living with disabilities occupied an even more marginalized position because of their disabilities.

The study will also draw on the works of key gender theory scholars to unpack the lives of people living with disabilities. J.W. Scott, a US feminist historian, has discussed how until the 1960s women's experiences and opinions had been deliberately left out of official historical accounts and rendered invisible. This was done by men who were dominant as actors and recorders of history. According to Rosemarie Garland-Thomson, a feminist scholar specialising in disability studies, historically, people have tended to be defined in a universalising manner using adult male characteristics of independence, ability, and strength. However, those who have not met these criteria, such as women and people with disabilities have been seen as less able, weak, and dependent. This has led to their marginalisation in their societies.

Thomas Gerschick a professor in Gender Studies, argues that the heterosexism that females confront in a male-dominated society can be compared to the battle fought amongst disabled persons in an "able-ist" society; both situations reflect an unequal power differential.⁶³ Eli Clare,

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⁶⁰ Deborah Posel. *The Making of Apartheid, 1948-1961: Conflict and Compromise.* (USA: Oxford University Press, 1991), Merle Lipton. *Capitalism and Apartheid: South Africa, 1910-1986.* (Cape Town: New Africa Books, 1986), Dan O'Meara. "The 1946 African mine workers' strike and the political economy of South Africa." *Journal of Commonwealth & Comparative Politics, 2* (1975): 146-173 and Saul Dubow. *Scientific Racism in Modern South Africa.* (Cambridge: Cambridge University Press, 1995).

⁶¹ Joan Wallach Scott, ''The Problem of Invisibility'' in S.J. Kleinberg (ed.), *Retrieving Women's History*, (New York: Berg Publishers Ltd, 1988): 17.

⁶² Rosemarie Garland-Thomson. "Integrating disability, transforming feminist theory." *NWSA journal* 14.3 (2002): 26

⁶³ Thomas Gerschick. "Toward a theory of disability and gender." *Signs: Journal of women in culture and society* 25 (2000): 1265.

a poet and researcher of disability issues in the United States, also connects this marginalization to the hegemonic influence of white supremacy, patriarchy, and capitalism on society's view of the disabled body.⁶⁴ Thus, people who are not white, women, and those who come from lower socio-economic classes, have faced greater difficulties in their lives.

The theoretical work focused on intersectionality will be key here too. Bell Hooks, Kimberle Crenshaw, Patricia Hill Collins and Evelyn Brooks Higginbotham, all US race and gender scholars argue that the experiences of black women cannot be understood solely on being black. According to Crenshaw "the concept of intersectionality highlights the fact that women of colour are situated within at least two subordinated groups that frequently pursue conflicting agendas." ⁶⁵ Indeed, African-American problems were compounded because of intersecting or overlapping oppressions of race, gender and class that led to various forms of social discriminations, housing inequalities and poverty. Brooks-Higginbotham, Bell Hooks and Patricia Collins claim that women have experienced "interlocking" forms of oppression that have negatively affected their lives. ⁶⁶ This is also the case in this research in which women with disabilities experiences a variety of oppressions. ⁶⁷

Lastly, I have also drawn on oral history theories and methods to write this thesis. This method became a significant research tool for historians in the 1950s and 1960s, especially for social historians. Like social history, oral history is a theoretical approach that has tried to get at the

⁶⁴ Eli Clare. "Stolen bodies, reclaimed bodies: Disability and queerness." *Public Culture* 13 (2001): 360.

⁶⁵ Kimberle Crenshaw. "Mapping the margins: Intersectionality, identity politics, and violence against women of colour." *Stanford Law Review*, 3 (1991): 1255.

⁶⁶ Evelyn Brooks Higginbotham. "African-American women's history and the metalanguage of race." *Signs* 2 (1992): 274; Bell Hooks, "Black Women: Shaping Feminist Theory" in K. Bhavani (ed.), *Feminism and Race*, (New York: Oxford University Press, 2001) and Patricia Hill Collins. *Black Feminist Thought: Knowledge*, *Consciousness, and the Politics of Empowerment*. (United Kingdom: Routledge, 2002).

⁶⁷ Tony Emmett and Erna Alant. "Women and Disability: Exploring the Interface of Multiple Disadvantage." *Development Southern Africa* 23 (2006): 445-460.

voices of marginalized people, using interviews as its primary method. Oral history can be used in order to increase knowledge of the lives and experiences of individuals with impairments and other subordinate groups of people that have not usually been the focus of historical accounts.

Italian oral history scholar, Alessandro Portelli asserts that oral history is useful as it provides primary research data involving people's personal experiences. ⁶⁸ Paul Thompson, a British sociologist and oral historian, has written extensively on the development of life stories and oral history. ⁶⁹ However, he claims that interviewers must be alert to "the problem of bias, contradiction and interpretation in evidence". ⁷⁰ Thus it is essential to remain critically aware of oral sources when writing history. Ronald Grele also argues that spoken words as evidence are sometimes unreliable and they need to be interrogated carefully like written sources. ⁷¹ Oral interviews are sometimes open to exaggeration and there is also the problem of memory loss overtime. There are also often agendas or motives involved which emerge from the side of the interviewer and/or interviewee. ⁷²

Although one needs to be critical when using oral sources, and aware of its problems, they are still valuable for the historian to use. Oral sources are essential particularly in this study because they bring to the fore the experiences of people living with disabilities and it also allows individuals to express what is of value to them. In addition, it is vital to acknowledge that oral interviews are significant in filling the gaps of the archives because it is necessary to remember that ordinary

⁶⁸ Alessandro Porteli. What makes Oral History Different? In: Robert Perks and Alistair Thomson. (eds). *The oral history reader*. (United Kingdom: Routledge, 1998): 68.

⁶⁹ Paul Thompson, *Voice of the past: Oral history*. (Oxford: Oxford University Press, 2000).

⁷⁰ Thompson, *Voice of the past: Oral history:* 25.

⁷¹ Ronald J Grele. *Envelopes of Sound: The Art of Oral History*. (Chicago: Precedent Publishing, 1975): 197.

⁷² Alessandro Portelli. *The Death of Luigi Trastulli and Other Stories*. (Albany: State University of New York Press, 1991): 82 and Lisa Klopfer. "Oral History and Archives in the New South Africa: Methodological Issues." *Archivaria*, 1 (2001): 22.

people were not often officially recorded in the archives. The oral interviews capture experiences of ordinary, illiterate and marginalized people. Oral interviews are crucial as they "tell us not just what people did but what they intended to do, what they believed they were doing and what they now think they did". This implies that the past and present are associated in these oral interview encounters. Donald Ritchie contends that "oral history is fundamental to our comprehension of the way of life and encounters of the past."

South African historian, Charles van Onselen, calls for researchers to use a variety of sources, both oral and archival, to comprehend fully any historical issue.⁷⁵ According to van Onselen oral testimonies and written sources are crucial because they both assist in "the process of contextualization and verification."⁷⁶ This is the approach that I have used in this study.

METHODOLOGY AND SOURCES

Qualitative research looks at deeper meanings and understandings of lived experiences. Unlike quantitative research that collects and examines statistical data trends, qualitative research tries to engage with, at a more in-depth or detailed level, the complexity of people's lived experiences. Qualitative research does not aim to be representative with careful sampling procedures, as is the case of quantitative research. The outcomes of qualitative enquiry are descriptive rather than predictive. It usually uses interviews and questionnaires as a method of collecting data on a one-on-one basis or in focus group interview situations. I have used a qualitative study approach with a blend of both archival and oral sources, and also secondary sources. This approach provides a

⁷³ Portelli. "What Makes Oral History Different?" 70.

⁷⁴ Donald Ritchie, *Doing Oral History*. (New York: Oxford University Press, 2003): 32.

⁷⁵ Charles Van Onselen. "The Reconstruction of a Rural Life from Oral Testimony: Critical Notes on the Methodology Employed in the Study of a Black South African Sharecropper," *The Journal of Peasant Studies*, 20, 3, (April 1993): 494-514.

⁷⁶ Van Onselen. "The Reconstruction of a Rural Life from Oral Testimony": 496.

deeper understanding of how people with physical disabilities experienced life under apartheid in South Africa, as well as into the post-apartheid period.

The archival materials consulted for this thesis have been used in conjunction with oral interviews that were conducted with both staff members and clients who belonged to the CCA/APC. The archival records are housed in a room at the APC's provincial headquarters in Durban. The CCA/APC archival material is vast because it covers the period from 1960 up until the 2000s. This archive is made up of files and boxes of minutes of meetings, workshop reports, correspondence, and organizational booklets. I was able to go through all of this institution's available archival material (up to and including the early 2000s) to write this thesis.

It is essential to state that the APC does not have systematically organized archival materials. As a result, many of my archival references lack a specific box or file number. Most of this organization's records are packed in boxes without an organized filing system, which makes it more difficult for the researcher to use. What did assist me was that most documents were kept in date order in the files or boxes, which helped me to establish a chronological narrative when I went through the various documents. The Provincial Director, Lesley Dietrich told me that the Association hopes to properly catalogue and -preserve their archival documents in the near future.

I have also used newspapers articles concerning disability found at Association for the Physically Challenged. These include the *Natal Mercury* and *The Witness*. With respect to the chapter covering more recent developments, I have used publicly accessible online government documents. These include White Papers, which look at interventions made by the democratic government between 1994 and 2016 and highlight the change of policies related to disability in South Africa.

Furthermore, I have conducted several interviews (18 in total) to gather data for my thesis. Gatekeeper permission was obtained from the APC's provincial director, Lesley Dietrich, to use this organization's archival records, to speak to employees, including social workers, and to interview some of the APC's clients to gather different views on the experiences of people who have lived with physical disabilities in KwaZulu-Natal.

In terms of my interviews firstly, I did a face-to-face interview with the provincial director, who has been at the organization for more than 15 years. I was able to interview approximately 17 clients of the APC, made up of a mix of men and women of different ages (some of whom were around during the apartheid era, but also the post-apartheid period). All the clients interviewed were Africans from poor socio-economic backgrounds and people with different physical disabilities who have belonged to and/or still belong to the CCA/APC. I met all the interviewees as per their request, at the APC Sherwood branch in Durban at times convenient to them during 2016.

I managed to access these interviewees through the assistance of Dianne Mariah-Singh, a senior social worker at APC. After I explained the nature of my study to her, she then explained my study to other branch social workers who then told their APC clients about it. Only a small number of clients expressed an interest in participating in my study and Dianne helped me organise the interviews. As a result, I was not able to interview people from a range of different ethnic and race backgrounds because although people from various backgrounds were told about my project, few wanted to participate. This has restricted my insights in this thesis. I could not make larger claims about trends because the sample of interviews I have done is small and my interviewees are limited to Africans living in KwaZulu-Natal.

Informed consent letters were obtained from all my interview participants. All the interviews were conducted in IsiZulu to accommodate the participant's language choices. The interviews were semi structured in nature to allow for certain focused questions to be asked as well as more openended discussion of issues that came up during the interviews. Finally, although written permission was obtained from participants to use their names in this research, I have used one pseudonym and that is Ntokozo Mkhize, because this person did not want her name used.

STRUCTURE OF DISSERTATION

The primary point of this study is to consider the history of persons living with physical disabilities, not those with mental disabilities because the APC only catered for people with physical disabilities, which is the main access point of this study. It looks at their experiences in terms of race, access to resources, and gender, and explores cultural superstitions and stereotypes regarding disability from the apartheid era up to the 2000s. In order to accomplish the aforementioned objectives, after this introduction chapter (Chapter One), this thesis is partitioned into five chapters and a conclusion.

Chapter Two looks at the broader background or context (drawing primarily on secondary literature). It provides an overview of the history of service provision for people who lived with physical disabilities (all races) in South Africa before the Cripple Care Association was formed in 1939. It also analyses negative stereotypes that were generated about people with disabilities, as well as cruelty and unequal treatment experienced by such people.

Chapter Three examine the history of the formation and work of the CCA/APC. It looks at why it was formed, when was it formed, what type of organization it was (private vs. public), how big it was (single province, multi provinces), what work it did, its clients, its activities and programmes

to support people who lived with disabilities. Before the 1960s, the CCA played a significant role in catering for white people with physical disabilities but in the 1960s, it shifted its concern to helping black clients too, including African clients. This chapter includes the perspectives of the Provincial Director of this Association, as well as uses archival documents. This chapter uses both archival and oral sources to outline the major objectives of the CCA. It considers the work it did for its clients who lived in Natal and areas within the KwaZulu Bantustans, and considers the 1939 to 1970s period.

In the fourth chapter, I analysed the experiences of people with physical disabilities who belonged to this Association during the latter apartheid years. The main aim of the chapter is to investigate the social experiences of individuals with physical disabilities in the Natal province and KwaZulu from the 1970s to the 1980s, looking at their experiences of and difficulties accessing resources.

The fifth chapter looks at the role played by the democratic government and its disability policies from the 1990s to the 2000s. The primary aim of this chapter is explore the role played by South African disability activists and the change of policies that took place under the new government. This chapter also looks at organizational developments related to the APC (which was renamed) in the post-apartheid period.

The sixth chapter seeks to expand upon the themes raised in the fourth chapter by moving beyond the policies and the Association's organizational history to investigate the social experiences of people with physical disabilities in the post-apartheid period. The central objective of this chapter is to consider whether there has been a shift over time in terms of distributing and use of resources between the apartheid and the post-apartheid periods in the KZN region.

Lastly, the conclusion chapter will sum up fundamental themes and points of argument that have been discussed in this thesis.

CHAPTER TWO

The History of People with Disabilities in South Africa before 1939.

In the past there would have been many people living with various mental and physical disabilities. These disabilities would have been something they had either been born with or had developed as a result of injury or illness. Little was known about such persons in South Africa, as there are not many books written about their lives and challenges. Although it is difficult to trace in any comprehensive manner the history of people who lived with impairments in South Africa in the early twentieth century, it is not impossible. Often researchers must draw on secondary sources that do not deal with disability directly, but focus on other issues, and mention the issues of mental or physical disabilities as a secondary consideration.

This chapter seeks to provide some background and contextual material. It draws on secondary literature to consider the history of service provision for people who lived with disabilities in South Africa before the Cripple Care Association was formed in 1939. It also considers the negative stereotypes that circulated about people living with disabilities, and the cruelty that occurred as a result.

South Africa's history is infused with discrimination based on race, class and gender.⁷⁷ Looking back over 200 years, the colonial state and later segregationist and apartheid state's infrastructures were shaped by violent suppressions of native people, seizure of their lands and resources, and the

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⁷⁷ Heather Deegan. *Politics South Africa*. (London: Routledge, 2014): 7.

practice of unfair laws, that forced Africans to work for small wages to generate prosperity for the country's white minority.⁷⁸

Early Zulu Views and Treatment of People Living with Disabilities

Culture has shaped perceptions of disability in South Africa. In isiZulu-speaking communities, people who lived with disabilities have been referred to historically as *Izidalwa*. In English, this meant "a person who was deformed by nature". This term implied a person who could not do anything because of his or her condition. The association of the body and ability in Zulu societies was common which resulted in the creation of negative cultural stereotypes about people living with physical or mental challenges.

In Zulu societies before colonization, Kevin Washington has argued that men were dominant actors in the patriarchal household. ⁸⁰ For many – though not all isiZulu-speaking men – this dominance was determined by having cattle, a household, many wives and children so that in turn a man would be respected by his peers. Men living with disabilities were regarded as the opposite of this norm. This was particularly the case for those men who could not attract wives or build large households. They were regarded as people who did not have means or power to succeed in their societies, so they were regarded as outcasts and given names to exclude them because they were seen as weak or powerless. ⁸¹

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⁷⁸ Gillian Burke and Peter Richardson. "The profits of death: a comparative study of miners' phthisis in Cornwall and the Transvaal, 1876–1918." *Journal of Southern African Studies* 4 (1978): 168.

⁷⁹ Michael Eskayl. "Disability within the African culture." *Contemporary Voices from the Margin: African Educators on African and American Education* 12 (2012): 203.

⁸⁰ Kevin Washington. "Zulu traditional healing, Afrikan worldview and the practice of Ubuntu: Deep thought for Afrikan/Black psychology." *The Journal of Pan African Studies* 4 (2010): 28.

⁸¹ Ken Lipenga. "Disability and masculinity in South African autosomatography." *African Journal of Disability* 3 (2014): 9.

Many Zulu women experienced oppression because of the dominance of men in their households. Bell Hooks argues that black women were regularly at the lowermost end of the "social ladder" compared to men and amongst females of other races. Historically, Zulu women were viewed as subordinate to men and their primary responsibilities, for which they were valued, were playing the roles of mothers, wives and crop growers. Women who could not attract a husband, could not have children, and could not do agricultural work, were not regarded as "real" women. This is significant because it shows the oppression that was experienced by isiZulu-speaking women with disabilities because the perception in society was that they were failing to fulfil the expected duties that able-bodied women had to fulfil.

Furthermore, in some Zulu families, people felt ashamed about having disabled members in their families and as a result they forced them to live and spend their days hidden within the confines of their homes, and discouraged them from socializing and engaging in public interactions with the rest of their communities. Some families also treated disabled family members cruelly, which included beatings, food deprivations, and squalid living conditions. This was coupled with offensive name calling, such as *isinqeke*, when translated means "a person who cannot walk".⁸⁵

Although some people believed that disabilities were caused by natural or biological causes, respect for ancestors played a vital role in Zulu life and influenced many people's beliefs. These individuals believed that ancestors guided proceedings on earth, according to Zulu tradition. People valued their ancestors to obtain defence and ward off malicious spirits. Those following Zulu cultural tradition regarded the ancestors as intermediaries between the living and the spiritual

⁸² Bell Hooks. "Black women: shaping feminist theory." Revista Brasileira de Ciência Política 16 (2015): 196.

⁸³ Cherryl Walker. "Women, tradition and reconstruction." Review of African Political Economy 22 (1994): 348.

⁸⁴ Walker. "Women, tradition and reconstruction": 349.

⁸⁵ Patrick Devlieger. "Why disabled? The cultural understanding of physical disability in an African society." *Disability and Culture* 4 (1995): 98.

realm. They spoke to the ancestors rather than to God directly through the burning of incense. The ancestors then asked God to comfort the people during hard times. ⁸⁶ Patrick Devlieger, an assistant professor in the Department of Disability and Human Development at the University of Illinois in Chicago has argued that relatives were, according to the Zulu culture, forbidden from dating, as this could lead to a negative impact on their children. He has argued that isiZulu-speaking people believed that such illicit unions were taboo and would result in children born with disabilities, because they had angered their ancestors. ⁸⁷

"Traditional healers" played an important role in treating persons with disabilities in isiZuluspeaking communities. Historically, these healers provided services including the administration
of rituals and recommendations of specific herbal remedies for various afflictions. This was also
applicable to persons with disabilities and their families worked with traditional healers to ask
their ancestors to forgive them for what they regarded as sins they might have committed. For
those who believed that a disability was caused by their ancestors, the healing process involved
slaughtering a goat, which was regarded as a symbol of sacrifice to ask their ancestors for
forgiveness and to cleanse away any wrong deeds. 88 Harriet Ngubane argues that often, the
"disorders and diseases of African people are based on Zulu cosmology and this means that their
interpretation is bound up with African ways of viewing health and diseases." 90 Course,
although these traditional healing processes were used in an attempt to end the "dis-ease" faced

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⁸⁶ Harriet Ngubane. *Body and mind in Zulu medicine*. *An ethnography of health and disease in Nyuswa-Zulu thought and practice*. (London: Academic Press Inc., 1977): 41.

⁸⁷ Devlieger. "Why disabled? The cultural understanding of physical disability in an African society": 98.

⁸⁸ Roy Moodley, Patsy Sutherland, and Olga Oulanova. "Traditional healing, the body and mind in psychotherapy." *Counselling Psychology Quarterly* 21 (2008): 156.

⁸⁹ Ngubane. Body and mind in Zulu medicine: 46.

by a family or their disabled loved one, most people living with physical disabilities were not cured through traditional or other healing methods.

Colonial Era: Mining and Disability in South Africa

During the colonial period, African communities were introduced to new capitalist enterprises, which led to physical impairments because of dangers that accompanied these businesses. An important area where we come across persons with disabilities is in the mining sector, after the discovery of gold and diamonds in the second half of the nineteenth century in Johannesburg and Kimberley. During this period, the discovery of mineral wealth in South Africa attracted the growth of towns and later larger cities in the vicinity of the mining areas, and the migration of people, including Africans to these towns and cities to find work. Some people became physically disabled working for the mining sector in their efforts to make money to sustain themselves and their families. Poverty was one of the major influences that led people to work in the mining sector. A combination of coercive legislation, taxes, and restrictions to land access directed many African men into mines as labourers, which provided a breeding ground for poverty and ill health. The mining sector became a major employer of African men because white capitalists wanted unskilled cheap black labourers. They also wanted physically strong men to do the hard manual labour needed.

⁹⁰ Martin Meredith. *Diamonds, gold, and war: The British, the Boers, and the making of South Africa*. (Johannesburg: Public Affairs, 2008): 36.

⁹¹ Cornelius William. A history of South Africa. (Oxford University Press, 1978): 28.

⁹² Hoosen Coovadia. "The health and health system of South Africa: historical roots of current public health challenges." *The Lancet* 374 (2009): 822.

However, mining provided a dangerous and unhealthy work environment for Africans that jeopardized the lives of many. ⁹³ In the first two decades after the discovery of gold and diamonds in the late 1800s, the problem of death and permanent disability in the mining sector was immense. ⁹⁴ An important cause of ill health, disability and death amongst African mine workers were lung diseases. Use of deep level excavation machines in confined spaces released dust which was then inhaled into miners' lungs, while the later use of water to reduce the dust load produced damp and humid mine conditions that were also conducive to the spread of diseases. ⁹⁵ Tuberculosis and silicosis were common lung diseases that affected the health of miners. ⁹⁶ They led to difficulties breathing, physical disabilities caused by bodily weakness, and often death. ⁹⁷ Medical historian Anne Digby has argued that the so-called "dust diseases" of the mining industry potentially involved hundreds of thousands of miners over several decades. ⁹⁸

Other than diseases, many African mine workers were left temporarily or permanently disabled by the physical dangers of deep level mining, which sometimes led to rock falls or collapsing mine tunnels that injured, maimed or killed mine workers. ⁹⁹ The most crucial influence that led to fatal and non-fatal accidents were the employment of inadequately trained men on hazardous work operations and insufficient supervision. ¹⁰⁰

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⁹³ Shula Marks. "The silent scourge? Silicosis, respiratory disease and gold-mining in South Africa." *Journal of Ethnic and Migration Studies* 32 (2006): 569-589.

⁹⁴ Shula Marks. "The silent scourge? Silicosis, respiratory disease and gold-mining in South Africa": 569.

⁹⁵ Randall Packard. *White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa.* (United States: University of California Press, 1989): 36.

⁹⁶ Marks. "The silent scourge? Silicosis, respiratory disease and gold-mining in South Africa": 570.

⁹⁷ Marks. "The silent scourge? Silicosis, respiratory disease and gold-mining in South Africa": 580.

⁹⁸ Anne Digby. "The medical history of South Africa: an overview." *History Compass* 7 (2008): 1112

⁹⁹ Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 45

¹⁰⁰ Alan Jeeves "The control of migratory labour on the South African gold mines in the era of Kruger and Milner." *Journal of Southern African Studies* 2 (1975): 15.

The unequal distribution and access to health care facilities on the mines was a major factor that led to the increase of people who lived with physical impairments in South Africa. On the West Rand, during the first decade of the twentieth century, white miners were examined by specialist doctors from the Mining Phthisis Medical Bureau and had access to private physicians with better facilities. African miners, by comparison, were examined by Mine Medical Officers. These Mine Medical Officers had limited health facilities compared to white private physicians.

Randall Packard has shown how before 1914 "medical officers frequently compromised their medical principles to accommodate the economic wishes of the industry" which tried to cut costs wherever it could. Many of these mine doctors on the Witwatersrand gold mines, for example, explained the spread of lung diseases amongst African miners using racialized theories that argued that Africans were physiologically "weak". This advanced capitalist interests as the blame fell on Africans rather than required white capitalists to pay up to improve working conditions. The medical profession was unconcerned about vital issues such as mine ventilation as well as the poor housing conditions of miners that led to TB's spread. These arguments continued during the 1920s and 1930s, even though it was becoming evident by this time that infected migrant labourers were spreading TB from the Rand to poor rural areas when they returned home after their contracts ended. The second of the returned home after their contracts ended.

¹⁰¹ Charles Hilliard Feinstein. *An Economic History of South Africa: conquest, discrimination, and development.* (Cambridge: Cambridge University Press, 2005): 45.

¹⁰² Packard. White plague, black labor: Tuberculosis and the political economy of health and disease in South Africa: 55.

¹⁰³ Jock McCulloch. "Air hunger: the 1930 Johannesburg conference and the politics of silicosis." *History Workshop Journal*. 72 (2011): 322.

¹⁰⁴ Randall Packard. "Tuberculosis and the development of industrial health policies on the Witwatersrand, 1902–1932." *Journal of Southern African Studies* 13 (1987): 191.

¹⁰⁵ Elaine Katz. *The White death: silicosis on the Witwatersrand gold mines 1886-1910.* (Johannesburg: Witwatersrand University Press Publications, 1994): 63.

¹⁰⁶ Digby. "The medical history of South Africa: an overview": 1208.

¹⁰⁷ Digby. "The medical history of South Africa: an overview": 1200-1209.

Although a system of compensation for African miners was established in the early 1900s for those injured on the job, it was very limited. In 1911, the Chamber of Mines started reimbursing injured Africans, depending on the seriousness of their injuries, a sum ranging from £3 to £24 (as a once off payment). This meant that if a miner was seriously injured (and ultimately impaired as a result) or even worse, killed while they were working on the mines, the mining company was required, by law, to reimburse that person (or a fatally injured employee's family) a fixed amount as compensation. For example, £10 was given for the injury of both hands and both feet or one foot and one hand, or for the loss of sight of either eye. £5 was payable for the loss of one foot, or one hand, or one eye. Historian, Alan Jeeves has argued that in 1911: "At the amount of £10 compensated to members of the families, the African miner was reduced in death as in life and barely worth the cost of safety procedures that would restrain the drive to step up production". 110

With regards to the above quotation, it is central to acknowledge that in the mining sector production and profit maximization was more important than the life of an African. ¹¹¹ Although there was compensation available for Africans, it was difficult for them to receive it. Often, the mining companies blamed Africans for injuries and developed theories such as that of "contributory negligence" in which they claimed that a miner contributed to his injury because he knew the hazardous nature of his work. ¹¹² In 1910, the Natives' Grievances Mining Commission

¹⁰⁸ Jeeves "The control of migratory labour on the South African gold mines in the era of Kruger and Milner": 4.

¹⁰⁹Jeeves "The control of migratory labour on the South African gold mines in the era of Kruger and Milner": 8. ¹¹⁰ Jeeves "The control of migratory labour on the South African gold mines in the era of Kruger and Milner": 9.

Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 202.

¹¹² Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 188.

found that a physically impaired African received less than the benefits paid to a white mineworker. This shows the injustices and inequalities of capitalism to African people.

In 1911, the government passed a law called the Native Labour Regulation Act. This Act "reduced the industrial power of blacks by making strike action by them a criminal offence." However, it did serve to encourage better compensation for African mine workers who obtained injuries and diseases, such as silicosis and tuberculosis, on the mines. 114 This law was introduced because Africans continued to be victims of diseases and disability in the mining sector due to harsh working conditions. 115 In his book, *White Plague, Black Labour*, Packard discusses the case of Alfred Motseki who was working in the West Rand mine between 31 July 1912 and 4 July 1918. In 1919, he was diagnosed with silicosis. In 1919, the board that represented African miners with grievances filed a compensation claim on behalf of Motseki. 116 The West Rand mining company disagreed with the claim contending that Motseki attained silicosis before the compensation act was passed. Justice Gregorowski, a sitting judge, disagreed with the West Rand mining company and argued:

a white man has a more comprehensive benefit than the native labourer, he does not lose his right to compensation merely because he contracted silicosis before the law was passed. He is entitled to it, whereas the native labourer is remediless if the mine which he contracted silicosis denies him.¹¹⁷

¹¹³ Rodney Davenport. "African townsmen? South African natives (urban areas) legislation through the years." *African Affairs* 68 (1969): 104.

¹¹⁴ Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 196.

¹¹⁵ Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 204-206.

¹¹⁶ Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 203.

¹¹⁷ Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 205.

This judgement forced the West Rand mining company to compensate Motseki and 61 Mozambique miners who had been repatriated without compensation from the West Rand mine because of silicosis. However, over the years, many Africans were not compensated at all, or were insufficiently compensated, which placed much strain on their families to look after them if they were sick or physically disabled.

The "Native Reserves" and Disability in South Africa

Another area that we come across the mention of disability issues is in the "native reserves." Africans that worked in the mines came from these areas and returned to these areas after their work contracts ended, or if they became too sick or injured to work. The "native reserves" system can be traced back to the deeds of Theophilus Shepstone, the Secretary for Native Affairs in 1840s Natal. This reserve system led to the development of segregated areas for Africans under the control of "traditional authorities", such as African chiefs. The Shepstone's system was rolled out across the entire country in 1913 not long after the arrangement of the Union of South Africa in 1910.¹¹⁹ The declaration of the Native Land Act of 1913 forbade the purchase of land by Africans outside the designated "native reserves". It also developed as part of a set of policies to deprive land from Africans and to resolve the problem of a scarce labour supply. With the beginning of this Act, ¹²¹ mine-owners and farmers "expected that since the area of the Native reserves was not

¹¹⁸ Packard. White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa: 209.

¹¹⁹ South African History Online. "Land act, dispossession, segregation and restitution". [online] Available at www.sahistory.org.za [Accessed 12 December 2016] - See more at: http://www.sahistory.org.za/article/creationnative-reserves-and-migratory-labour-system-south-african-mines#sthash.qYX1Ckpy.dpuf

¹²⁰ South African History Online. "The creation of native reserves and migratory labour system to South African mines". [online] Available at www.sahistory.org.za [Accessed 10 January 2017].

¹²¹ South African History Online. 'The creation of native reserves and migratory labour system to South African mines'.

big enough to ensure survival for the rising number of African inhabitants, Africans would be obliged to search for work on the mines and white farms." ¹²² The Act forbade African from moving outside the reserves, if they lacked a valid pass to do so. ¹²³ The prevailing attitude toward African settlement can be seen by the Transvaal government commission in 1923, which stated that:

the native should only be allowed to enter the urban areas, which are essentially the white man's creation, when he is willing to enter and to minister the needs of the white man and should depart therefrom when he ceases to minister.¹²⁴

Despite efforts to confine black people to the reserves, the urban black population increased rapidly between 1921 and 1936 as people sought economic opportunities. Lack of suitable provision of housing and other services by urban authorities for Africans led to the development of congested, unhygienic hostels and shantytowns in the urban black areas. Similar to the mines, diseases like TB spread amongst the inhabitants in these urban area. Moreover, as mentioned earlier when African miners and other urban residents returned to families in the reserves, they spread tuberculosis to the reserves. Randall Packard argues that by the late 1920s, for example, more than 90% of adults in parts of the rural reserves of Transkei and Ciskei were disease-ridden with tuberculosis. TB was significant as its progression often led to physically weakened bodies

¹²² William Beinart and Colin Bundy. *Hidden struggles in rural South Africa: politics & popular movements in the Transkei & Eastern Cape, 1890-1930.* (United States: University of California Press, 1987): 41.

¹²³ South African History Online. "The creation of native reserves and migratory labour system to South African mines".

¹²⁴ Nicholas Hyman "The Beginnings of Urban Segregation in South Africa: The Natives (Urban Areas) Act of 1923 and its Background." *The Journal of African History* 14 (1973): 172-173.

¹²⁵ Coovadia. "The health and health system of South Africa: historical roots of current public health challenges": 823.

¹²⁶ Coovadia. "The health and health system of South Africa: historical roots of current public health challenges": 815-819

¹²⁷ Randall Packard. *Preindustrial South Africa: a virgin soil for tuberculosis?* (Pietermaritzburg: University of Natal Press, 1989): 67.

(difficulties breathing and rapid weight loss), and even physical disabilities depending on the location of the TB infection and how advanced it was.

These "reserves", which were later renamed and consolidated into ten African "homelands" or "Bantustans" by the apartheid government, were affected by much poverty. The Bantu Homelands Citizenship Act of 1970 made Africans living in South Africa illegal citizens, and made Africans legal inhabitants in the homeland designated for their particular ethnic group. ¹²⁸ In addition to being mostly rural territories on the least productive land and becoming, what Harold Wolpe and Martin Legasick called "dejected labour pools", for white commercial farms and the mines; they also became dumping grounds for people that were regarded as unproductive. ¹²⁹ These included the unemployed, the sick, the elderly and the disabled. These rural areas became overcrowded areas with few job opportunities. For example, after African mineworkers acquired a disability, they became unemployed, they had no income, and they were forced to return to the rural reserves to depend on their families for their survival. ¹³⁰ Many had papers demonstrating the appalling compensation payments they received for injuries sustained. In addition, because many could not find work in the reserves, there were heightened feelings of grievance amongst disabled rural dwellers who sought help to acquire legitimate payment for the injuries they acquired. ¹³¹

Furthermore, these rural "reserves" or "homelands" provided few social services and limited access to health care facilities for African people. 132 Indeed, it was missionary doctors and nurses

¹²⁸ John Dugard. "South Africa's Independent Homelands: An Exercise in Denationalization." *Denver Journal of International Law and Policy* 10 (1980): 11.

¹²⁹ Martin Legassick and Harold Wolpe. "The Bantustans and capital accumulation in South Africa." *Review of African Political Economy* 4 (1976): 89.

¹³⁰ Aran MacKinnon. "Africans and the myth of rural retirement in South Africa, ca 1900–1950." *Journal of cross-cultural gerontology* 23 (2008): 172.

¹³¹ Legassick and Harold Wolpe. "The Bantustans and capital accumulation in South Africa": 92.

¹³² Harold Wolpe. "Capitalism and cheap labour-power in South Africa: from segregation to apartheid 1." *Economy and Society* 1 (1972): 431.

who played a crucial role in the early twentieth century to help African communities throughout the remote rural areas away from the cities in South Africa. Missionary doctors gave much assistance in the fight against diseases and provided health care services in the form of clinics and rural hospitals among African communities. They also trained different African health care workers in "simple first aid work" in an attempt to stop what they regarded as "backward" and "harmful" "traditional healer" practices, and to spread Christianity. These services were vital for those suffering from various health problems and those needing assistance, such as people living with physical or mental disabilities. The inadequate provision of health care facilities provided by the state at this time left health care service provision in African rural areas primarily to missionaries.

Mental Illness and Disability in South Africa

Another area we learn something about the lives and issues affecting people living with disabilities is in the realm of mental health care. Mental illness, mental disabilities, but also psychological strains of being physically disabled, have had a significant influence on the lives of people in South Africa. Moreover, in tracing disability issues it is essential to reflect on mental health issues to get an understanding of the challenges experienced by a variety of people. Furthermore, the scholarship mentioned in this section often dwells on general issues affecting people with mental and physical challenges prior to 1939.

In South Africa, there is a long history of undertreating and discrimination towards people living with mental disabilities and those suffering from other types of mental illnesses. Psychiatry, a

¹³³ Norman Etherington. "Missionary Doctors and African Healers in Mid-Victorian South Africa." *South African Historical Journal* 19 (1987): 85.

medical discipline developed to treat or manage what doctors defined as mental health problems or disorders, was established in the region of South Africa during the colonial period (the 1800s). Early psychiatric efforts were linked to the building of asylums, such as those on Robben Island, Valkenberg and Fort Beaufort asylums in the Cape region, and the Natal Government Asylum (or as it became known, Town Hill) in Natal. These early institutions provided a custodial type of service (like jails that served to lock away what were regarded by medical authorities at the time as "dangerous" or "troublesome" patients), rather than providing treatments, as biomedical treatments were poorly developed. They were also influenced by ideas about racial segregation. Indeed, if black and white patients were not placed in separate facilities, they were placed in separate wards and received unequal treatment in terms of food, accommodation and health care services.

A number of historians have analysed the experiences of African patients deemed mentally disordered by biomedical doctors in early twentieth century South Africa. Robert Edgar and Hilary Sapire have written on the experience of a female religious prophet, Nontetha Nkwenkwe who amassed a sizable popular following in the Eastern Cape for her visions and teachings during the early twentieth century. ¹³⁵ She was labelled as mentally ill and locked away in Fort Beaufort and later Weskoppies mental asylums supposedly to treat her, but also to remove what state authorities saw as a potential threat to their political order. ¹³⁶ However, because of resource limitations experienced by colonial states during this period, many states could not lock up large numbers of

¹³⁴ Anne Digby. "The medical history of South Africa: an overview." *History compass* 7 (2008): 1194-1210, Harriette Jane Deacon. "Madness, race and moral treatment: Robben Island Lunatic Asylum, Cape Colony, 1846-1890." *History of Psychiatry* 7(1996): 287-297 and Julie Parle. "The fools on the hill: The Natal Government Asylum and the institutionalization of insanity in colonial Natal." Journal of Natal and Zulu history 19 (2001):1-39.

¹³⁵ Robert Edgar and Hilary Sapire. *African Apocalypse: The Story of Nontetha Nkwenkwe, a Twentieth-Century South African Prophet.* (Athens OH: Ohio University Center for International Studies, 2000): 56.

¹³⁶ Edgar and Sapire. African Apocalypse: The Story of Nontetha Nkwenkwe, a Twentieth-Century South African Prophet.p.36

Africans. Edgar and Sapire have argued that they invariably: "Only confined Africans in asylums when they disrupted the regimes and disciplines of work on white farms, in the kitchens and mines or when they threatened social peace more generally, whether in the street or native reserves". 137

Medical historian Julie Parle, has also analysed histories of patients regarded as mentally ill in Natal and Zululand in the late nineteenth and early twentieth centuries. ¹³⁸ She argues that during this period, few psychiatrists spent time trying to understand African ill-health causations, and instead tended to lock up patients regarded as "troublesome" or of "unsound mind", particularly those seen as violent to themselves or others in their society, in asylums. ¹³⁹ One early psychiatrist, who did experiment with different healing options at Natal Government Asylum (later renamed Town Hill Hospital) in Pietermaritzburg, was Dr James Hyslop. Parle discusses how Hyslop developed what he called "moral therapy", where he encouraged calmness in a tranquil setting (Hyslop encouraged the planting of trees and development of beautiful gardens around the institution for his patients), and involved his patients in "meaningful occupations", such as gardening, to keep their minds busy. ¹⁴⁰

Finally, one should note that in societies where states had limited finances to lock away large numbers of Africans in mental asylums, psychiatrists still played an important role in pathologising Africans as "Other". This has been captured by historian, Megan Vaughan in her book, *Curing their Ills: Colonial Power and African Illness*. Vaughan argues that more important

¹³⁷ Edgar and Sapire. *African Apocalypse: The Story of Nontetha Nkwenkwe, a Twentieth-Century South African Prophet*: 63. For a similar situation in another African colonial context, see Lynette Jackson. *Surfacing up: Psychiatry and social order in colonial Zimbabwe, 1908-1968.* (New York: Cornell University Press, 2005).

¹³⁸ Julie Parle. *States of mind: searching for mental health in Natal and Zululand, 1868-1918.* (Pietermaritzburg: University of KwaZulu-Natal Press, 2007).

¹³⁹ Parle. States of mind: searching for mental health in Natal and Zululand, 1868-1918: 23-35, 42, 138-140.

¹⁴⁰ Parle. States of mind: searching for mental health in Natal and Zululand, 1868-1918: 44-46115.

than incarcerating "the madman or the leper", the discipline of colonial psychiatry in Africa helped "pathologise 'normal' African psychology", which deemed all Africans as "Other" or different from Europeans, and thus justified their inferior treatment by Europeans. ¹⁴¹ Indeed, psychiatry helped "mould subjects" in the colonial imagination in an era of growing scientific racism, which in turn affected how Africans, including disabled Africans, were negatively viewed and treated in colonial and segregationist contexts.

Because of the lack of public state facilities to treat the mentally ill, but also people living with mental and physical disabilities, and the expense that treatment at private institutions entailed, during this early period, most of the time, families took responsibility to care for such family members in their homes, outside the walls of institutions. Indeed, scholars such as Julie Parle and Leslie Swartz have argued that it was only if all options to heal or manage such individuals failed that families would consider taking their loved ones to mental hospitals. Those who decided to take their members to asylums did so primarily because they could not adequately care for them or because they became too violent or aggressive and threatened to do harm to themselves or others.

This is illustrated by Parle in her example of Ida Elsie Tollner who was admitted to the Natal Government Asylum in May 1907. Parle discuss how Ida Elsie Tollner was only brought to the asylum as a last resort and that her family tried many other healing approaches, including popular

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¹⁴¹ Parle. "The fools on the hill: The Natal Government Asylum and the institutionalization of insanity in colonial Natal": 10-17.

¹⁴² Parle. *States of mind: searching for mental health in Natal and Zululand:* 62. For more on this subject, see Peter Bartlett and David Wright, eds. *Outside the walls of the asylum: The history of care in the community 1750-2000*. (London: A&C Black, 1999).

Julie Parle, States of Mind: searching for mental health in Zululand, 1868-1918, chapter 4 and Leslie Swartz. Culture and Mental Health: A Southern African Perspective (Cape Town and Oxford: Oxford University Press, 1998): 77-94.

¹⁴⁴ Parle. States of mind: searching for mental health in Natal and Zululand: 61.

and "traditional" therapies, such as "the extract of the throat of a goat" to try to assist them. ¹⁴⁵ As we shall see later in this thesis, care provided outside institutional walls, in homes and by family members, proved essential for many people who lived with disabilities in apartheid South Africa.

Polio and Physical Disabilities in South Africa

The spread of physically debilitating diseases is another place one finds discussion of disability. Polio is an example of another disease that maimed or physically impaired people in the first half of twentieth century. Before the twentieth century, the disease was known as an infection acquired largely by children, hence the name "childhood paralysis." Yet, by the early twentieth century, there was no known cure for polio. Key periods noted for polio outbreaks in South Africa were the summers of 1917/18 and 1944/5. 147 Both outbreaks were linked to greater mobility of populations during these war years. 148

Polio was caused by a virus that was highly contagious. It was usually spread when contaminated faecal matter entered an area's drinking water or a person's food, or when an infected person touched another person. Although it was spread predominantly in areas with poor sanitation, this disease was not limited to the poor or those living in squalid conditions, and spread through the assistance of insect vectors such as flies, to infect those living in wealthier classes too.¹⁴⁹

A lot of body dysfunctionality was caused by the polio virus in South Africa during the early twentieth century. Medical historian Howard Phillips has argued that the virus was serious as it

¹⁴⁵ Parle. States of mind: searching for mental health in Natal and Zululand, 1868-1918: 151.

¹⁴⁶ Mary Margaret Wade. "Straws in the wind: early epidemics of Poliomyelitis in Johannesburg, 1918-1945." (PhD Diss. University of South Africa, 2009): 37.

¹⁴⁷ John Rodman Paul. A History of Poliomyelitis. (New Haven, Conn: Yale University Press, 1971): 21.

¹⁴⁸ Wade. "Straws in the wind: early epidemics of Poliomyelitis in Johannesburg, 1918-1945": 42.

¹⁴⁹ See Naomi Rogers. *Dirt and disease: polio before FDR*. (New Jersey: Rutgers University Press, 1992): 31 and Paul, History of Poliomyelitis: 23.

affected the central nervous system and destroyed motor cells, which paralyzed certain muscles, and thus could negatively affect a person's ability to move. It could also hinder breathing if it spread to affect the respiratory system. Polio weakened or destroyed the muscles of the torso, and one side of the torso was often left weaker than the other. Scoliosis or spinal curvature often developed from polio infections too. This led to weakness in the neck and spine, which led to a person's head dropping towards their chest. Many people developed physical disabilities in South Africa during polio outbreaks, which increased the number of people who lived with disabilities in the country.

Wars, Trauma and Disability

Analysis of books and articles on war also show how some disability in South Africa was caused by traumatic experiences. A number of scholars have discussed how involvement in wars, such as the First World War, left people with physical impairments and psychological traumas. During such wars, many soldier were psychologically scarred by the horrors that they saw or participated in during battles. This led to mental breakdowns and psychologically distressed states, producing conditions such as "shell shock" and "war neurosis". ¹⁵⁴ This made it difficult for some soldiers to reconnect with family and friends or to function as they had done before they had left to fight in wars. ¹⁵⁵

¹⁵⁰ Howard Philips. *Plague, pox and pandemics*. (Johannesburg: Jacana Media, 2012): 97.

¹⁵¹ Wade. "Straws in the wind: early epidemics of Poliomyelitis in Johannesburg, 1918-1945": 43.

¹⁵² Philips. Plague, pox and pandemics: 102.

¹⁵³ Charles Robert Cruttwell. A history of the Great War: 1914-1918. (United States: Chicago Review Press, 2007).

¹⁵⁴ Edgar Jones and Simon Wessely. "'Forward psychiatry' in the military: its origins and effectiveness". *Journal of Traumatic Stress* 16 (2003): 411-419.

¹⁵⁵ Ros Hirschowitz, and Orkin Mark. "Trauma and mental health in South Africa." *Quality of Life in South Africa. Springer Netherlands* 6 (1997): 169-182.

Other scholars have discussed how some soldiers suffered physical injuries from bullets and shrapnel from bombs whilst fighting in battles, which left them either temporarily or permanently impaired. Once they left the battle arena, these individuals then had to rely primarily on the love and care of family and friends, but also the assistance of professionals, such as doctors, to assist them to function in their daily lives once they returned home.

Twentieth Century State and Voluntary Services for People Living with Disabilities

It is crucial to say that South African governments after Union in 1910, through the 1920s and 1930s, did not prioritize provision of health care and other support services for people who lived with disabilities. Indeed, public health care services were undeveloped generally until the state passed the Public Health Act in 1919 to better organize public health care services. ¹⁵⁷ Even then, public health care services remained disorganized and lacked proper coordination, as responsibility to provide preventive, curative and/or health educational services, was tossed between different local, provincial and national government departments. ¹⁵⁸

During this period, there were no centrally controlled state-sponsored welfare services for disabled people. Provision of disability support services was not a major concern for early twentieth century governments. ¹⁵⁹ No legislation dealt with people living with disabilities before the Public Health

¹⁵⁶ Bill Nasson. "War Opinion in South Africa, 1914." *The Journal of Imperial and Commonwealth History* 23 (1995): 251.

¹⁵⁷ Susan Parnell. "Creating racial privilege: the origins of South African public health and town planning legislation." *Journal of Southern African Studies* 19 (1993): 479.

¹⁵⁸ Howard Phillips. "The origin of the Public Health Act of 1919." *South African Medical Journal* 78 (1990): 531-532. Curative services focused on treating already existing illnesses, while preventive and promotive services focused on enhancing and maintaining people's good health (i.e. stopping them from becoming sick in the first place). Use of vaccines, encouragement of better nutrition through creating vegetable gardens or taking nutritional supplements, as well as encouraging better sanitation and hygiene through health education were used by those with a preventive or promotive agenda.

¹⁵⁹ Coovadia. "The health and health system of South Africa: historical roots of current public health challenges": 828.

Act period. Instead, people with disabilities continued to be cared for by their family members, friends and neighbours in their homes and tried various self-administered, "traditional" and popular healing options to seek relief from pain and sickness.¹⁶⁰

Looking at the medical profession, by the 1930s, there were only three orthopaedic experts in South Africa and no orthopaedic nurses or social workers. Orthopaedic specialists were experts trained in recognizing and treating conditions that affected the musculoskeletal system, including bone tuberculosis, a main cause of physical impairment amongst South Africa's citizens. Indeed, orthopaedics was only beginning to differentiate itself as a specialty within the broader medical profession in the country, and internationally at this time. ¹⁶¹

As we shall see in the next chapter, most services and facilities provided for people who lived with disabilities in the early decades of the twentieth century were provided voluntarily, by individuals and private organizations, with philanthropic interests. The next chapter will focus on the work of an important private and philanthropic disability organization, the Cripple Care Association, which was formed in South Africa in the 1930s.

¹⁶⁰ Leslie Swartz "Culture and Mental Health: A Southern African View". Psychodynamic Practice 8 (2002): 127-128

¹⁶¹ D. Penry Roberts. (2013). History of the Association for the Physically Disabled. [online] Available at: http://www.apd.org.za/about-us/history/. [Accessed 14 November 2016].

CHAPTER THREE

The History of the Formation and Work of the Cripple Care Association (CCA), especially its Natal Branch, 1930s-1980s

This chapter will investigate the history of the establishment and work of the Cripple Care Association (CCA) in South Africa, particularly its Natal branches. It will look at why this Association was created, when was it formed, what sort of organization it developed as (private or public), how big it became in terms of its outreach, what work it did, its clients, and its activities and programmes to assist people who lived with disabilities. This chapter will also look at a significant shift in 1960s, in which this historically white organization's concern shifted to focus on black clients too.

Formation of the CCA¹⁶²

The 1930s were an important decade for the development of support services for people with disabilities in South Africa. In early 1934, the National Council of Women of South Africa (which had been formed in 1933 as a concerned group of women to oppose the then Prime Minister J.B.M Hertzog's Representation of Native's Bill and the Native Trust or "Hertzog Bills") called a public meeting in Johannesburg to try to come up with a resolution to help people with disabilities in their city. Those who went to this meeting agreed to work to create a training home for children with physical disabilities in Johannesburg. An action committee was nominated, which was

¹⁶² In this thesis, I do not focus on organisations such as the Natal Bantu Society, the Natal European and Coloured Civilian Blind Association, the Child Welfare Society, or Deaf and Blind societies because they did not work with the CCA, which is the focus of my study.

¹⁶³ APC Archive, Durban, Penry Roberts. History of the Association for the Physically Challenged. Durban Association for Physically Challenged Pamphlet, 2012

tasked with the duty of raising funds to build such a home. The main purpose of this home, as they saw it, was to provide schooling and care services for children with physical disabilities. Just six months later, most of the money needed to build this home had been raised and the Crippled Children's Training Home was opened in October 1934.¹⁶⁴

The proceedings leading up to the establishment of the Cape Cripple Care Association included the founding of the Invalid Children's Aid Committee, under the Society for the Protection of Child Life in Cape Town. Consequently, this led to the development of Maitland Cottage Home, the Lady Michaelis Orthopaedic Hospital, Princess Alice Orthopaedic Hospital, and St. Joseph's Home for Chronically Invalid Children in the 1930s.¹⁶⁵

Encouraged by the level of support they received from individuals and other welfare organizations to further the cause of children and people who lived with physical disabilities, their committee also founded the Cripple Care Association of the Transvaal on the 10th of December 1934. A couple of years later, on the 25th of February 1937, the Cape Cripple Care Association was formed. This was created by private individuals too, such as Dr. Pieter Roux, Mrs. H.C. Horwood and Mr. J Kipps, who had also became involved with disability issues through their involvement in the formation of the Invalid Children's Aid Committee, which had raised funds for the Crippled Children's Training Home. 166

On the 26th of September 1937, William Morris Nuffield, a British born industrial entrepreneur and philanthropist, who had developed an interest in furthering medical and educational developments around the world, made a gift to South Africa of £100,000. This was done in the

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¹⁶⁴ APC Archive, Durban, Roberts. History of the Association for the Physically Challenged: 1.

¹⁶⁵ Association for the Physically Challenged. History of the Establishment of Cripple Care Association. Posted on 5 August 1998 http://users.iafrica.com/r/re/reable/History_body.htm (Accessed 7 August 2017)

¹⁶⁶ APC Archive, Durban. Roberts. History of the Association for the Physically Challenged: 1.

wake of terrible polo outbreaks that had affected Britain and her ex-colonies such as South Africa, and he hoped to stimulate greater interest of the South African government and private organizations to address the urgent needs of people with disabilities in this country.¹⁶⁷

However, at that time there were only a few small and uncoordinated voluntary organizations working to advance the causes of disabled people. Thus, a condition of the release of these funds was the creation of a coordinating and advisory body to direct and ensure the wise spending of this money. 168

On the 5th of March 1939 the Cape Cripple Care Association called a conference of interested organizations and persons in Cape Town to discuss the formation of a National Council. At this conference, a physical disability charter was adopted. This resulted in the birth of the National Council for the Care of Cripples (basically people with mobility challenges) in South Africa, in March of that year. The following quotation highlighted, in the words of the time, some of the wide-ranging aims and the objectives of the Council:

To safeguard a national service for cripples, to task and connect the work of the different Associations, subdivisions and institutions involved or interested in this work. To inspire associations already taking responsibility for the care of cripples and support in forming new associations when and where essential. To create policies and to endorse and support methods for the early discovery and the rapid and effectual handling of children and others who might become cripples. To help schemes, for the treatment, schooling, training, service and general prosperity of cripples. To be the authorized station for communication in materials of broad-spectrum policy between integral bodies, the Government and Provincial establishments. To act as a consultative body on all matters relating to the care of cripples. To work with international societies whose goals are comparable to those of the Council, and, if considered desirable, to associate with such groups.

¹⁶⁷ Nuffield Foundation. (2013). "History of Lord Nuffield". [online] Available at: www.nuffieldfoundation.org > About the Nuffield Foundation. [Accessed 14 November 2016].

¹⁶⁸ APC Archive, Durban. Roberts. History of the Association for the Physically Disabled: 2.

¹⁶⁹ APC Archive, Durban. Roberts. History of the Association for the Physically Disabled: 2.

¹⁷⁰ Mary Margaret Wade. "Straws in the wind: early epidemics of Poliomyelitis in Johannesburg, 1918-1945." (PhD Diss. University of South Africa, 2009): 42.

Commonly to concern itself with all materials and questions relating to the care of cripples, and the deterrence of cripples all over the Union, South-West Africa, Basutoland, Bechuanaland Protectorate and Swaziland.¹⁷¹

It was only after the National Council was formed that it initiated the establishment of the Cripple Care Association in Natal, with its first branch established in Pietermaritzburg on the 8th of July 1939, followed two months later with another branch in Durban. Together, these two branches made up the Natal CCA.

Soon, the branches of the CCA were operating all over the country. Other than the Natal branches, the following branches had come into operation by the early 1940s: the Cripple Care Association of the Cape, the East London CCA, the Society for the Care of Cripples in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association, and the Pretoria and Northern Transvaal Cripple Care Associations. They benefitted over the years from various Trusts and De Beers funds, which aided them to fund projects, upgrade facilities, cover running costs and purchase vehicles and equipment. The country of the Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Kimberley, the Orange Free State Society in Aid of Crippled Children, the Transvaal Cripple Care Association of the Cape in Cap

During the 1930s and 1940s, in a racial segregation context, the Cripple Care Association was formed to help a mainly white clientele with physical disabilities to access social services, such as government grants, treatments, access to special schools. Services were offered free of charge to people who joined the CCA as members. The CCA developed training programmes to train people in various skills such as craftwork, sewing and beadwork, and provided employment opportunities

¹⁷¹ APC Archive, Durban, Natal Cripple Care Association (hereafter NCCA). Annual General Meeting Report. Services to Persons with Disabilities in Durban, 22 September 1965

¹⁷² APC Archive, Durban, NCCA. Annual General Meeting Report. Services to Persons with Disabilities in Durban, 8 August 1964: 8.

¹⁷³ Henry Gluckman. Abiding Values; Speeches and Addresses. (United States: Caxton, 1970): 343.

¹⁷⁴ Interview 2 of Lesley Dietrich. Conducted through email by S. Nxumalo in Durban, 12 November 2016.

for them. In addition, the Cripple Care Association assisted people to access orthopaedic services. 175

It is important to understand that the idea of "handicrafts for and by the handicapped" is a controversial issue. Although this liberal vision of self-improvement tried to give people with disabilities more agency or independence (particularly the ability to earn some income from their own handicraft activities), nonetheless it still only envisaged a limited horizon for people with impairments. Of course, this perspective also tended to focus on privileged whites in the South African context. In this context, the horizons of black disabled people were regarded as more limited.

In 1942 the National Council of the CCA, drew on Nuffield donation funds to expand a number of orthopaedic homes and wards in hospitals around the country where people with physical disabilities could obtain treatment for months, and even years, if required.¹⁷⁶ Furthermore, training in orthopaedics was made a priority. In August 1942, funding was assigned to the Universities of Cape Town and the Witwatersrand for the creation of Lectureships in Orthopaedics at their medical schools. Another Nuffield scholarship was made soon afterwards for the creation of an Orthopaedic training school for European nurses in Cape Town, and Council brought expert sister tutors form overseas to train nurses in orthopaedic work.¹⁷⁷ Bursaries were also created from this funding for post-graduate training in orthopaedic surgery. It is essential to state that this prestigious funding was meant for whites only.¹⁷⁸

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¹⁷⁵ APC Archive, Durban, NCCA. Annual General Meeting Report. Services to Persons with Disabilities in Durban, 8 August 1964: 7.

¹⁷⁶ APC Archive, Durban, NCCA. Annual General Meeting Report. Services to Persons with Disabilities in Durban, 8 August 1964: 4.

¹⁷⁷ APC Archive, Durban, NCCA- Annual General Meeting Report. Services to Persons with Disabilities in Durban, 8 August 1964: 10.

¹⁷⁸ APC Archive, Durban, NCCA- Annual General Meeting Report. Services to Persons with Disabilities in

The CCA operated as a private organization in the 1930s and 1940s. Its work was recognized by the Minister of Health in the early 1940s. ¹⁷⁹ In the government's 1944 National Health Commission Report, it noted that physical impairment was not only a matter of individual human suffering but should also be of great national concern. Soon afterwards, after being appointed as Minister of Health, Henry Gluckman claimed that the large task of assisting people with physical impairments should not be the responsibility of the CCA alone, but dealing with this issue called for a national response. 180 In August 1947, Gluckman insisted that:

Co-operation must be established with other agencies; professional groups, voluntary organizations, Union and Provincial Government departments and local authorities; arrangements made for crippled children and for their physical and economic rehabilitation. 181

He also claimed that the ideal scheme for "cripple care" entailed one that visualized a division of orthopaedic services in the medical profession and "regional orthopaedic hospitals" that could provide "a complete range of diagnostic, therapeutic, vocational training and medical facilities."182

Unfortunately, this abovementioned scheme by the Minister was not achieved because he did not remain in power for long. His farsighted ideals were replaced by a more conservative approach from 1948 when the Afrikaner Nationalist apartheid government came into power and replaced his health ministry. 183

Durban, 8 August 1964: 7.

¹⁷⁹ Gluckman. Abiding Values; Speeches and Addresses: 342.

¹⁸⁰ Gluckman. Abiding Values; Speeches and Addresses: 342.

¹⁸¹ Gluckman. Abiding Values; Speeches and Addresses: 342.

¹⁸² Gluckman. Abiding Values; Speeches and Addresses: 342.

¹⁸³ Randal Packard. "The "healthy reserve" and the "dressed native": Discourses on black health and the language of legitimation in South Africa." American Ethnologist 16 (1989): 692.

Getting back to the issue of training, between 1955 and 1956, 40 white nurses were provided with orthopaedic training in South Africa at both the Universities of Cape Town and the Witwatersrand. ¹⁸⁴ Others went overseas to complete their training. Initially, the principal intention of the CCA was to coordinate orthopaedic services to persons with disabilities, but in the 1950s, they soon realized that a far greater need lay in assisting persons to cope with broader social difficulties. They thus made a decision to train social workers to provide assistance to persons living with physical disabilities. In 1956, ten students were accepted at UCT to train as social workers from all over the country. ¹⁸⁵

By 1956, National Council was helping to subsidize almost every aspect of orthopaedic work in South Africa. This included provision of bursaries for postgraduate studies in many branches of orthopaedics, including orthopaedic surgery and physiotherapy. ¹⁸⁶ By the late 1950s, the National Council of the CCA and its provincial Cripple Care Association had succeeded in organizing and subsidizing the provision of orthopaedic services in all major cities and many towns. Some were even organised in a few rural districts, such as an orthopaedic clinic, which was opened in Wolmaransstad in the Southern Transvaal in 1950. ¹⁸⁷

During the 1950s, the CCA introduced a major shift to its objectives, and started focusing on providing for the needs of physically disabled black South Africans too. According to Lesley Dietrich, who became the Natal Provincial Director of the Association in 1986, the CCA started becoming a "multi-racial" organization in terms of employment of staff and in its clientele.

¹⁸⁴ Stephens Ntsoakae Phatlane. "Poverty, health and disease in the era of high apartheid: South Africa, 1948-1976". (University of South Africa: PhD Diss. 2009): 41.

¹⁸⁵ APC Archive, Durban, NCCA. Annual General Meeting Report. Services to Persons with Disabilities in Durban, 10 September 1974: 1.

¹⁸⁶ APC Archive, Durban, Roberts. History of the Association for the Physically Challenged: 3.

¹⁸⁷ APC Archive, Durban, Roberts. History of the Association for the Physically Challenged: 4.

However, because of apartheid laws, which restricted interactions between people of different "race groups", the CCA, certainly in these early years, had to create a number of different branches to cater for clients from different "races". ¹⁸⁸

A Black Clientele

Interestingly, at a time when the apartheid Afrikaner Nationalist government was entrenching its power in the 1950s and 1960s, the CCA became a less exclusively white-oriented organisation. Why this was the case is difficult to extrapolate from the archival records. However, one could surmise that it's more liberal leanings, and original founding philosophy of helping people who were socially marginalised, might have helped push it in this direction in response to an era when black South Africans were increasingly oppressed.

During the 1950s and 1960s, although the CCA remained a private organization, this organization started working with the state and other stakeholders to assist a wider variety of people who lived with physical disabilities in South Africa. A good example of this was work done for the so-called "Coloured" community during this period. An important incentive that lay the groundwork for this initiative was the provision of a grant in 1942 by the Nuffield Foundation to assist "Coloured cripples in Natal." This stimulated a stronger working relationship with the Department of Coloured Affairs in the 1950s. In 1959, the Natal CCA created what became known as the "Rainbow Crèche" in Pinetown (a suburb outside of Durban), which catered for Coloured, but also in time, Indian children living with physical disabilities. ¹⁸⁹ The work for CCA's Coloured members was reported on at a Durban CCA Annual General meeting in the 1960s:

¹⁸⁸ Interview 2 of Lesley Dietrich.

¹⁸⁹ Saul Dubow. Scientific racism in modern South Africa. (Cambridge: Cambridge University Press, 1995): 79.

We are very happy to report that with the cooperation of Department of Coloured Affairs premises in three separate Coloured areas have been made available in Durban for services needed by Coloured cripples. These premises are self-contained and independent and will be used exclusively for cripple care work.¹⁹⁰

At the above AGM, Professor Theo Pauw, a South African physiotherapist at the time, made the case for the need for a more accommodative environment to make places more accessible to people with disabilities. He argued that 75 per cent of people, which included black South Africans, living with disabilities during the 1950s and 1960s, had restricted opportunities to live fruitful lives. If looking at the 1960s alone, the figure worsened and up to 85% of people were out of reach of such services. Prof Pauw also made the case during the 1960s for expanded and improved rehabilitation services, improved intra-cultural communication, and the need to expand training opportunities for people with disabilities to improve their employability. ¹⁹¹

This was largely influenced by the fact that during apartheid, predominantly white urban areas were far better serviced than black rural "reserve" areas. The introduction of apartheid in 1948 worsened the inequalities experienced between blacks and whites. Indeed, the coming to power of the Afrikaner Nationalist apartheid government rested on a system that built and maintained divisions, and thus inequalities, between South Africans from different "racial groups." Another crucial factor that led to white privilege, in terms of accessing resources, was that a variety of sponsors contributed to their cause. Moreover, it is vital to remember that companies that made

¹⁹⁰ APC Archive, Durban, NCCA - Annual General Meeting Report. Services to Persons with Disabilities in Durban, 10 September 1974: 7.

¹⁹¹ APC Archive, Durban, NCCA- Annual General Meeting Report. Services to Persons with Disabilities in Durban, 10 September 1974: 10.

donations to welfare work like that done by the CCA during apartheid were mainly owned by whites, who supported white causes. 192

In 1964, the CCA's concern shifted to providing assistance to Africans too. This was largely due to the recognition of problems that Africans with disabilities experienced on a daily basis, especially in less serviced rural areas. An important person who drove this initiative in the Natal region was Sister Norma Lovell. She was a former staff member at KwaHlengabantu Home, which was opened in Edendale in 1954 for "physically handicapped" Africans by the Methodist missionary, Dr D.S. Shepstone. Later, the KwaZulu Bantustan government took over the financial costs of running the KwaHlengabantu Home. 193 Lovell was also an executive committee member of the Natal CCA. While working at KwaHlengabantu Home, which provided nursing care and support services for people with long-term care needs, Sister Lovell visited a number of chiefs in the rural areas in and around Edendale to talk about the hardships experienced by "crippled" people. It was while she was at KwaHlengabantu working with African patients for many years that Sister Lovell realized the need for rural clinics. 194

At a Natal CCA meeting in August 1963, Lovell championed the need for this association to expand its services. She asked them to ponder whether the "CCA was providing enough assistance in helping people with disabilities by its conduct of neglecting African people with disabilities particularly in rural reserves areas." ¹⁹⁵

¹⁹² George Brooks. "Apartheid in South Africa." *Ufahamu: A Journal of African Studies* 16 (1988): 36.

¹⁹³ APC Archive, Durban. Alan Govender. "Cripple Care take to the Bantu". Natal Mercury, 15 December 1971.

¹⁹⁴ APC Archive, Durban. Govender. "Cripple Care take to the Bantu": 1.

¹⁹⁵ APC Archive, Durban. Govender. "Cripple Care take to the Bantu": 3.

An important outcome of these mobilizing efforts was the development of After Care Nursing Clinics. This initiative was meant to include people with disabilities who were previously disadvantaged in terms of accessing health care facilities, particularly those living in rural areas. Aftercare Nursing was a method of providing treatment and care in the homes of individuals who were clients of the CCA. These After-Care activities operated in the Mount Edgecombe, Stanger and Tongaat areas and catered for people of all races. 196

Another significant Natal CCA executive committee member who motivated for extending CCA services to black South Africans was Joyce Le Brun. ¹⁹⁷ Le Brun played a vital role in the development of services that catered for Africans with physical impairments in the 1960s. ¹⁹⁸ In her autobiography entitled *From Pain to Purpose* we learn that Le Brun, who was born on 2 September 1919 in Natal, was stricken with polio at the age of two and spent many years in Addington Hospital recuperating. After her discharged, she worked at Umlazi Mission Hospital as an orthopaedic technician, working with early orthopaedic specialists in caring for patients with injured joints and bones. ¹⁹⁹ According to Michael Gelfand, Umlazi Mission Hospital, which opened in 1943, developed a specialist block housing several wards, to help "crippled African children". ²⁰⁰ During her time at Umlazi Mission Hospital, she developed an interest to help and care for people with disabilities. She became closely associated with the establishment and work of the Uplands Home for Children with Handicaps, which was a private home created to assist

¹⁹⁶ APC Archive, Durban, NCC- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 25 March 1970: 2.

¹⁹⁷ APC Archive, Durban. Joyce Le Brun. *From Pain to Purpose*. (Durban: Durban Cripple Care Association, 1972). ¹⁹⁸APC Archive, Durban, NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 25 March 1970: 3

¹⁹⁹ APC Archive, Durban. Le Brun. From Pain to Purpose: 10.

²⁰⁰ Michael Gelfand. *Christian Doctor and Nurse: The History of Medical Missions in South Africa From, 1799-1976.* (Johannesburg: Aitken family and friends, 1984): 33.

white children with physical impairments in Pietermaritzburg²⁰¹ Later, she left her work at the hospital to become the secretary for the Uplands Home in 1956.²⁰²

After her official retirement in 1963, she could not remain idle and in 1964 started the Ematupeni. Cripple Care Centre in Umlazi Township, an African residential area located south of Durban. Having worked for many years at Umlazi Mission Hospital, she had become acutely aware of the need to develop support and training skills development services for adult Africans with physical impairments. People with physical disabilities treated for years at the Umlazi Mission Hospital became adults, which meant they had to leave the children with disabilities wards, resulting in no services for them. This resulted in the development of a partnership with the Umlazi Mission Hospital and the Bantu Affairs Department in 1964. A six months survey was conducted in Durban and as there were no facilities for Africans, the Bantu Affairs Commissioner gave the Natal CCA permission to form a task team under the leadership of Joyce Le Brun, to develop a centre, using a derelict state-owned building in the Umlazi area. Later, a second building was acquired. This little estate became known as the Ematupeni Cripple Care Centre for which the Bantu Affairs Commissioner charged a nominal rent per year.

In 1967, the Ematupeni Centre employed two African female social workers. The African social workers' salaries were subsidized by Bantu Affairs Department because after the 1960s the government partially assisted the CCA with its services.²⁰⁵ Other black staff were also employed

²⁰¹ APC Archive, Durban. Le Brun. From Pain to Purpose: 11.

²⁰² APC Archive, Durban .Le Brun. From Pain to Purpose: 14.

²⁰³ APC Archive, Durban. NCCA- Annual General Meeting Report. Umlazi Homelands- near Durban. A Work and Assessment Centre Established and Administered by the Ematupeni Branch of Cripple Care, 25 April 1970: 74.

²⁰⁴ APC Archive, Durban. NCCA- Annual General Meeting Report. Umlazi Homelands- near Durban. A Work and Assessment Centre Established and Administered by the Ematupeni Branch of Cripple Care, 25 April 1970: 11.

²⁰⁵ APC Archive, Durban. NCCA- Annual General Meeting Report. Umlazi Homelands- near Durban. A Work and Assessment Centre Established and Administered by the Ematupeni Branch of Cripple Care, 25 April 1970: 10.

to assist at this Centre. Between May 1967 and March 1983, Gilbert Shangase, who came from the Mbumbulu district, was employed as a shoe repairer and craft instructor at Ematupeni. During this same period, Mrs Francis Mbombo, who came from Newcastle, worked as a cleaner at this Centre until her retirement in August 1984. At the beginning of 1968, and for several years thereafter, Patrick Ngcobo from Ladysmith and Amos Ngubane from uMzimkhulu drove buses, which fetched clients from their homes to take them to and from Ematupeni and Zimele (another Centre that I will discuss below). In 1968, the two centres also employed a qualified nursing sister, Sister Kuluse from Durban at Umlazi Township, who visited the centres weekly. Sister Kuluse worked for many years at these Centres until her retirement in the mid-1980s. The salaries for above-mentioned workers were paid for by the CCA.

Ematupeni was developed as Centre that worked with Africans with physical impairments. Once it opened, this Centre, which was first headed by George Devereux as chairman, brought a Bantu Advisory Committee into being. This Committee included knowledgeable individuals in their field of specialization from within and outside the disability community (including African advisors), and existed to access and respond to the special needs of African individuals with physical disabilities.²⁰⁹

Le Brun played an active role in teaching clients to make beautiful and useful articles from colourful beaded felt that they could sell. They produced shopping bags, handbag purses and

²⁰⁶ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 4 September 1986: 1.

²⁰⁷ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 4 September 1986: 3.

²⁰⁸ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 4 September 1986: 5.

²⁰⁹ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 25 March 1970: 2.

coasters of a very high standard. Africans who produced these items got paid for their work, and their goods got sold in local curio shops. In the 1970s, inquiries to purchase such articles were also received from 50 countries overseas, including Germany, Holland, Britain and America. These arts and craft works were attractive to tourists and readily bought by curio shops and tourists.

During the first five years of Ematupeni's existence, 164 adult "crippled" pupils were trained at the Centre. 210 According to the AGM report of 1969

32 pupils were placed in normal employment in the offices, factories, flats, industries and one was employed as an Induna at the Centre, 7 died and 39 were not registered in the Township and had to leave, the whereabouts of 7 were unknown, 2 were unsuitable and after a trial were dismissed, 2 were transferred to Montebello Chronic Sick Hospital, 15 were so disabled that they cannot do any profitable work but are just occupied with very simple work and sing harmoniously whilst they do it and 1 has gone to the trade school.²¹¹

Furthermore, in the 1970s the Ematupeni Cripple Care Centre also ran a school scheme in which they paid for the fees, the books and the uniforms of children living with physical disabilities whose parents are not earning enough money to afford such expenses.²¹²

In 1965, a year after the opening of Ematupeni, another centre was founded by Joyce Le Brun and other members of Natal CCA. Zimele (meaning "Stand on your Own") was also developed in partnership with the Bantu Affairs Department. This Department made an old building, a former

²¹¹ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 25 March 1970: 1-4.

²¹⁰ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 25 March 1970: 2.

²¹² APC Archive, Durban. NCCA- Annual General Meeting Report. Umlazi Homelands- near Durban. A Work and Assessment Centre Established and Administered by the Ematupeni Branch of Cripple Care, 8 July 1971: 3.

police station in the township of KwaMashu (located north of the Durban CBD), available to the CCA to develop as another "Cripple Care Centre". ²¹³

This Centre aimed to assist African adults with physical impairments to become more independent in terms of their lives and finances. Like Ematupeni, people with disabilities did not live on these premises but they came to this Centre to be trained and to work. European volunteers came on a weekly basis to the Centre to teach its clients various skills. The work done at Zimele included making soft toys from waste fabrics, producing cane furniture, leather work, repairing shoes, as well as knitting and needle work. Large factories, shops and companies were contacted to ask for donations of off-cuts and samples. The promise of a constant supply of fabric off-cuts enabled Zimele to create products under the label "New Lines", which meant new products produced from waste fabric. 214 Zimele's art and craft producers were then paid for their products, which were then sold at a variety of markets and, from 1968, also at a small shop in Durban, which sold Zimele and Ematupeni products.

In 1969, Zimele established a garden on the property where some of the Centre's male clients worked. Fruit bearing trees were planted as well as vegetables, some of which were used to feed those working at the Centre and some were sold.²¹⁵ There was one part-time paid helper, Ann Girlle, apart from Joyce Le Brun on the European staff at the Centre. Girlle oversaw the kitchen.

²¹³ APC Archive, Durban. NCCA- Annual General Meeting Report. Zimele, KwaMashu- near Durban. A Work and Assessment Centre Established and Administered by the Zimele Branch of Cripple Care, 8 July 1971: 12.

²¹⁴ APC Archive, Durban. NCCA- Annual General Meeting Report. Zimele, KwaMashu- near Durban. A Work and Assessment Centre Established and Administered by the Zimele Branch of Cripple Care, 8 July 1971: 13.

²¹⁵ APC Archive, Durban. NCCA- Annual General Meeting Report. Zimele, KwaMashu- near Durban. A Work and Assessment Centre Established and Administered by the Zimele Branch of Cripple Care, 8 July 1971: 11.

This Centre also had a full time paid African driver for the bus coach, who fetched and dropped of clients for work.²¹⁶ In 1969. Jovce Le Brun wrote about the value of Zimele Centre:

A few weeks ago in 1969, lack of helpers prompted me to have the cripples working at the Centre on two days a week without European help. Girlle is in charge but there is no supervision of the work and, to date, the experiment has been successful. This is in keeping with the ultimate aim of such Centres being run by the Bantu. The potential of a Centre such as this is enormous. With sufficient staff a thriving industry could be built using the waste from factories, etc. and a useful, happy life, earning a reasonable wage, independent of disability grants, could be found for the African cripple.²¹⁷

In 1967, Zimele also employed two female social workers to assist them to identify needy cases in the KwaMashu area.²¹⁸

In 1969, Zimele developed an Assessment Centre on its premises, to assess the physical capabilities of African clients to determine whether they could be recruited to work in factories, in kitchens as domestic workers, and as gardeners. That same year, nine African men were placed in employment in the open market as gardeners, factory operatives and in shoe repair jobs, while one woman was placed in domestic service.²¹⁹

It is vital to remark on the manual labour and unskilled job prospects for African people during the apartheid period. Indeed, gardening, domestic work and factory employment were examples of work commonly assigned to disabled Africans, just like able-bodied Africans during this period.

²¹⁶ APC Archive, Durban. NCCA- Annual General Meeting Report. Zimele, KwaMashu- near Durban. A Work and Assessment Centre Established and Administered by the Zimele Branch of Cripple Care, 8 July 1971: 15.

²¹⁷ APC Archive, Durban. NCCA- Annual General Meeting Report. Services to Persons with Disabilities to all races in Durban, 5 August 1970: 10.

²¹⁸ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 25 March 1970: 5.

²¹⁹ APC Archive, Durban. NCCA- Annual General Meeting Report. Zimele, KwaMashu- near Durban. A Work and Assessment Centre Established and Administered by the Zimele Branch of Cripple Care, 8 July 1971: 9.

They had very little opportunity to better their work prospects because of their "race". ²²⁰ Therefore, Le Brun played an important role in providing greater opportunities for disabled Africans, but her efforts ultimately continued to support the limited job prospects for black South Africans in the apartheid era.

During the 1970s, Joyce Le Brun also played a central role in the formation of Lucigen Children's Centre, which was opened in Durban in 1973, together with three professionals: Sylvia Shearer (a Psychologist), Kay Erskine (a Physiotherapist) and Elsie Lucas (an Occupational Therapist). This group developed with a specific interest to work with "developmentally delayed children" at risk of developing learning difficulties and emotional adjustment problems. During their first year, they rented buildings in Essenwood Road on Durban's Berea before they were able to raise enough funds to buy an old home in Harris Crescent, in the Sherwood area, which they renovated to create offices and a small pre-school for children with disabilities. ²²¹

From its start with just a small number of clients the Lucigen Children's Centre grew over time, increasing the variety of services it offered to more and more school-going children with learning disabilities. The necessity for these services arose out of the inadequate psychological services provided to school-going children by the Department of Education at this time, as well as the growing call by parents of teenagers to make better provisions for such services. Parents wanted their children to reach their potential and recognized that achieving success at school connected

²²⁰ Harold Wolpe. "Capitalism and cheap labour-power in South Africa: from segregation to apartheid 1." *Economy and Society* 1 (1972): 443.

²²¹ APC Archive, Durban. NCCA- Annual General Meeting Report. Services to Persons with Disabilities in Durban, 5 August 1970: 15.

²²² APC Archive, Durban. NCCA- Annual General Meeting Report. Services to Persons with Disabilities in Durban, 10 September 1972: 9.

closely with obtaining financial stability in a highly competitive marketplace. Resolving the barricades to learning was thus a significant issue for these parents.²²³

Joyce Le Brun received civic honours by the City of Durban in August 1972, and a certificate of merit for bravery and the award of Woman of the Year by the Union of Jewish Women of South Africa (Durban Branch) in October that same year.²²⁴ These were awarded to her in recognition of the skills training centres, educational programmes and nursery schools she played a role in creating, as well as the empowerment initiatives she led to assist racially disadvantaged sections of society to find employment and to become self-sufficient.²²⁵ Le Brun passed away on the 26th of October 1979.²²⁶

The last example of a pivotal voluntary initiative developed by the CCA during the 1970s was the Jabulani Centre in Zululand (near Empangeni). It was located in the KwaZulu Bantustan because of the apartheid vision of separate development. Originally founded in 1965 as a Centre for "Zulu cripples" by farmer Ian Scott Barnes and his wife, it was developed specifically for isiZulu speaking people with disabilities to develop skills through using their hands. As was reported in a *Daily News* newspaper article, the Barnes used an old farm building to give shelter initially to four IsiZulu-speaking people with physical impairments whom Mrs. Barnes trained to produce hand-made articles. ²²⁷ The clients thus lived, trained and worked in this building.

²²³ APC Archive, Durban. NCCA - Annual General Meeting Report. Services to Persons with Disabilities in Durban, 8 March 1972: 7.

²²⁴ APC Archive, Durban. Le Brun. From Pain to Purpose: 14.

²²⁵ APC Archive, Durban. Le Brun. From Pain to Purpose: 12.

²²⁶ APC Archive, Durban. NCCA- Annual General Meeting Report. Durban and Coast Central Including Ematupeni and Zimele, 10 April 1971: 17.

²²⁷ APC Archive, Durban. Daily News Reporter. "Cripple Care Cash Appeal by Prince". *Daily News*, 21 July 1972.

Although this private initiative started small, it slowly grew in size as more people in the surrounding area heard about it. It was eventually handed over to the Zululand Cripple Care Association in 1971, when it became too large for the Barnes's to manage it on their own. By the early 1970s, the Centre housed 30 disabled men and more people asked to join, including women who were also accepted.²²⁸ In 1971, it was renamed the Jabulani Rehabilitation Centre. Translated from isiZulu into English, "Jabulani" means "happiness".

At this this centre, clients were taught how to make curios and accessories for local and overseas markets from the skin and horns of impala, springbok, zebra, wildebeest and other game culled from areas around the centre. According to a CCA Jabulani Rehabilitation Centre report, this was an important strategy for local people who had been dumped in the "reserves" to try to uplift themselves. ²²⁹ It provided them with training, a creative outlet for the energies, and work opportunities. This development also, according to the above report, tried to shift the negative view associated with disabled people as unproductive members of their society.

Over time, the Centre grew in size with more and more people interested in living and working there, which put pressure on its organisers because of limited financial resources. This is evident in the words captured in a CCA AGM report of 1983:

Jabulani Centre continues to provide training and sheltered employment for disabled Zulus who despite their handicaps wish to work and learn a handicraft. Unfortunately due to insufficient accommodation we have not been able to help the growing number of applicants who write or referred to us from all over Natal and KwaZulu. With the help of a loan from Natal Cripple Care sleeping quarters for an additional twenty men will be built this year. This will enable us to increase the number of disabled to 120.²³⁰

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²²⁸ APC Archive, Durban. NCCA- Annual General Meeting Report. Jabulani Rehabilitation Centre, 30 September 1983: 8

²²⁹ APC Archive, Durban. NCCA-Jabulani Rehabilitation Centre Report, 30 September 1983: 10.

²³⁰ APC Archive, Durban. NCCA-Jabulani Rehabilitation Centre Report, 30 September 1983, 12.

By the 1980s, the Natal Cripple Care Association was operating branches in Durban, Dundee, Kokstad, Newcastle, Pietermaritzburg, Vryheid and Empangeni. This led to the development of residential facilities in Newcastle and Pietermaritzburg, as well as Protective Employment Workshops in Durban and surrounding areas, as well as Zululand and Pietermaritzburg. Craft training workshops by the 1980s were also being held in Newcastle and in southern regions of the Natal province. More social workers were also employed at most of the branches too.²³¹

Interestingly, during the 1970s, white social workers began to work in teams with black social workers for various Natal CCA branches. For example, Miss Jessiman and Mrs. Magwaza operated collectively in dealing with clients who visited the Lucigen Children's Centre in 1973. ²³² It is imperative to argue that although the apartheid system worked to divide all "race groups", by the 1970s, the CCA quietly resisted the unequal services provided in apartheid South Africa and worked to provide equal access to resources for all race groups. Lesley Dietrich, the present Provincial Director of the KZN APC claims that the interests of the Association have always been with the underprivileged and less fortunate, and by the 1980s, African clients were a key component of the CCA. Indeed, when she joined the CCA in 1986, she told me in an interview that: "Africans formed a huge part, definitely the majority part, of the clientele. Indian and Coloured and white South Africans were also part of the clientele". ²³³

Of course, this work was not easily achieved in the apartheid context. In the mid-1980s, Dietrich remembered that when she joined the committee of Cheshire Homes, an organization with similar

²³¹ Interview 2 of Lesley Dietrich. Conducted through email by S. Nxumalo in Durban.

²³² APC Archive, Durban. NCCA- Annual General Meeting Report. Services to Persons with Disabilities in Durban, 6 August 1973: 10-16.

²³³ Interview 2 of Lesley Dietrich. Conducted through email by S. Nxumalo in Durban.

interests to assist people with physical disabilities, in 1985, its committee members realized that they were being followed by security police when they went to their Durban Chatsworth meetings. Chatsworth was an Indian township created as a racially separate area under apartheid laws, and Dietrich claims that as a white person entering a black area, she and other white colleagues were often followed when they entered black townships. Fraternisation across racial lines, even for charitable purposes, was viewed as a possible threat and so was monitored. It was at one of these meeting when she met the Director of the Natal Cripple Care Association, and was encouraged to join the CCA in October 1986.²³⁴

Furthermore, government salaries paid to social workers remained separate and unequal during the apartheid period because white social workers were paid by the House of Assembly and their income was far better than African social workers who were paid by the Bantu Affairs Department. Moreover, some branch initiatives, especially those located in black areas experienced more difficulties in raising sufficient funds compared to their counterparts. This was largely due to its dependence on government funding, which was not equal for white and black welfare services, and because white clients received additional donations from wealthy private sponsors.²³⁵

In this chapter, I have delved into the history and formation of the Cripple Care Association. In the next chapter, we shall gain a glimpse into the lives, and consider the difficulties experienced by African people who lived with disabilities in the Natal province and the KwaZulu Bantustan during the apartheid period.

²³⁴ Interview 2 of Lesley Dietrich. Conducted through email by S. Nxumalo in Durban.

²³⁵ APC Archive, Durban. NCCA - Annual General Meeting Report. Services to Persons with Disabilities in Durban, 6 August 1973: 11.

CHAPTER FOUR

The Social Experiences of People who lived with Disabilities in Natal and KwaZulu from the 1970s to the early 1990s

The main aim behind this chapter is to explore the lives and experiences of six Africans who lived with physical disabilities during the apartheid period in what is today known as the region of KwaZulu-Natal. This chapter focuses on the era of the early 1970s to the early 1990s. This chapter commences with a consideration of a few methodological issues. This will be followed by more detailed analysis of the various aspects of the study's participants and their lived experiences. The latter part of this chapter will step back from analysis of my interviewees' individual lives to consider points of overlap or similarities.

The content in this chapter is drawn from interviews as it seeks to analyse the experiences of people with physical disabilities who lived during apartheid period. I purposely chose to do interviews with people who belonged to different branches of the CCA, including Ematupeni in Umlazi, the South Coast branch and the central branch in Durban. All the interviews were conducted in isiZulu because of the interviewees' language preference. I found my interviewees through the assistance of Dianne Mariah-Singh, a senior social worker whom I met at the Association for the Physically Challenged in Durban central in 2016. Once I explained my project to her, she assisted me by explaining my project to other social workers based at different branches around KwaZulu-Natal. These social workers then told their clients about my study and asked if anyone wanted to participate. Once they got some names, these social workers then arranged suitable times for the interviews in the APC branches.

In the end, although I conducted 17 interviews, not all of these interviews provided useful material for this chapter, and so I have used six interviews here to flesh out this apartheid era chapter. The interviews I use here are of five African women and one African man who are today between the ages of 42 and 54 years old who were willing to be interviewed. Interestingly, more women came forward to be interviewed for my project, and so it is important to highlight a gendered bias that comes into play. All six of the people whose interviews I used were born and/or grew up in apartheid era African urban or rural areas. Moreover, most of these interviewees, except one, came from and identified with isiZulu-speaking communities. Although I would have liked to have interviewed a few people from other "race" groups to get their comparative experiences, individuals from these "race" groups did not express an interest to their social workers to participate in my study.

All the people who participated in my study were at the time, members of the CCA/APC and were employed in their branches as crafters, handbag makers and as shoe repairers. They also all received a stipend for their work from the CCA/APC. They were all living with a variety of physical (mobility) disabilities. However is essential to note that none of the people I interviewed had been born with their impairments, rather they were caused by illnesses or injuries during their childhood years or when they were adults.

When I met these individuals to interview them, all were very welcoming and I got the sense that they felt relieved to tell their stories. Indeed, most came from communities where they felt that their views were not taken seriously. Before I started each interview I explained the purpose of my study to ensure that my interviewees' were well-informed about my research project and would feel more comfortable to tell me about their experiences. The interviews were all done one-on-one, in person, and lasted roughly an hour each.

Sibongiseni Khumalo

Sibongiseni Khumalo was born on the 6th of February 1962 in the KwaZulu Bantustan in the area of Umhlabayalingana at KwaMsane location which is about 368 kilometres south of Durban. In 1982 at the age of 20, he joined a privately owned forestry and sawmilling company at Seven Oaks near Greytown, as a sawmill machine operator that created wooden planks. Working with this machine was dangerous and he told me during his interview that workers were not even given protective equipment such as hard hats, ear protection or gloves. In 1985, Mr. Khumalo was injured on the job when his left hand got caught in a machine belt whilst making wooden planks. Four fingers were cut off which led to the dysfunction of his left hand. As a result, he lost his job because he needed two healthy hands to operate the plank machine. In 1985, he returned to his home in Umhlabayalingana at KwaMsane. While living in KwaMsane he tried to get compensation from the company for his work caused disability but he was not paid out because the owner told him that he did not follow the correct safety procedures when using the machine. At that time, he was the only person who supported his mother, younger sister, and three children. This condition led to a difficult situation.²³⁶ He told me the following during our interview:

Me and the mother of my children separated in 1984 because we had misunderstandings and I decided to take my children with me. It was two boys and one daughter. I was the only person that supported my three children, my younger sister and mother. After I was injured and left the company the situation at home got worse. No one was working at home other than me. As time went on, in 1986, my condition forced my younger sister, who was 17 at that time, to search for employment in the urban areas, which resulted her dropping out of standard 7. I remember that situation. It was painful and I could not stop it because hunger was playing an active role at home. I knew that I wanted to study but poverty at home forced me not to attend school and my sister was following this path too. I did not want my children to follow in my footsteps to not become educated but this situation forced them to search for a means of survival because none of them is educated. The apartheid system has affected me in an unpleasant way. 237

²³⁶ Interview of Sibongiseni Khumalo. Conducted by S. Nxumalo in Durban. 11 September 2016.

²³⁷ Interview of Sibongiseni Khumalo.

Mr. Khumalo had plans for his family in which he wanted his children and younger sister to receive a good education and make something of their lives, but it turned out this was not to be as they were forced to leave school to search for employment to help support their family. ²³⁸

In Zulu culture, men were usually regarded as the main breadwinners for their families and this included being the primary providers of food and other necessities for their families. During the twentieth century, this role played an important role in defining the masculine attributes of a Zulu man. According to Mr. Khumalo, his inability to use his one hand led to him living a miserable life in which everyone he knew felt shame for him because he could not met the standards of being a man in his society. He asserts that he saw himself as worthless because he had to depend on his younger sister who regularly sent back money to her family to help them survive each month, which was something he hated doing. She managed to find a job working as a domestic worker in Durban.²³⁹

In his interview, Mr. Khumalo told me that in 1987, he tried to apply for a disability grant but he was not successful and he strongly affirms that this was due to the system in place at the time of the apartheid government, which did not want to assist black people. Mr. Khumalo maintained that the period of the 1980s was difficult for him as he kept seeing able-bodied people waking every day to get ready to go to work however, his life felt stuck and there was no progress. The days were the same for him, which entailed sleeping all day doing nothing productive. ²⁴⁰ Furthermore, his community also called him hurtful names in relation to his condition. ²⁴¹ He was

²³⁸ Interview of Sibongiseni Khumalo.

²³⁹ Interview of Sibongiseni Khumalo.

²⁴⁰ Interview of Sibongiseni Khumalo.

²⁴¹ Interview of Sibongiseni Khumalo.

described or spoken about as *isinqeke*, which means "a person who is unable to do anything," or "is dysfunctional". This labelling was harmful to his life. He even told me that he hated God because he saw his life as a mess. He argued that many in his society used his disability as the primary thing to identify him with, which was wrong. Mr. Khumalo believes that disability is not the most aspect of his life. He did not choose to become disabled but it happened accidentally through conditions beyond his control. He claims that people who judged him during apartheid should have focused on the person foremost and not his disability. Furthermore, he told me how people frequently separated or isolated people who are different, and failed to recognize their humanity, which went well beyond their disability.²⁴²

Another story that highlights the close link between disability and person's gender identity is that of William Zulu. Mr. Zulu lived in the KwaZulu Bantustan in Zululand in 1968. His physical disability occurred as a result of two factors: spiral tuberculosis and an unsuccessful surgery in his teenage years. William Zulu's idea about the unattractiveness of his paralyzed body took root while he was admitted to hospital to undergo surgery and to recover from his operation. He claims that the hospital was viewed by those in his community as a place to accommodate people who were weak or sick. He linked the idea of his masculinity (i.e. what it meant socially to be a man, or expectations to be a man in Zulu society) with his experience of disability. It is important to state that historically, Zulu communities put emphasis on the link between masculinity and sexuality, and they celebrated men who had many wives and children.

²⁴² Interview of Sibongiseni Khumalo

²⁴³ Ken Lipenga. "Disability and masculinity in South African autosomatography." *African Journal of Disability* 3 (2014): 6

²⁴⁴ Lipenga. "Disability and masculinity in South African autosomatography": 2.

²⁴⁵ Lipenga. "Disability and masculinity in South African autosomatography": 4.

Since he was not able to engage in sexual intercourse or have children because he was paralyzed from the waist down, he struggled to obtain recognition as a man in his society. In addition, his uncle gave him the nickname "Bachelor Boy" because he did not have a girlfriend thus could not qualify in terms of what was expected of a man in his society.²⁴⁶

Returning to my interview with Mr. Khumalo, he also told me that in rural areas, such as the area where he grew up and lived, he did not know of any organisation during the apartheid era that assisted disabled people like him. He claimed that:

It was impossible to find social workers in our area. As a disabled person I had to live a life by myself without any assistance from the government or social workers. Even medical treatments were difficult to access because clinics were located in very far places.²⁴⁷

He told me that he only began to hear about social workers after the democratic government came into power in South Africa.²⁴⁸

Lindiwe Mavis Dladla

Lindiwe Mavis Dladla was born on the 4th of August 1964.²⁴⁹ She grew up in the Port Shepstone area at Umuziwabantu, an African rural area. She lived with her mother, uncle and aunt. Her father passed away in 1972, when she was eight years old, after of a short illness. Miss Dladla told me that she got her disability when she was young and that it entailed paralysis of the right side of her body, particularly her arm and leg. Her family believed that this was caused by disease or a poor relationship between members of her family and their ancestors. In isiZulu speaking communities,

²⁴⁸ Interview of Sibongiseni Khumalo.

²⁴⁶ Lipenga. "Disability and masculinity in South African autosomatography": 7.

²⁴⁷ Interview of Sibongiseni Khumalo.

²⁴⁹ Interview of Mavis Dladla. Conducted by S. Nxumalo in Durban. 18 October 2016.

disability in the past was strongly linked to religious or supernatural beliefs, and the belief that disabilities could be inflicted on individuals by displeased ancestors, especially if an individual or household had drifted away from certain standards set by their societies.²⁵⁰ Although her family took steps to consult "traditional healers" and carried out rituals to help relieve her from this condition, it did not end her paralysis.

Eventually, to try to help her daughter, Miss Dladla's mother converted to Christianity and abandoned her traditional values. Miss Dladla claims that her mother did not allow her to go to hospital for treatment, but instead took her to faith or spiritual healers to try to assist her.

However, this situation did not help to improve her condition either. ²⁵¹

This association with the ancestors has led to unequal treatment of people who lived with disabilities. Miss Dladla recalled being called many derogatory names by members of her community during apartheid. She claims that her peers called her *inducu*, which means "a person who cannot do anything", or "is valueless". She felt worthless to her peers and family and felt hopeless in her situation.

She recalls feeling very dependent on her aunt. Since she could not walk and did not have access to a wheelchair, she had to be carried outside into the sun to get warm on cold winter days and would be carried back to her room late in the day. Moreover, when there was an important person that came to visit her family's home, she remembers how her family made her stay inside her room

²⁵⁰ Harriet Ngubane. *Body and mind in Zulu medicine*. *An ethnography of health and disease in Nyuswa-Zulu thought and practice*. (London: Academic Press Inc., 1977): 36.

²⁵¹ Interview of Mavis Dladla.

²⁵² Interview of Mavis Dladla.

because they felt that it was an embarrassment to have a person like her around. Even when she raised an important view she was neglected. ²⁵³ She told me:

I remember once when one person of the society visited my family at home and I was sitting in the sun for heat purposes and my uncle was sitting next to me. My uncle called the children to remove me because he felt that I was an embarrassment to him. He even told the visitor that he must not bother about me I am just a punishment from God (isidalwa) which meant that I could not do anything and I am worthless.²⁵⁴

Life was difficult for Miss Dladla because she felt much frustration by her situation, which was expressed in angry outbursts during her interview:²⁵⁵

I was a curse! Even my family did not consider me as a value to them. Rather they were judging as my community did. I saw my peers enjoying their lives. Some felt shame for my situation. Some would point fingers at me and some would say I am always angry. I remember some of the days I would be frustrated by the way people treated me. I would get emotional and direct my anger to everyone who was near at that time. In my outbursts, I tried to express that I was not different to them, and that they should treat me with respect. Physical disability did not define me but my condition. I had dreams like everyone on earth but I realized that I was nothing other than a 'cripple.' Life was not easy for me.²⁵⁶

Miss Dladla experienced much rejection and discrimination because of her condition. She felt that few able-bodied people in her society socialized directly with persons with disabilities. Instead, they depended, profoundly upon stereotypes in their reactions to and interactions with them.²⁵⁷

Psychologist B.A. Wright analyses the significance of development of a person's self-concept as a "social looking glass." ²⁵⁸ He argues that a person's individual thoughts and feelings about

²⁵⁴ Interview of Mavis Dladla.

²⁵³ Interview of Mavis Dladla.

²⁵⁵ Interview of Mavis Dladla.

²⁵⁶ Interview of Mavis Dladla.

²⁵⁷ Interview of Mavis Dladla.

²⁵⁸ Beatrice Wright. *Physical disability-A psychosocial approach*. (New York: Harper Collins Publishers, 1983): 21.

themselves arise chiefly from interactions with others. According to Wright, the self-esteem of persons with disabilities is thus more often than not a "replication of social stereotypes about them." ²⁵⁹ Constant denial of their importance and presence, for example, produces weakness, self-consciousness and anxiety. Therefore, society's attitudes affect self-perception. This was the case for Miss Dladla as her self-perception was influenced by her family and community's negative stereotypes about her. This in turn affected how she interacted with her peers and limited the variety of possibilities in her life. ²⁶⁰

It is also important to note that during the apartheid period, Miss Dladla did not receive any form of support such as a disability grant to assist her. Rather she maintains she felt isolated and abandoned in her rural area. She claims that because there were no wheelchairs her family had to move her around in a wheelbarrow, which was very embarrassing to her. During our interview, I also asked her the role played by the CCA in her life but she told me that she did not know about this organization because of her lack of knowledge of such organizations and its lack of reach into her rural area.²⁶¹

Ntokozo Mkhize

Miss Ntokozo Mkhize was born on the 8th of August 1964. She grew up in an isiZulu-speaking community in a rural area near to Port Shepstone called KwaDweshulwa. Although she attended a local primary school for a few years, she told me in her interview that she dropped out in grade four. At the time, her mother worked on a farm as a farm labourer in KwaDweshulwa while her

²⁵⁹ Wright. Physical disability: A psychological approach: 25.

²⁶¹ Interview of Mavis Dladla.

²⁶⁰ Interview of Mavis Dladla.

father grew vegetables and sold them in a local market to sustain their family of four. ²⁶² Until she reached marriageable age, Miss Mkhize joined her father in his vegetable garden work and assisted him to sell them.

Miss Mkhize told me that she dropped out of school because of patriarchal gender stereotypes held about girls by her parents. They felt that getting *ilobola* and marriage for their daughter was more important than education. *Ilobola*, which was also known as bride wealth, occurred when a man of marriageable age (or his family) provided payment to his future bride's family with the aim of entering a customary marriage. According to Jeff Guy, cattle played a significant role for African people because the organization and control of cattle (wealth) remained in the hands of men, and served as a currency to exchange for women. Once married, wives were then responsible for bearing her husband many children. In cases where an African woman was infertile, a husband had a right to demand his cattle back.²⁶³

As a result, women were viewed as the property of men in these patriarchal societies, first the property of their fathers who engaged in *ilobola* discussions on behalf of their daughters, and later of their husbands. Historically, Zulu culture had created the mentality that Zulu women should measure their feminine identities and progress in life through *ilobola* and their relationships with men, but also in their ability to have many children. ²⁶⁴ Women who did not get married and did not have children were regarded as lesser women as a result. Miss Mkhize felt that these gendered

²⁶² Interview of Ntokozo Mkhize. Conducted by S. Nxumalo in Durban. 18 October 2016.

²⁶³ Jeff Guy. "Gender oppression in southern Africa's precapitalist societies" in C. Walker (e d) Women and Gender in Southern Africa to 1945. (Cape Town: David Philip, 1990): 36.

²⁶⁴ Interview of Ntokozo Mkhize.

ideas greatly affected her sense of self as a woman, as she never married. However, she did bear two children in the 1980s.

During my interview with Miss Mkhize she told me that she acquired her disability because of HIV/AIDS. Miss Mkhize was infected with HIV at the age of 17 when she engaged in a sexual relationship while living as an unmarried woman. During the 1980s, after being diagnosed, and because of her lack of knowledge about this virus, as well as her inability to access quality health facilities in her rural area, Miss Mkhize started making her own medicinal preparations to help herself, which she had learnt from her mother. In isiZulu, these medicinal preparations were known as *iboza* and involved boiling the bark of a particular tree in water and drinking it on a daily basis. ²⁶⁵

Although it is unclear whether her disability was caused as a side effect of using this "traditional" medicine or complications suffered from her HIV/AIDS status, early in 1986 she recalled developing a severe infection in her left ear. This infection persisted for a couple of years until in 1989 when she was taken for surgery which left her hearing impaired in this ear. In 1987 her father passed away which required her to search for other employment. She managed to find work as a domestic worker in Port Shepstone along the Hibiscus South Coast. However, her hearing disability had an effect in her work. Soon after starting this work, she lost her job because her white employer believed that her deafness prevented her from taking orders. Even local factories did not want to hire her because of her hearing impairment. As a result, her mother and sister helped to support her. 266

²⁶⁵ Interview of Ntokozo Mkhize.

²⁶⁶ Interview of Ntokozo Mkhize.

Miss Mkhize experienced many difficulties in her community because people used to gossip about her. She claims that some used to refer her as *lento engezwa le*, which means "a person who does not hear and is deaf". Even children used to refer to her in this manner. She told me her deafness greatly influenced her life. It used to make her angry as she would see people laughing and talking to each other but, because of her hearing loss, could not always hear what they were saying, catching snippets here and there, which frustrated her. She told me that her disability also made her an angry person, which meant she did not have many friends. She felt she would have been a happier person if people were more patient with her and tried to understand her. She asserts that during the apartheid era, she did not know of any organizations that assisted people who lived with disabilities in her rural area.²⁶⁷

Nomkhosi Zondi

Nomkhosi Zondi was born on the 8th of July 1965 in Msinga village which is close to Greytown in the KwaZulu Bantustan.²⁶⁸ She did not go to school because she claims that in her family they did not consider education essential for women. Miss Zondi's father passed away in 1972 from injuries sustained from a beating. Just three years later, when she was ten years old, she got sick and doctors diagnosed her and told her that she was suffering from muscular dystrophy, which led to paralysis on the left side of her body, including her left leg. She explained to me that when she got sick, her mother (who worked as a labourer on a white farm in the area), struggled to make ends meet and to assist her daughter.²⁶⁹ Miss Zondi struggled to cope with her disability, as there

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²⁶⁷ Interview of Ntokozo Mkhize.

²⁶⁸ Interview of Nomkhosi Zondi. Conducted by S. Nxumalo in Durban. 18 October 2016.

²⁶⁹ Interview of Nomkhosi Zondi.

were limited resources for people who lived with disabilities in the rural Msinga area where she grew up.²⁷⁰

It is important to remember that many people who worked on white farms during apartheid experienced exploitative working conditions. For example, Miss Zondi's mother worked long hours and earned low wages, which meant that she could not afford to hire someone to provide special care for her daughter.²⁷¹ During apartheid children of farm workers were usually expected to follow in the shoes of their parents by working on farms too, and as children, helped their parents on the farms. The aim was to sustain a cheap black labour-force for white farmers. As a result, this affected many African children who were denied formal schooling. Many black disabled children were also denied an education, as many schools did not accommodate such children.

When Miss Zondi became ill, her mothers' white "baas" (employer) decided to evict them from his farm insisting that her mother should find another place to raise her child because his farm was not the place to take care of "crippled" people. They moved to another rural area called Ngome near Greytown close to Miss Zondi's aunt, and thus family support. When Miss Zondi's mother lost her job, it brought many hardships to their family.²⁷²

Many families suffered farm evictions during the apartheid years. Based on the research done by the South African Human Rights Commission in 1982 more than 60% of adults expelled from white farms had lived on those farms for over ten years, while nearly 15% of those adults and 56%

²⁷¹ Interview of Nomkhosi Zondi.

²⁷⁰ Interview of Nomkhosi Zondi.

²⁷² Interview of Nomkhosi Zondi.

of children who were driven out from farms were born on those farms. ²⁷³ Many adults were removed because of their age (they were too old) or too sick, or because they or family members lived with disabilities and thus were regarded as too unproductive to stay and continue to work as labourers on the farms. The research also shows that those most especially affected by removals were women and children. Indeed, more than three quarters of those removed from farms in the 1980s were women and children. ²⁷⁴ Miss Zondi and her mother had to rely on her aunt's meagre wages as a cleaner in a shop in Greytown for survival after they were evicted from a farm for months before her mother could find employment as a domestic worker at Greytown. ²⁷⁵

During her interview, Miss Zondi told me that living with disabilities in her rural community was an ordeal. Many did not understand the special needs of people like herself, who lived with disabilities. She also suffered name calling and negative stereotypes that were created by members of her community about her condition. She was called *isiphiwo*, which means "someone who is dysfunctional". She remembered that as a young woman, she found it difficult to watch other people of her generation progressing through life and getting married. ²⁷⁶ As mentioned in an earlier example, in the past women in Zulu culture measured progress in their lives through *ilobola* and marriage. ²⁷⁷

For person with my condition it was difficult to get married. Who would want to marry a person with my condition? Because it would have been difficult to even give birth to children for my husband. Life for me has been terrible.²⁷⁸

²⁷³ SAHRC (South African Human Rights Commission), "Final Report on the Inquiry into Human Rights Violations in Farming Communities". Pretoria, 2003 SAHRC, http://www.sahrc.org.za/sahrc_cms/exec/search.cgi (accessed 24 November 2016).

²⁷⁴ SAHRC (South African Human Rights Commission), "Final Report on the Inquiry into Human Rights Violations in Farming Communities": 12.

²⁷⁵ Interview of Nomkhosi Zondi

²⁷⁶ Interview of Nomkhosi Zondi.

²⁷⁷ Interview of Nomkhosi Zondi.

²⁷⁸ Interview of Nomkhosi Zondi.

Miss Zondi also remembered her difficulty during apartheid of obtaining devices to assist her in terms of her mobility. During the apartheid era, she remembered her family was forced to use a wheelbarrow to move her anywhere. During the 1980s, her family hardly have any money to pay for food and other basic essentials, never mind support her special needs:

As people with disabilities we are expected to eat healthy food. However, in the past I would eat unhealthy food because of hunger and because my family was struggling. My mother ... supported the family after she obtained a low-paying job as a domestic worker after we were evicted from the farm.²⁷⁹

It was only in the 1980s, when her mother managed to get a job in a clothing factory in Durban, which provided her with a better wage, that her mother could afford to hire someone to help to take care of her daughter, and their lives then improve a bit. Looking back, Miss Zondi maintained that in her Ngome area, there was no disability organization that assisted people like herself and she had never heard of the CCA during these times.²⁸⁰

Ntombinjani Zulu

Another difficult experience told to me was that of Ntombinjani Zulu. This interviewee was born in KwaNongoma in the KwaZulu Bantustan on the 5th of July 1968. According to Miss Zulu her disability began in 1977 when she was nine years old. She told me that her disability was caused by witchcraft. "Witchcraft" is a widely used term that has historically been used by Africans to explain poor health issues. According to Hammond-Tooke:

Witchcraft involves the cruel activities of someone who controls a power inherent in a person, a mystical being or material substance to harm others. The witch can be anyone, and allegations of witchcraft frequently occur between neighbours or families, reflecting conflicts subsequent from competition over limited means. ²⁸²

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²⁷⁹ Interview of Nomkhosi Zondi.

²⁸⁰ Interview of Nomkhosi Zondi

²⁸¹ Interview Ntombinjani Zulu. Conducted by S. Nxumalo in Durban. 11 September 2016.

²⁸² D. Hammond-Tooke. *Rituals and Medicine*. (Johannesburg: AD Donker, 1989): 86.

Miss Zulu claims that her left leg became seriously infected and despite numerous attempts to treat it, it got worse and her doctors had to amputate it. She told me that because her doctors could not explain the main cause of this infection, she believed she had been bewitched. She claimed that this occurred because her mother was in a polygamous relationship and her mother was the second wife to her husband. However, because her father spent most of his time with her mother, this frustrated his first wife and made her jealous, and so she used "*muthi*", which negatively affected her leg.²⁸³

In July 1982, Ntombinjani Zulu's father passed away and her mother left KwaNongoma with her three children and moved to Ulundi. In Ulundi, they lived with Miss Zulu's aunt. Ntombinjani Zulu told me that life was difficult for her when they moved to Ulundi because her mother was the person who supported the family through the money she earned working on a farm. She explained how it was hard living with a disability, as she received no assistance from the government. She claimed that there were no organizations that assisted people with disabilities in her rural location and she never heard of the CCA at this time.

Furthermore, she did not attend school because of her condition. It is imperative to remember that during apartheid most schools did not accommodate persons with disabilities. In addition, transport was a problem in rural areas and schools were located miles away, which made it problematic for people living with impairments to access them. In addition, the apartheid

²⁸³ Interview Ntombinjani Zulu.

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government was not interested in providing special needs training for teachers in black schools to assist persons living with disabilities. ²⁸⁴

Reflecting on her experiences, Miss Zulu asserted that she was viewed as an unimportant figure in her community. Furthermore, many people in her community either tried to exclude her or looked down upon her:

I was seen as a worthless person who cannot walk because of my situation. I have been dependent for all my life because during apartheid there were no opportunities for people like us. We were beggars. Social workers were limited so it was awkward for us. We experienced challenges and nobody could understand that because if we told them our views we were regarded as insane and sick people.²⁸⁵

She told me that the person who believed in her most was her mother. However, it was difficult because during the day she had to stay alone at home. Before her mother left for work in the early hours of the morning she would bring everything nearby that Miss Zulu would need for the day. She claimed that when her mother was at work she would have to stay in her room for the whole day. She would only shout for assistance when she needed the toilet, and her aunt Fikeni, who was not working at the time, would assist her. Miss Zulu argued that she found it hard to sit all day in the same room doing nothing. However, she had no choice but to accept the situation. She maintains that during the afternoon she would be happy when her mother returned from work:

I would be so happy when my mom came home from work because she was the one who made me feel alive every day. She would come late in the afternoon and sometimes bring some chips or cakes. It was a nice experience that made me feel that I was loved. Although life was difficult, my mom was always by my side. ²⁸⁶

²⁸⁵ Interview Ntombinjani Zulu.

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²⁸⁴ Interview Ntombiniani Zulu.

²⁸⁶ Interview Ntombinjani Zulu.

However, in 1985, when she was 17 years old, her mother passed away because a truck crashed into the car she was travelling in one late afternoon when she was returning home from work. She died from the injuries sustained in this accident. It was difficult for Ntombinjani Zulu to accept her death, but there was nothing to do to change the situation. From then on, her aunt Fikeni played an important role in her life replacing the void left by her mother's absence. After her mother's death, her aunt got employment on the same farm where her mother had worked. When she was hired, Miss Zulu told me that her aunt employed a person to look after her during the day while she was at work.²⁸⁷

Miriam Mgidi

Miriam Mgidi was raised in a poverty-stricken rural area known as Gcuwa in the Eastern Cape. She was born on the 12th of January 1974. In her interview, she told me that in 1979, when she was five years old, her mother moved to an area known as UMzimkhulu, in the KwaZulu Bantustan to search for employment. She grew up in a single parent household that relied on her mother's income that she earned working on a white farm. In a similar situation to other women already mentioned, Miss Mgidi did not receive any schooling. Instead, she helped her mother as a child labourer on the farm, packing wood. It is essential to consider that the country like South Africa, poverty tended to be a trend as apartheid policies limited the opportunities available to black people growing up in different generations from the same family. ²⁸⁸

In 1987 at the age of 13, Miss Mgidi was injured when the timber she was helping to pack fell on top of her and crushed her leg.²⁸⁹ After Miss Mgidi's accident, she lost her job as she could no

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²⁸⁷ Interview Ntombinjani Zulu.

²⁸⁸ Interview of Miriam Mgidi. Conducted by S. Nxumalo in Durban. 18 October 2016.

²⁸⁹ Interview of Miriam Mgidi.

longer do the work for the farmer she had done before. She also received no compensation for these work-acquired injuries.²⁹⁰ Historically, many people working on farms were hired on a contract basis so that employers did not have to pay them benefits if they got injured or retired. They were highly exploited and socially marginalized people.²⁹¹

Unemployment was common for people living with disabilities during apartheid, especially in the peripheral, isolated and economically underdeveloped rural areas. This was a major factor that led to chronic poverty and dependence amongst people with disabilities, but also the families who helped support them. Miss Mgidi told me that she lived a harsh life as she had to beg for everything and her community viewed her differently. She claims that people looked down upon her and saw her as insignificant because she did not marry and could not work. Although her mother was supportive, in the same year she attained her disability, her mother passed away, which brought added difficulties for this 13 year old. As a result, she then had to stay with her aunt who took care of her. However, she claims that her aunt did not value her either. She felt worthless and unimportant. Furthermore, because she needed assistance to move around, she felt she was an enormous burden to her aunt and her family: 294

When I told them that I needed the toilet, I was told that I was annoying and no one will help me. Sometimes I would be afraid to say I am hungry because I was afraid to nag them with my problems. When I had an opinion on something, I would be given pills and told to sleep. Life for me was very difficult.²⁹⁵

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²⁹⁰ Interview of Miriam Mgidi.

²⁹¹ Interview of Miriam Mgidi.

²⁹² Julian May and Juby Govender. "Poverty and inequality in South Africa." *Indicator South Africa* 15 (1998): 53-58.

²⁹³ Interview of Miriam Mgidi.

²⁹⁴ Interview of Miriam Mgidi.

²⁹⁵ Interview of Miriam Mgidi.

Nicholas Hobbs, an American Psychologist, has argued that: "prevailing arrogances by our societies about persons with disabilities not only determine the convivial anticipations and treatment accorded to a person with an incapacitation in the community, but additionally his or her self-perception and function." This means that, how people with disabilities perceived themselves as well to a large degree their emotional states, were influenced by the opinions and actions of those around them.

These issues clearly affected Miriam Mgidi as the way she was treated by family members and in her community made her even lose hope about life. She claims that she used to see herself as irrelevant because she did not even have friends, and no one wanted to associate with her, which worsened her situation. ²⁹⁷ She also did not get a disability grant during the apartheid period, and did not know about, or receive help from disability organizations such as the CCA.

Similarities of Experiences of people with Physical Disabilities during Interviews

People who lived with disabilities found it more difficult to access basic services in their black Group Areas, such as health services, transportation and schooling. As a result, all of my interviewees received little if any education. Moreover, because their areas did not have services to assist them with skills development or job placements, they remained jobless, which encouraged greater poverty for their families. People with disabilities became a marginalized group, whose issues seemed to be only of minor importance. During apartheid, "valuable people" were those who were productive contributors to their families and societies. Karl Marx argued that economic

²⁹⁶ Nicholas Hobbs. *The future of children categories and their consequences*. (San Francisco: Jossey Bass, 1973): 84

²⁹⁷ Interview of Miriam Mgidi.

structure played an important role in organizing societies.²⁹⁸ This also affected people with disabilities as many were viewed by able-bodied people as economic burdens and unproductive.

Living as a black person under the hierarchical "race" organized apartheid system meant the worst services and the least opportunities for African people. Yet, if Africans generally were viewed and treated as second-class citizens, African disabled people were viewed and treated as even less than this because of their disabilities. Those who were injured whilst working were not compensated for their injuries. Many were also forced to return to rural reserve areas if they worked and were injured in the city. During apartheid, my interviewees also highlighted that they could not travel around easily and that mobility was a big problem for people who lived with disabilities. Their rural environments were not made into accessible places by the government, and did not accommodate their needs. Many spoke about having to use wheelbarrows to move around, which was humiliating for them. There were also no jobs for them, and no government laws promulgated that protected their right to equal work opportunities.

Another common set of issues to emerge from my interviews was that societies created negative stereotypes about persons with disabilities. They were called names such as isidalwa, inducu, isinqeke and isiphiwo, which all revolved around the dysfunctionality of their bodies. They felt that able-bodied people did not respect them and continued to make unfair generalizations about people who lived with disabilities. This attitude of assuming that disability defined the person's

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²⁹⁸ Karl Marx and Frederick Engels. The German ideology: with selections from parts two and three, together with Marx's "Introduction to a Critique of Political Economy". Edited by C.J. Arthur In: *The new dialectic and Marx's Capital*. (London: Lawrence & Wishart, 1974).

identity continued to persist. The culture of not accepting people with disabilities as fully human persevered.

People with disabilities have also often been forced into the receiver role. This then became their identities because they needed help to do things and had to rely on other people. This even led to a lack of creativity and self-assurance. In this way, people with disabilities looked to be groomed into becoming receivers rather than self-determining people. The receiver role is conversely not necessarily the easy way out, as people become dependent on other people.²⁹⁹

Most of the people I have interviewed also came from under-developed and under-serviced rural areas so they did not have support in the form of assistance in their everyday lives, through for example counselling services and training. All of my interviewees told me that in their rural areas, none knew about or accessed CCA services during the apartheid period. This highlights that the CCA's services during the apartheid were limited to certain areas, particularly urban areas, while many people who lived with disabilities in less developed rural areas did not benefit from its skills training and job placement opportunities.

Most people from rural areas who lived with physical disabilities also made mention of the link in their societies between diseases/disability and supernatural beliefs in terms of causes of their disabilities. If it was resolved that their disability was caused by an angry ancestor and their ritual appearaments failed, it encouraged a greater sense of helplessness in individuals. However, belief in witchcraft as a cause for disabilities could have also promoted greater tensions or hostilities

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²⁹⁹ Colleen Howell, Schuaib Chalklen, and Albert Thomas. "A history of the disability rights movement in South Africa." *Disability and social change: A South African Agenda* 12 (2006): 53.

between people in a community if it was believed that an individual had been bewitched by another person.

Finally, my interviewees' statements have raised important gender issues to consider. Firstly, a person's disability could directly impact on their gender identity in isiZulu speaking societies. As discussed in some of my interviewees' life experiences living with physical disabilities could emasculate a man if his disability prevented him from earning a living, marrying or producing children, and it could undermine the femininity of women if they could not attract a husband or bear children. Secondly, many of my interviewees grew up in single parent households, which added to their financial hardships. In all except one case, all caregivers for my interviewees were females, especially mothers, but also aunts and sisters. In IsiZulu speaking societies, caring was regarded as woman's duty not a man's obligation. We therefore need to recognize the important behind- the-scenes support provided by many unsung women carers in the context of family homes where there was little or no organizational or institutional support for their disabled loved ones.

The next chapter will explore the policies created by South Africa's democratic government. Many of these policies were created with the intention of improving the lives of people living with disabilities. The following section will also consider the effects of democracy on the work of the Cripple Care Association.

CHAPTER FIVE

Democracy, Disability Policy Changes and the Cripple Care Association (CCA) /Association for the Physically Challenged (APC)

An image the world will remember of the first democratic elections in South Africa in 1994 is that of thousands of people with disabilities queuing at voting stations across the country under the hot African sun. They came to exercise their right to vote under the most difficult of circumstances. They came in wheelchairs, on crutches, navigating their way by means of white canes, in wheelbarrows and even physically carried on the backs of relatives and friends. Why did they come? They came because they knew that the policy and practice of apartheid had only served to compound their experience of discrimination, indignity and poverty as a result of society's response to their differentness. They came to participate in one of the most empowering experiences ever. They came because they had a vision of a better dispensation under new conditions of liberation and democracy. In support of their vision was the fact that the Interim Constitution had already outlawed discrimination on the grounds of disability. For the first time, disability was recognized in South Africa as a human rights issue, as opposed to the more traditional approach of health and welfare, a four hundred year old approach which still left disabled South Africans caught in a poverty trap of dependence and disempowerment.³⁰⁰

This speech, delivered by the then President Thabo Mbeki in 1998, captures well the feeling of hope that the 1994 elections gave to persons with disabilities. In this chapter I will examine the role played by South Africa's first democratic government in addressing issues affecting people with disabilities from the early 1990s into the 2000s. The principal intention of this chapter is to focus on the post-apartheid era and to look of whether this government brought improvements, via their policies to the lives of people with disabilities. This chapter will also look at how the CCA was influenced by the transition to democracy.

³⁰⁰ Thabo Mbeki. Speech by the Deputy President Thabo Mbeki at the Official Opening of the Perkins Brailler Project, transcript, UNISA. 16 January 1998 (accessed 4 November 2016), http://www.unisa.ac.za/contents/colleges/docs/1998/tm1998/sp980116.pdf.

On 2 February 1990, President F.W. de Klerk's made a speech at the opening of parliament in Cape Town that signalled a major change for South Africa. During his speech, he promised to un-ban South Africa's major anti-apartheid organizations and release Nelson Mandela, as well as other prisoners, who had been charged with political offences under apartheid. He also declared his government's willingness to negotiate with leaders from these anti-apartheid organizations to plot a new way forward for the country. ³⁰¹ Democracy rather than apartheid would become the political mantra of the 1990s.

South Africa's first non-racial, democratic election was held on the 27th of April 1994. The coming to power of the African National Congress (ANC) led government saw the beginning of what Sang Hyun Seo has called an "inclusionary democracy" and an end to "racial oligarchy". ³⁰² Chantelle Van Der Byl has asserted that this country's mostly non-violent transition to democracy was, and still is "regarded as a phenomenon." ³⁰³ It brought with it a lot of hope and optimism about the future, particularly for those who were previously disadvantaged, such as black South Africans, but also people living with disabilities.

According to the South African Government's Disability Background Paper:

Before 1994, programmes designed to meet the needs of persons with disabilities by government were based on the similar value system about disability, building on the segregated apartheid policies and entrenching further violations of human rights and dignity. Children with disabilities, the majority being white, were found in segregated special schools, and the majority of adults with disabilities (72.6 percent) remained unemployed or at best were found in sheltered employment with no opportunities for

³⁰¹ Arnold Guy. *South Africa: Crossing the Rubicon*. (London: Macmillan, 1992): 31. Also see Sang-Hyun Seo. "A study of democratic transition in South Africa: democratic through compromise and institutional choice". (PhD Diss. University of South Africa, 2008): 25.

³⁰² Seo. "A study of democratic transition in South Africa: democratic through compromise and institutional choice": 96.

³⁰³ Chantelle Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability". Retrieved from: www.dpme.gov.za/publications/20%20Years%20Review/.../20YR%20Disability.pdf. (Accessed 14 November 2016).

career choices. The first democratic government thus inherited a legacy of discrimination, a lack of understanding of disability as a human rights issue and social exclusion of persons with disabilities.³⁰⁴

This quotation, recorded in a document written by the post-apartheid government to portray a clear understanding of its role and responsibilities in implementing disability policies to encourage reform in the country, captures well the difficulties I discussed in the last chapter of the hardships that were experienced, particularly by Africans who lived with disabilities in apartheid South Africa.

It is important to note that people, who lived with disabilities, as well as their families and supporters, played an active role in the 1980s to bring the inequalities experienced by disabled people into the public domain. Colleen Howell, Shuaib Chalklen and Albert Thomas argue in their article, "A History of the Disability Rights Movement in South Africa" that people who lived with disabilities started better organizing themselves from the mid-1980s. This took place at the same time as mounting activism against apartheid, and these disability organizations aligned themselves with the wider anti-apartheid liberation movement. 306

Disabled People of South Africa (DPSA) is a good example of this. It was established in 1984. Created by a group of disabled people and their supporters, it was formed to encourage improvements in the lives of people with disabilities, as well as to promote greater awareness of their lives and difficulties amongst the able-bodied. From this period DPSA started an approach of encouraging the growth of a larger number of local organisations (which were affiliated to

304 Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 15.

³⁰⁵ Colleen Howell, Schuaib Chalklen, and Thomas Alberts. "A history of the disability rights movement in South Africa." *Disability and social change: A South African agenda* 12 (2006): 49.

³⁰⁶ Howell, Chalklen, and Thomas. "A history of the disability rights movement in South Africa": 63.

DPSA), to support and empower disabled people, and to promote disability issues with the aim of promoting improvements. 307

Chantelle van der Byl maintains that "the choices made to align DPSA to the political struggle", as well as "specific strategies adopted and actions undertaken by DPSA before 1994 laid the foundation of the principle of self-representation, advocacy and dignity." ³⁰⁸ Moreover, with the recognition and promotion of the right to self-representation by the new government, DPSA became a significant driver of progress for individuals who lived with disabilities.

An Office on the Status of Disabled Persons (OSDP) was created in 1994 as a new office in the government to influence policy decisions. Its aim was to encourage ministries to become more disability sensitive and to develop projects that focused on a particular group who had experienced the most severe forms of sidelining. An important aim of the OSDP was to bring to light disability as a major issue to be addressed in the public sector, as well as in civil society. 309 Richard Peet has argued in his article on development in post-apartheid South Africa that without DPSA and OSDP's influences:

South Africa's Reconstruction and Development Plan (RDP), which was a socio economic policy produced by the African National Congress (ANC) government and its alliances to address the massive shortfalls in social services across the country that the apartheid government had caused, would not have considered the needs and aspirations of persons with disabilities.³¹⁰

Furthermore, this Office on the Status of Disabled Persons produced a White Paper. A South African White Paper is an authoritative report that informs parliamentarians and citizens about a

³⁰⁸ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 8-16. ³⁰⁹ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 23.

³¹⁰ Richard Peet. "Ideology, discourse, and the geography of hegemony: From socialist to neoliberal development in post-apartheid South Africa." Antipode 34 (2002): 56.

³⁰⁷ Howell, Chalklen and Albert. "A history of the disability rights movement in South Africa": 56.

particular issue and presents the issuing body's viewpoint on the matter.³¹¹ It is also intended to help lawmakers understand an issue, solve a problem, or make a decision. This White Paper was called the Integrated National Disability Strategy (INDS) for South Africa. The main focus of this strategy paper was to create "a society for all" where "the needs of all citizens constitute the basis for planning and policy, and the general systems and institutions of society are accessible to all."³¹²

It is vital to state that before the transition to democracy in South Africa the DPSA, together with the Disability Rights Unit of Lawyers for Human Rights, produced a document in 1992 called the Disability Rights Charter. This charter set out to do a number of things. It aimed to redress the imbalances and the continual discriminations experienced by people who lived with disabilities in South Africa, and called for such people to enjoy equal opportunities to able-bodied people. It focused on the need for the country to provide accessible resources to assist such persons through development of rehabilitation services and health facilities. Furthermore, the charter emphasized that education, employment, sport and recreation, social justice, housing and transport should be made widely accessible to persons living with disabilities in South Africa. 313

Together with guidance from the United Nations, with its standard of equity for people living with disabilities and the Disability Rights Charter, the new democratic government directly worked to include and give equal rights to people with disabilities in Section 09 of the Constitution of South Africa in 1996.³¹⁴

³¹¹ Karen Miller. *Public sector reform: governance in South Africa*. (United Kingdom: Gower Publishing, Ltd., 2005): 96.

³¹² Sebenzile Matsebula, Marguerite Schneider, and Brian Watermeyer. "Integrating disability within government: the Office on the Status of Disabled Persons." *Disability and social change: A South African agenda* 14 (2006): 33.

³¹³ Howell, Chalklen, and Alberts. "A history of the disability rights movement in South Africa": 51.

³¹⁴ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 36.

The Integrated National Disability Strategy was significant as it moved understanding of disability away from health and welfare issues to a "rights-based matter". Stablished with the aim of removing obstructions experienced by persons with disabilities in all aspects of their lives, the INDS emphasized the important roles that government bodies, as well as civil-society groups had to play in structuring a more inclusive environment for people who lived with disabilities. The emergence of the INDS in the mid-1990s enabled the review of old laws and facilitated the development of new laws within the frameworks of the transformation agenda. As a result, a number of new laws were promulgated soon after the INDS was formed, such as the Employment Equity Act (Act 55 of 1998), the Skills Development Act (Act 97 of 1998) and the Promotion of Equality and Prevention of Discrimination Act (PEPUDA) (Act 4 of 2000). Together these laws, as Van der Byl argues "instituted a non-discrimination legal agenda focused on sustaining the rights of all people living with disabilities."

Disability Policy Transformation in Post-Apartheid South Africa Health Policy

With regard to health policies there were many transformations made and this was largely due to the greater demands from South Africa's citizens for access to treatment for HIV/AIDS, tuberculosis and other transferable diseases. However, the responsibility of the Department of Health to deal with issues like HIV/AIDS took many years. ³¹⁹ HIV/AIDS was a serious issue that faced South Africa in the post-apartheid period. According to Neville Hoad, in 2005, South Africa had over 5-million people who had contract HIV/AIDS. In addition, there were about 1000 new infections and about 600 people, dying every day from this disease. The problem that faced South

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³¹⁵ Brian Watermeyer. Disability and social change: A South African agenda. (Pretoria: HSRC Press, 2006): 36.

³¹⁶ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 41.

³¹⁷ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 42.

³¹⁸ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 42-58.

³¹⁹ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 59.

Africa between 1998 and 2008 was a government, led by President Thabo Mbeki, who denied the link, established by scientists, that HIV caused AIDS.³²⁰ He argued that the risks of antiretroviral drugs outweighed their benefits, and delayed access to treatment, which led to the deaths of thousands of HIV/AIDS sufferers. It took a great struggle from civil society organisations, such as the Treatment Action Campaign, including legal battles, and a change in leadership, before ARVs began being giving to patients.³²¹ During the 2000s, rollout of drugs for these diseases was made at public hospitals, though this has not always been smooth sailing with financial restraints and other capacity issues being major problems.

Furthermore, there were transformations made in terms of access to health care services for people with disabilities. Largely caused by the inequalities produced under apartheid, in the 1990s the democratic government also worked to provide free health care for pregnant women, as well as for children under six years of age, including children with disabilities. It is significant to note that "persons with disabilities receiving a care dependency or disability grant qualified for free health care in government clinics and hospitals too." 322

In reaction to the INDS, the national Department of Health built up the National Rehabilitation Policy in 2000, which had impacts on access to treatments specifically on people living with disabilities. With this approach, government, working with the disability sector, but also with various professional organizations, universities and international bodies, started to put the main standard of "equity" for people with disabilities into practice. Access to rehabilitation services, "a

³²⁰ Neville Hoad. "Thabo Mbeki's AIDS blues: The intellectual, the archive, and the pandemic." *Public culture* 17 (2005): 115.

³²¹ Edwin Cameron. "AIDS denial and holocaust denial-AIDS, justice and the courts in South Africa." *South African Law Journal* 120 (2003): 525.

³²² Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 62.

United Nations precondition for equality for individuals with impairments," was recognized as essential.³²³ Rehabilitation means services committed to improving or restoring something to its original state, for example, improving the quality of life of a person after such a person has suffered some form of impairment from illness, surgery and injury.³²⁴

These services were gradually provided for more South Africans in public and private hospitals or clinic facilities during the post-apartheid period. Paul Chappell and Christa Johannes-Meier, who have both done research on disability issues in South Africa claim that expanded rehabilitation service delivery has been possible for more people but that much still needs to be done. Using a qualitative research design, these researchers did individual and focus group interviews with people with disabilities and their family members in both urban and rural settings within six provinces of South Africa (KZN, Gauteng, Free State, North West, Limpopo and Mpumalanga) in the early 2000s. They found that problems restricting access to rehabilitation services include structural factors, such as lack of accessible transport or overcrowded health care facilities that caused long waiting times; continued negative attitudes and lack of knowledge among health care workers about the needs of people with disabilities, as well as language communication difficulties. These factors were worsened in rural areas where travel times were longer, costs higher, education and information were poorer, and there were fewer, more poorly resourced hospital services available.³²⁵

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³²³ United Nations. Dept. of Public Information. "The standard rules on the equalization of opportunities for persons with disabilities". United Nations, 1994. Retrieved from www.ohchr.org. [Accessed on 18 November 2016] ³²⁴ Kate Seelman. "Trends in rehabilitation and disability: Transition from a medical model to an integrative model." *Disability World* 1 (2003): 1-21.

³²⁵ Paul Chappell and Christa Johannes-Meier. "The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa." *Disability and Rehabilitation* 3 (2009): 11.

Furthermore, the Department of Health has also tried to provide in the early 2000s, health care services that enabled earlier identification and management of intellectual and emotional forms of impairments. This has been captured in the "Twenty Year Review of South Africa 19942014" background paper on disability:

Impairments that could lead to disability were affected by measurement challenges. Communication, intellectual and emotional categories only started to emerge from 2007, with more awareness in identifying all types of disabilities through appropriate measures. Thus, a neglected area of need in disability was addressed through the Mental Health Care Act of 2002, which outlined the rights of persons with intellectual and psycho-social disabilities and also prioritized the provision of community-based mental health services. 326

Social Security

South Africa's government social security system began in the racial segregation era with the government's attempt to provide welfare services for certain categories of white South Africans. These included military annuities (1919) for soldiers who had fought in the First World War, social benefits grants (1928) for old white people, benefits for war veterans (1941), as well as stipends for larger, underprivileged white families (1947). 327 During the apartheid period, the Pension Funds Act of 1956 provided pensions to injured and/or disabled at work. The purpose of this grant was to compensate individuals for loss of income, but it did not compensate people for every disability as is the case today and mostly compensated white South African workers. It was only in the 1970s when rapid industrialization brought larger numbers of African labourers into industries, and trade unions fought for improved benefits for African workers that benefits started extending to Africans too.

³²⁶ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 67.

³²⁷ Servaas Van der Berg. "South African social security under apartheid and beyond." *Development Southern Africa* 14 (1997): 491.

In the post-apartheid period, Section 27 of the Constitution of South Africa made provision for the development of an extensive social security system, which led to the promulgation of the South African Social Security Agency Act (Act 9 of 2004) and the formation of the South African Social Security Agency (SASSA). Children and adults with disabilities across all race groups have since then benefited from social support through disability grants that were introduced and paid out each month. 328

The White Paper on South African Social Welfare Policy explains the idea of social security "as poverty prevention, poverty alleviation, social compensation and income distribution." ³²⁹ In addition, the White Paper describes social security as the provision for people of sufficient monetary and social protection when unemployed, in times of illness, during maternity, disability, old age and widowhood to be able to contribute to their essential needs.

The research in South Africa shows that there has been a reduction of poverty because of the provision of social grants. This also relates to persons and families affected by disability. Many academics and organizations have claimed that disability is both a reason for and a result of poverty. Scholarship which has been conducted on the South African population has also found that access to disability grants have played an important role in raising family incomes. However, one also needs to be critical about this because there is the possibility that some disabled people feel pressured by exploitative family members because they receive grants. This can occur when a disabled person's caretaker uses that person's disability grant for their own personal uses

³²⁸ Rebecca Surender. "Social assistance and dependency in South Africa: An analysis of attitudes to paid work and social grants." *Journal of Social Policy* 39 (2010): 210.

³²⁹ White Paper on South African Social Welfare Policy, 1997 chapter 7.

³³⁰ Mitchell Loeb. "Poverty and disability in eastern and western cape provinces, South Africa." *Disability & Society* 23 (2008): 316.

³³¹ Madeleine Duncan, Leslie Swartz, and Harsha Kathard. "The burden of psychiatric disability on chronically poor households: Part 1 (Costs)." *South African Journal of Occupational Therapy* 41 (2011): 61.

because the person he or she cares for is highly dependent on them for their care, and thus an easy target for such activities to take place. The important issue here is whether the disabled grant receiver can retain autonomy in these situations because sometimes people with disabilities are not able to independently access or use their disability grants. In furthering the transformation agenda, the Department of Social Development also created a Disability Services Unit. This Unit has worked in partnership with non-governmental organizations to extend services to people living with disabilities.³³²

Educational Opportunities

The Constitution of South African under the South African Act 84 of 1996 provided a transformed educational structure too. White Paper 6 on Inclusive Education (EWP6) was important as it shifted the focus from providing separate facilities for children living with disabilities to providing more support and removing barriers in ordinary schools for such children.³³³ It is important to also acknowledge that the Disability Rights Charter stressed on the fact that:

Disabled people shall have the right to mainstream education with personal assistance where necessary, appropriate assistive technology and specialized teaching and parents of disabled children shall have the right to participate in the planning and provision of their children's education.³³⁴

In 2002, the Department of Education worked with South African NGOs, higher education facilities in the North West, the Eastern Cape and KwaZulu-Natal and the Danish International Development Agency (which provided funding) to pilot a project focused on inclusive education.

³³² Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 68.

³³³ South African Schools Act 84 of 1996. (Pretoria: Government Printers 1996): 3.

³³⁴ Howell, Chalklen and Albert. "A history of the disability rights movement in South Africa": 42.

As a consequence of this pilot project, the Department of Education produced a number of guideline documents to screen, identify and assess learners, as well as to aid in what government called their "appropriate placement." Children living with disabilities, who were incontinent, were also provided with help in the form of incontinence clinics at special needs schools. Parents of Children with Special Needs (PACSEN) played an important role here, working in partnership with the government.³³⁵

Higher education is important for everyone living in South Africa, particularly to those who were denied access to this opportunity during the apartheid period. Since the early 1990s, much emphasis has been placed on providing better access to higher education facilities for people living with various disabilities. Knowledge Matshedisho Rajohand has written much on the subject of "Access to Higher Education for Disabled Students in South Africa." Provision of disability units at eleven higher education institutions has been key. These have provided support services for students, though budget restrictions on some campuses or insufficient staff have made some campus disability services less functional compared to others. ³³⁶ In 2008 the Department of Education also introduced a university bursary scheme for students studying at one of the country's public universities who were "academically able but in financial need." This money was provided to help cover tuition costs, but also study material, assistance devices, employment of aids to assist if required, as well as accessible accommodation and transport.

³³⁵ Shafika Isaacs. "ICT in education in South Africa." *Survey of ICT and Education in Africa: South Africa Country Report* 21 (2007): 21

³³⁶ Matshedisho Rajohane, Knowledge. "Access to higher education for disabled students in South Africa: A contradictory conjuncture of benevolence, rights and the social model of disability." *Disability & Society* 22 (2007): 54

³³⁷ Van Der Byl. "Twenty year Review South Africa 1994-2014: Background Paper Disability": 70.

Employment

Job opportunities are vital to developing and sustaining people who live with disabilities. Moreover, gainful employment helps make employees feel a sense of being independent. Skills development has been regarded as one of the major factors to help curb inequalities and poverty. This was promoted in the government's Employment Equity Act, which lay out strategies to avoid discrimination in the work place on the grounds of disability. In 2000, the government set a goal of 2 percent for employment of persons with disabilities for all government sectors. This was done through the establishment of the policy of affirmative action, which fell under the Employment Equity Act. ³³⁸

Uduak Archibong and Oluyinka Adejumo argue that affirmative action is a method to make the workplace more representative and less discriminatory to workers. It ensures that "qualified people from chosen groups have the same opportunities in places of work." This included black South Africans, but also women and people with disabilities. Historically, these people had been sidelined in many areas of work.

Furthermore, the Skills Development Act was passed in 1998 to empower people with disabilities to access learnership programmes to improve their skills. To enhance the ability of employers to deal efficiently with disability matters, the Technical Assistance Guidelines for Employment of People with Disabilities was written up by the Department of Labour in 2004. These guidelines were also meant to guarantee equitable accommodation and equal opportunities for persons with

³³⁸ Paseka Ncholo. "Reforming the public service in South Africa: A policy framework." *Public Administration & Development* 20 (2000): 87.

³³⁹ Uduak Archibong and Oluyinka Adejumo. "Affirmative Action in South Africa." *Journal of Psychological Issues in Organizational Culture* 3 (2013): 24.

disabilities in the working environment.³⁴⁰ The Compensation for Occupational Injuries and Diseases Act of 1997 (COIDA) also highlights a determined efforts on the part of the government to recognize and compensate disabilities caused by work-related injuries. However, its emphasis was on reimbursement rather than re-employment for people who sustained such injuries.³⁴¹

Redistribution of Wealth Policies

Francis Lund's research on state social benefits in post-apartheid South Africa has argued that the democratic government has also attempted to address "problems of socioeconomic reimbursement for previously marginalized people." ³⁴² Good examples of this are the Preferential Procurement Act (PPA) and Broad Based Black Economic Empowerment (BEE). PPA outlines the procedures that must be followed by service providers in order for them to qualify for tender selection. BBE was a programme introduced by the South African government to "redress the imbalances of apartheid" by giving certain previously underprivileged groups, such as African, Coloured and Indian citizens economic privileges previously not accessible to them. ³⁴³

Although it is significant to acknowledge a variety of policies implemented by the democratic government in South Africa that have bettered the life experiences and opportunities for people with disabilities, it is also important to acknowledge that there are still many challenges that negatively affect the lives of such people. One of the problems relates to some government departments (usually at the provincial or municipal levels) that continue to downplay the needs of

³⁴⁰ Robert Venter, Matthew Grossett, and Stephen Hills. *Labour Relations in South Africa*. (Cape Town: Oxford Southern Africa, 2003): 64.

³⁴¹ Thami Ndlovu. "Compensation for Occupational Injuries and Diseases Act: a case for amendment." *De Rebus* 406 (2001): 13.

³⁴² Frances Lund. "State social benefits in South Africa." *International Social Security Review* 46 (1993): 17.

³⁴³ Simon Roberts and Lance Van Sittert. "'Black Economic Empowerment', business and the state in South Africa." *Development and Change* 39 (2007): 941.

people with disabilities, or marginalise them as a minority group. Many government departments and municipalities also do not do enough to align their strategies in helping people with disabilities. Government departments often only focus on people with disabilities when it is time to celebrate the International Day of Disabled Persons, and after this day or event, they are forgotten. This means that their needs are not sufficiently prioritised, and thus often go unmet.

Although it is a Constitutional right in the post-apartheid period, some people with disabilities are still not able to access basic education. Indeed, the high level of functional illiteracy amongst disabled adults is a direct result of the lack of educational opportunities for children with disabilities, especially in rural areas. This has resulted in low skills levels and thus limited access to employment opportunities, which has led to continued poverty. Michael Aliber has argued that many in South Africa still regard children with disabilities as incapable, as ill or as a burden on society. In other words, they represent a "problem" to be dealt with separately from other children's issues. Aliber maintains that "more than 80% of black children with disabilities live in extreme poverty in inhospitable environments. They have very poor access to appropriate health care facilities and early childhood development opportunities". When born into families of poor socio-economic backgrounds, such children frequently grow up believing that their disabilities are an economic and social curse and burden on their families. As a result, they often perceive themselves to be worthless. Government has not addressed these persisting issues.

There are other issues to consider too. Although it is essential to recognise the work done by the Department of Social Development in providing social grants for people living with disabilities,

³⁴⁴ Michael Aliber. "Chronic poverty in South Africa: Incidence, causes and policies." *World Development* 31 (2003): 483.

we also need to recognise that the ideology behind giving such grants is still flawed. This department still uses the health model of understanding disability to guide its policies, which relegates people with disabilities to being cared for rather than being supported to play active roles in their societies. Other than giving grants, the Department of Social Development could do more to improve knowledge about disability, especially in rural areas. For example, they could organise more outreach campaigns and workshops to further educate such communities about disability issues, and help such communities appreciate greater possibilities and opportunities for disabled people amongst them to improve their lives.³⁴⁵

Finally, with regard to the establishment of Black Economic Employment (BEE) initiatives, many black South Africans with disabilities have not benefited from BEE benefits. Lack of access has played a huge role in the persistent marginalization of persons with disabilities. In recent years therefore, disability activists have called for the need to revise BBE Charters and Codes to include recognition of people with disabilities. They have also lobbied to provide disabled people with access to more commercial opportunities as well as monitoring and assessment of their needs to remove disability specific obstacles in the business sector.³⁴⁶

From the Cripple Care Association (CCA) to the Association for the Physically Challenged (APC): Changes that Affected this Organization in the Democratic Era

The Cripple Care Association shifted its name to the Association for the Physically Challenged in 1993. The major reason that influenced this name change was South Africa's move towards a democratic direction of inclusion. Those running the organization voiced concern with the use of

³⁴⁵ Aliber. "Chronic poverty in South Africa: Incidence, causes and policies": 476.

³⁴⁶ Lund. "State social benefits in South Africa": 13.

"cripple" in the organization's original name.³⁴⁷ They felt that the continual usage of this term was insensitive and did not capture the complex range of physical disabilities that their many clients lived with.³⁴⁸ Furthermore, the merger of the old Bantustan of KwaZulu and Natal into one province – KwaZulu-Natal – in late 1993 also compelled the organization to transform its name to reflect everyone without any discrimination.

After 1994, the clientele demographics of the APC organization changed. The branches that had originally allowed only white clients with disabilities began to accept blacks as members. A good example of this was the Durban CCA branch. As the biggest branch in the province, and one that had historically had a white membership, by the 1990s, it became increasingly dominated by African and Indian clientele. Other historically white branches also followed this pattern, and are now made up of a "racially" mixed clientele. The branches that were created in the old townships of Umlazi and KwaMashu, such as Ematupeni and Zimele, have remained dominated by African clients because they continued to serve clients in their immediate environment, who have remained mostly African demographics.

The democratic government has played a more central role since 1994 in subsidizing some of the operations of the APC, although the APC continues to operate as a private organization. According to the KZN Provincial Director Lesley Dietrich, the Association has received over the last few years annual subsidies from the KwaZulu-Natal government to help cover the cost of its residential facilities, and protective employment workshops.³⁴⁹ These workshops have provided opportunities for people with disabilities to develop and improve their skills and to earn an income

³⁴⁷ Interview 1 of Lesley Dietrich. Conducted face-to-face by S. Nxumalo in Durban. 18 September 2016.

³⁴⁸ Interview 1 of Lesley Dietrich.

³⁴⁹ Interview 1 of Lesley Dietrich.

through the products that they make, which helps subsidize their disability grants.³⁵⁰ The subsidies received constitute approximately 50% of the APC's annual expenditure. The Association also benefited during the post-apartheid years from funding from National Lottery funds. These funds have enabled the APC to purchase accessible vehicles, upgrade facilities and assist with running costs.

Dietrich told me that in 1996 she was able to extend social work services offered by the APC, which helped its clients. During this period, she was able to expand her staff contingent from two social workers to eight social workers to work in all four branches of the APC around Durban, whereas before expansion in staff numbers had not been possible.³³⁴ Historically the duties of social workers included working with people who matched their "own race group" because of segregation laws, which limited some of the duties of social workers. However, in the post-apartheid period, APC social workers were able to work with and help clients of all "race groups." Social work services aim to empower people with disabilities by providing them with suitable knowledge to access applicable services, the skills to solve their problems and to achieve their full potential to lead self-regulating and more independent lives.³⁵¹ In the democratic era, the KZN APC has attended to many social issues and many home visits. For example, 2011 alone, almost 1,580 interviews were conducted with clients either telephonically or face-to-face about the issues they faced on a daily basis.³⁵² Inquiries, which were attended to, included the following, which were recorded as "service provisions" provided by the APC in its archival records:

applications for social disability grants and identity documents (IDs), Psychosocial provision for people with disabilities and their families, unemployment problems and appointments in the workshops, housing services and school placement as well

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³⁵⁰ Interview 1 of Lesley Dietrich.

³⁵¹ Interview 1 of Lesley Dietrich.

³⁵² APC Archive, Durban. Service Provisions to People with Physical Disabilities by the APC. APC Pamphlets, 2013.

as applications for bursaries, Application for assistive devices and Road Accident Fund (RAF) claims, applications for housing and applications for learnership programmes.³⁵³

To promote individual self-development and to provide supportive services, group work methods have been used in recent years. There were 22 support and life skills groups that were facilitated by social workers for KZN APC clientele between 2010 and 2011.³⁵⁴ This increased to 37 group sessions conducted by social workers between 2011 and 2012. The beneficiaries consisted of adult women and men as well as youth and children with physical disabilities. The topics that were covered during group sessions included: hygiene, social skills, self-employment, disability and dating, self-awareness and development, communication skills, problem solving, assertiveness training, anger management, decision-making, positive lifestyle, HIV/AIDS education, other health issues, improving communication, and disability issues.³⁵⁵

Provincial Director Dietrich also told me that during the last two decades there has been tight monitoring and evaluation of disability services with several visits to the APC each year by the KZN Department of Social Development to observe the environment for its suitability for persons with disabilities. This did not happen during the apartheid period. This was to ensure that service delivery was carried out according to similar standards as government subsidized some of its operations.³⁵⁶

Another influence of the democratic transition to the organization was transformation in its service programmes. During the apartheid era, the CCA trained people to work as domestic workers,

³⁵³ APC Archive, Durban. Association for the Physically Challenged. Service Provisions by the APC.

³⁵⁴ APC Archive, Durban. Association for the Physically Challenged. Service Provisions by the APC.

³⁵⁵ APC Archive, Durban. Association for the Physically Challenged. Service Provisions by the APC.

³⁵⁶ Interview 2 of Lesley Dietrich.

gardeners, and in factories, but after 1994, this perspective shifted. People living with disabilities began to be placed in learnership programmes. A learnership is a work-based education programme that leads to job placements. Learnerships are directly related to an occupation or field of work. The APC works as an organization that deploys people after training them to certain government departments and private companies. The organization has also embarked on providing clients with Adult Basic Education Training (ABET), which provides people with disabilities with the opportunity to attend classes to upgrade or complete their matric studies. It is an important initiative that tries to give previously disadvantaged people who were earlier denied access to education, a chance to further their studies. The provides people who were earlier denied access to education, a chance to further their studies.

However, while it is true that significant strides have occurred in being responsive towards the needs of people with disabilities, this initiative has not accommodated all people with disabilities as some are still excluded from quality basic education, which has in turn negatively affected the placement of people with disabilities in employment. The reason for this is that many learnership programmes require a certain entry level minimum grade for its learners, which a number of disabled people do not meet having not been able to attend school. This continues to pose a problem in redressing inequalities faced by people with disabilities and continues to keep people trapped in a cycle of poverty, making it impossible to improve their lives. Furthermore, many people who do these learnership programmes remain unemployed after completing them, as there are insufficient jobs, especially in under-resourced rural areas, to accommodate them. The lack of

³⁵⁷ Simon McGrath and Salim Akoojee. "Education and skills for development in South Africa: Reflections on the accelerated and shared growth initiative for South Africa." *International Journal of Educational Development* 27 (2007): 431.

educational campaigns also limits the flow of information to people with disabilities about these learnership programmes. ³⁵⁸

With regards to employment of people with disabilities, able-bodied people often have negative understandings about people with disabilities, viewing them as lesser human beings. These impressions then cause discrimination within the workplace, and can contribute to an unfriendly working environment for people with disabilities. Furthermore, Russell Wordsworth, in his South African research, looked at generic barriers to employment of people with disabilities in the open labour market. He identified inaccessibility of buildings and infrastructure as the predominant physical barriers to employing people with disabilities.

Other services provided by the APC increased during the democratic period. With more funding, the APC has been able to obtain more wheelchairs for its clients.³⁴³ It has also expanded its outreach. The organization was not widely known during the apartheid period, particularly in rural areas, but after 1994, it increased its services that it offered to people with disabilities. This was particularly the case in previously disadvantaged rural communities.³⁶¹ It has also increased its volume of workshops, while the APC has increased its interactions with other organizations with similar visions. For example, when democratic South Africa became more actively involved in the distribution of antiretroviral drugs for HIV/AIDS sufferers, the APC actively involved itself

³⁵⁸ Abhijit Banerjee. "Why has unemployment risen in the new South Africa?" *Economics of Transition* 16 (2008): 736.

³⁵⁹ Jeanne Neath and Kay Schriner. "Power to people with disabilities: Empowerment issues in employment programming." *Disability & Society* 13 (1998): 222.

³⁶⁰ Rusell Wordsworth. Hiring people for their abilities and not their disabilities. 2003 [online]. Available from: http://www.upetd.up.ac.za/ thesis/available/etd-11232004-133118/unrestricted/00dissertation. Pdf. [10 August 2017] 6.

³⁶¹ Interview 1 of Lesley Dietrich.

in HIV/AIDS awareness programmes, and in health and wellness promotions in a variety of communities in South Africa. 345

The APC has also been able, in our more technologically advanced society, to encourage access of information to persons with disabilities through the development and use of adaptive technologies. For example, this organization has developed computer labs for their clients in most of the branches of the APC to enable its clients to access information and to do their assignments, particularly those involved in ABET. The amount paid to clients for the work at APC has increased too compared to the apartheid period. During apartheid, clients were rated by the work they produced each day, however now they are being rated and paid hourly. ³⁴⁶

The awareness about human rights and legal support has been enhanced in the more recent political dispensation too. The APC has established an initiative to work with communities by developing campaigns to educate able-bodied people about people living with disabilities. During the apartheid period, there were few psychologists associated with the CCA, but now they have increased in number, which has expanded counselling and therapy for clients. When social workers determine that a client had a particular psychological or emotional problem, they referred that client to the outside services of qualified psychologists free of charge, as this service is subsidized by the APC.

The organization has also enhanced its skills development and income generation projects.³⁶² Projects have increased compared to the apartheid period because they have also encouraged the

³⁶² Interview 1 of Lesley Dietrich

development of artists and poets. One of the clients named Lucky Shandu, has performed his poems on Ukhozi FM radio, which received good reviews from his listeners.³⁴⁸

The APC has had many good intentions; however, when looking at its work during the post-apartheid period, the ideals of this organization and reality have not always been the same thing. Indeed, in reality, there are still many glaring inequalities, failure of policies and inadequate facilities that are still commonplace and which negatively affect disabled people's lives in KwaZulu-Natal.

As mentioned earlier, structural and other problems still affect the lives of many disabled South Africans. The APC has limited funding to roll out the kinds of assistance it would like to implement. Some services have also been cut in recent years, due to budgetary restrictions, such as transport services that enabled the APC to drive clients located at some distance to and from APC centres. There is still a need for a universal, inclusive and standardised transport framework that will make it easier for more people with disabilities to access the opportunities provided by APC.³⁶³

In addition, the organization, despite many efforts made, has not been able to influence significantly government departments to align with their strategies to improve the lives of people with disabilities. This is evident in rural areas where campaigns and workshops about issues facing people with disabilities are a significant necessity but are often not instigated. An important problem is that there is no platform to ensure coordination and exchange of information and ideas

³⁶³ Interview 1 of Lesley Dietrich

between the government and APC. This has resulted in limited effectiveness of both APC and government programmes. ³⁶⁴

Many of potential APC clients have also been excluded from their services because of lack of quality basic education in under-resourced and inaccessible schools. This is a larger structural problem that the APC needs assistance from the government to solve. However, the APC could do more to organise information campaigns aimed at informing educational officials about inclusive education and the implications of its implementation for future work opportunities for people with disabilities. Furthermore, the limited advocacy campaigns by the APC have not done enough to target the parents of children with disabilities. As a result, many parents and families of disabled children remain unaware of their rights in relation to access to education and education support.

Many policies have been implemented by the democratic government to improve the services for people living with disabilities. And, in the post-apartheid period, the APC has also played an important role by working with the government to expand their service offerings for their disabled clients. However, as this chapter has demonstrated, there is also still a long way to go. In the next chapter, I will consider some of the first-hand the experiences of people who have lived with disabilities. It will consider their experiences from the 1990s to the 2000s period.

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³⁶⁴ Interview 1 of Lesley Dietrich

³⁶⁵ Interview 1 of Lesley Dietrich

CHAPTER SIX

The Social Experiences of People Living with Physical Disabilities in Post-Apartheid South Africa

As we have seen, the democratically elected government adopted significant policies to try to transform the lives of people living with disabilities in South Africa. This chapter will analyse data from six interviewees living in the province of KwaZulu-Natal to understand their disability experiences in democratic South Africa. These interviews were made up of Africans, both men and women, and most of whom came from rural areas of KwaZulu-Natal. I will start this chapter by looking at the experiences of two people I discussed in chapter three to explore their experiences, though I will concentrate on their experiences in the post-apartheid period. I will then move on to explore the experiences of four new interviewees. These interviewees were younger in age than my interviewees examined in chapter three and were born just before or at the start of South Africa's democratic dispensation.

Sibongiseni Khumalo

Sibongiseni Khumalo, whose injury at a sawmilling company resulted in a physical disability to his left hand and who had felt unsupported during apartheid, told me that the post-apartheid era gave him some hope. During the 1990s, Mr. Khumalo claims that he joined the Durban central branch of the APC after being advised about their work and assistive services from a local social worker. Initially, he became a volunteer as a shoe repairer and APC staff assisted him with his application for a disability grant, which he received. After a few months, he became a paid

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³⁶⁶ Interview of Sibongiseni Khumalo.

employee doing shoe repairs. Because of both the money he got working for the APC and his disability grant, he was able to rent a house in Mayville, Durban. ³⁶⁷ He told me that the APC has had a positive influence in his life. His membership and work experiences have encouraged him to see life differently compared to earlier years when he was still living in a rural area. Mr. Khumalo argues that he now feels productive once again and can help support his family. Because of the income he now receives, he was able to help support his grandchild to complete her nursing studies and she now works as a nurse at Mseleni Hospital. ³⁶⁸ Therefore, for Mr. Khumalo, his experience had been changed significantly in post-apartheid South Africa compared to his apartheid-era experiences, which had brought him much despair and sorrow.

However, he still had negative experiences as a person living with a disability during the post-apartheid period. Mr. Khumalo told me that he is still perceived as inferior because of his disability, particularly by members of his own community. He argue that the negative perception of people living with disabilities has not changed even though government has implemented a variety of progressive policies.

Mavis Dladla

Mavis Dladla's physical paralysis of the right side of her body meant a life of much frustration and immobility during apartheid because of the lack of support she received from an unsympathetic government, unaccommodating environment and negative stereotypes that marginalized persons with disabilities. However, in the post-apartheid South Africa in the 1990s, Mavis Dladla went to apply for a disability grant at the Department of Social Development, which

³⁶⁷ Interview of Sibongiseni Khumalo.

³⁶⁸ Interview of Sibongiseni Khumalo.

was successful.³⁶⁹ She claims that during the process of her application she met a social worker at this government department, which told her about the APC and her life possibilities if she chose to associate with this organization. She claims that after she got her disability grant she was able to buy a wheelchair, which made her much more mobile. Furthermore, in 2002 she decided to accompany her sister, who worked in Durban as a domestic worker, to visit the APC. She remembered that they welcomed her warmly and treated her with respect. She recalled being taken to Ematupeni Centre in Umlazi Township. Miss Dladla contends that soon afterwards her sister introduced her to a local councillor, whom she was able to tell about her difficult life experiences. In her interview, she told me that after about two months the Durban municipality began to build a house for her in Umlazi. The Department of Social Development also assisted her by supplying her with groceries and blankets. Miss Dladla argued that when she came to Durban she saw herself as a new person. At Ematupeni she became a paid worker doing craft work and knitting, which helped her support herself.³⁷⁰

Lindiwe Dlamini

Miss Dlamini was born on the 7th of September 1985, which made her 31 years old at the time of her interview. She was born in Ntabamhlophe, a rural area in Zululand, but she grew up in the town of Estcourt in Natal. Miss Dlamini is her mother's only biological child. Growing up, her family was made up of four people: other than herself, it was her mother, father and stepbrother. She grew up in a poor family because her father passed away in 1991 and because her mother became blind which meant they depended for survival on her mother's disability grant. Miss

³⁶⁹ Interview of Mavis Dladla.

³⁷⁰ Interview of Mavis Dladla.

Dlamini's mother died in 1994, which forced her to live with her aunt. She studied at Abantungwa High School and reached grade eleven, which she never completed.³⁷¹

Miss Dlamini became physically disabled in 2007 at the age of 22. She told me that it occurred one day in March when she was at home and it had been raining outside. While walking outside she fell because it was slippery and badly injured in her leg. Not able to walk she was taken to a local hospital and the doctors insisted that her leg needed to be cut because her leg sinews had been severely damaged. Her doctors told her that she must have had polio when she was young, which weakened her leg, and that the fall had just done the final damage. She remembers that as a child she did not walk straight but because her parents had no knowledge of diseases such as polio, she was not attended to. She told me that she also thinks that giving birth in 2004 to a child who could not walk and then who died at three years of age was another sign of her underlying health problems. She claims that having a disabled child had a negative effect on her life because her child did not receive a disability grant. In addition, it was difficult to raise him because his father was still attending high school and so she received no support from him, and her aunt earned little to support them at the time working as a domestic worker. She told me that life was a "struggle" at this time and that she was living "a miserable life" trying to figure out how she could better support her child. 372

Although Miss Dlamini developed her disability in the post-apartheid era, she still experienced difficulties as a result of negative stereotypes about her condition in her community. She claims that growing up in rural areas marginalized her in so many ways, such as producing unnecessary difficulties accessing information, lack of available accessible transport, and no social workers to

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³⁷¹ Interview of Lindiwe Dlamini. Conducted by S. Nxumalo. 18 October 2016.

³⁷² Interview of Lindiwe Dlamini.

assist her. She argued that in her area she was seen as trivial because people in her community had the mentality that she could not do anything. She explained that some people in her community used to perceive her as a dependent person who relied on her disability grant for her survival. Some told me that she aspired for more in her life. She felt that many people around her did not see that she also had needs and desires like everyone else in her society. Receiving a state disability grant assisted her to complete her matric studies at school. When she gave birth to her daughter in 2015, her disability grant also assisted her to provide for her child's needs.³⁷³

Miss Dlamini joined APC on the 8th of February 2016. She asserted that when she was at home she would see the local women taken by car somewhere. One day she asked them where they were going, and they told her that they were working at the APC and that if she liked she could join them. From there she joined the APC. She volunteered for a period of six months and after that she became a paid worker. She was assigned to a knitting group. However, in June this year the APC stopped fetching people from various places because of financial constraints, which compelled Miss Dlamini to rent a house in Mayville in Durban, to be closer to her work.

She claims that joining the APC changed her life for better. This was largely because she associated herself with people who had similar problems to her. Miss Dlamini told me that the organization has treated her with respect. In addition, when she faced challenges at home she could talk to a social worker about her problem. What is more, she told me that the APC established an important opportunity for physically disabled people in the form of Adult Basic Education (ABET), which has encouraged many people with disabilities to feel that they can do something with their lives. She contends that after being a member of the organization, she is happy and feels

³⁷³ Interview of Lindiwe Dlamini.

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more independent in her life. As a member of the APC, Miss Dlamini also feels a sense of belonging in a larger community of people who face similar physical challenges that she does in life. 374

Nkosingiphile Nxumalo

I also conducted an interesting interview with Nkosingiphile Nxumalo who told me about her experiences in a democratic South Africa. Miss Nxumalo was born on the 6th of May 1989 in Mayville and she is 27 years old. She was born into a wealthier family as her father made his living as a farmer and owned two shops where he sold cows and goats.³⁷⁵ However, after her father passed away in 1991, things changed. She remembered injuring herself when she was 3 years old:

In 1992 when I was a child I hurt my toes on one foot climbing a fence. I thought it was not something serious and that I would get better soon but this problem developed. At home we were not people who believed in doctors, so I was taken to a spiritual healer (umthandazi) but I did not get better and this problem got worse every day. Eventually I asked my mom to take me to a hospital. After that I could not walk, and slept all day. This sickness was developing every day in a sense that I had this wound on my foot which led to the dysfunction of my leg.³⁷⁶

When her mother eventually took her to a hospital to be examined by a doctor, she told me how she made her doctors' lives difficult because her condition was painful and made her full of anger. Her doctors recommended amputation of her toes to relieve her from pain, which her mother agreed too. After that, she told me that she felt better after the surgery and her foot healed. Miss Nxumalo did not attend school because she claims that schools were located too far at that time and her disability made her mobility difficult.³⁷⁷

³⁷⁴ Interview of Lindiwe Dlamini.

³⁷⁵ Interview of Nkosingiphile Nxumalo. Conducted by S. Nxumalo. 18 October 2016.

³⁷⁶ Interview of Nkosingiphile Nxumalo.

³⁷⁷ Interview of Nkosingiphile Nxumalo.

During the 1990s, her mother applied and received a monthly disability grant to help support her every month, but after several years, it stopped because the government believed that she was old enough and fit to work and she should support herself by finding her own employment.³⁷⁸ Miss Nxumalo informed me that she tried to apply for a number of jobs, but none of them were successful. As a result, she remained unemployed and received no assistance from the state. She claims that all documents needed by SASSA to apply for a disability grant have been provided, but they keep declining her application without a valid explanation:

The doctor's valuation is done according to firm standards which guide medical doctors in their endorsements about my condition to SASSA. Interpretations such as weight, height, blood pressure and urine are prepared by the nurses prior to seeing the doctor. My medical records assist the doctor fill out the papers that get forwarded to SASSA. But, my application keeps getting declined.³⁷⁹

The conditions for a person to qualify for a disability grant at SASSA are as follows:

Disability grants are available to people with physical, mental, psychiatric, intellectual and sensory disabilities. In order to qualify for a disability grant you must have a diagnosed medical condition that reduces your ability to function in vour everyday life and obtain work.³⁸⁰

Scholars Chloe Hardy and Marlise Richter have argued that "just being diagnosed with a condition such as hypertension, diabetes or HIV does not mean you will automatically qualify for the grant."381 The person seeking to apply for a disability grant needs to have the support of their doctor who needs to have done a thorough examination of that person and produced medical

³⁷⁸ Interview of Nkosingiphile Nxumalo.

³⁷⁹ Interview of Nkosingiphile Nxumalo

³⁸⁰ Chloe Hardy and Marlise Richter. "Disability grants or antiretroviral? A quandary for people with HIV/AIDS in South Africa." African journal of AIDS research 5 (2006): 88.

³⁸¹ Hardy and Richter. "Disability grants or antiretroviral?": 92.

records to attest to that person's disability. Only then can that person, using their doctor's referral letter and other medical documentation, apply for a grant. ³⁸²

Miss Nxumalo's case highlights that post-apartheid government disability grants, when only given temporarily, can bring much hardship into a person's life. However, how can Miss Nxumalo acquire employment when she has fought illness, been unable to walk, and thus unable to obtain formal schooling to allow her to get a good job? I think government has implemented temporary policies to try to assist persons with disabilities but at the same time, they do not consider the impact that these temporary assistance policies have on people living with disabilities. In South Africa, people with disabilities without formal schooling are less employable considering the hierarchy of employment in which manual labour is meant for those who are unskilled and usually able-bodied people.

Miss Nxumalo informed me that joining the APC helped her a great deal. She joined the APC's central branch in Durban in February 2016 and she works there making arts and crafts items, which get sold. She has told me that being an APC client has influenced her life in many ways because she has attained many skills from this organization. Miss Nxumalo believes that the APC's goal is to try to equip people with disabilities with various skills so that they can feel a sense of independence in their lives. She claims that without qualifications, many able-bodied people have considered persons with disabilities as worthless but the APC has helped to start shifting that mentality by further educating and providing skills development programmes for their clients.³⁸³

³⁸² Hardy and Richter. "Disability grants or antiretroviral?" 87-90.

³⁸³ Interview of Nkosingiphile Nxumalo.

Miss Nxumalo contends that it is important to consider that in South Africa disability has meant something very specific. An individual impairment has always been associated with a person's capacity to do something. This point has been corroborated by Brian Watermeyer. He argues that traditionally, the social disadvantages experienced by people living with disabilities was not seen as due to an unaccommodating environment, but an individual's inability to do something. Miss Nxumalo told me that in her community, she has never been taken seriously and that her physical impairment is what determines everything in her life. 385

In every society, there are competitive models of disability, with some being more prominent than others are at diverse times. According to Michael Oliver and Bob Sapey, the most common understanding of disability in many societies until recent decades has been the individual model, which links disability with the ability (or lack thereof) to do things by a person with impairments. This also applies to the area where Miss Nxumalo comes from in which her community considers her problem in relation to her ability. During our interview, Miss Nxumalo told me that she has always felt sidelined in her community and even by family members. This was largely influenced by the perception that disability is an individual problem neglecting the fact that communities and families are a big part of the problem because they marginalize and exclude people living with disabilities. Consequently, it is still shocking that in the current era of democracy, government has not put more effort in to working together with more concerned private organizations or NGOs to teach people in different communities more about the needs but also abilities of people living with disabilities. That is the reason that many people living with disabilities continue to be marginalized

³⁸⁴ Brian Watermayer. Disability and social change: A South African agenda. (Pretoria: HSRC Press, 2006): 43.

³⁸⁵ Interview of Nkosingiphile Nxumalo.

and excluded at the same time, forcing them to remain dependent on able-bodied people in their communities.

Miss Nxumalo told me that people at the APC taught her their job is to try to help to make environments more accommodating for people living with disabilities, and to improve awareness through campaigns that help to educate able-bodied people about the various capabilities people living with disabilities have to offer their societies.³⁸⁶

Lucky Shandu

Lucky Shandu grew up in the province of KwaZulu-Natal in a rural area known as Bhodlane near to Tongaat. He was born on the 8th of January 1991 and he is 28 years old. During our interview he told me that he comes from a poor family background. Whilst growing up, his father was the only person who supported his family with the money he earned as a farm worker. His mother did not work. He claims that he was living a "normal life" until he was 10 years old when he and his mother went to visit her side of the family in rural Nqutu near to Dundee. ³⁸⁷ While visiting the family, his mother was attacked by a group of thugs in her family's home. Mr. Shandu told me of his traumatic experiences where he watched his mother get raped by all of these men. After being raped his mother was stabbed and died from these injuries. Mr. Shandu remembered then being badly beaten up by the men, before being dumped into a nearby river where he thinks they presumed he would drown. ³⁸⁸ Lucky claims that he could not remember much after that:

All I could remember was finding myself in hospital and the doctor telling me that my body would not function as usual because veins on the left leg and hand were damaged due to the severe beating I received.³⁸⁹

³⁸⁶ Interview of Nkosingiphile Nxumalo.

³⁸⁷ Interview of Lucky Shandu. Conducted by S. Nxumalo in Durban. 18 October 2016.

³⁸⁸ Interview of Lucky Shandu.

³⁸⁹ Interview of Lucky Shandu.

The experience of Lucky Shandu that occurred in the post-apartheid South Africa is harsh and cruel and his disability was caused by the viciousness of people who are part of this society.

The life he lived after this horrific incident was not easy. After his mother passed away, he was sent to live with an aunt who lived in Bhodlane. There he tried to continue with his schooling after the attack, but found it difficult to do so. Other than the fact that this physical disability made it difficult for him to get to and from school because of limited accessible transport, the memory of his mother's vicious rape and death emotionally traumatized him, which made it difficult to concentrate at school. As a result, he dropped out of school.

As a physically disabled person, he told me that his family did not take him seriously. They neglected his views and he was continuously told to keep quiet and to take his pills because he was considered to be mad. The family believed that after he was attacked, he became mentally disturbed. It was hard for Mr. Shandu because he claims that no one cared about his situation and his family did not even help him to apply for a disability grant. He felt like he had to beg for everything in life. He claims that his communities did not have hope in him. Rather, they took him as a "useless" person who could not do anything. ³⁹⁰ He told me that he used to fetch water for neighbours in exchange for a plate of food to eat. He took this condition as his identity and he even cursed his life.

It was only in early 2016 that Mr. Shandu was introduced by a friend to people at the APC's Durban South Coast branch. Initially he did volunteer work at the APC, before he became a paid worker making wardrobe hangers. The organization taught him craft making skills and is also

³⁹⁰ Interview of Lucky Shandu.

paying him a stipend for the products he makes. In addition, Mr. Shandu claims that the organization has opened sport facilities for people with physical disabilities, although he claims that he has not used these facilities because he prefers to focus on gym.³⁹¹

According to Mr. Shandu at APC, everyone is treated equally. Members of the APC are assigned to qualified social workers to whom they can report challenges they experience in life. Furthermore, Mr. Shandu is now a recipient of government social grant, which the APC helped him to obtain. When he moved to Durban in February 2016, he was given a house in Mayville by the municipal local councillor. Moreover, he was able to renovate this house with money received from his grant and stipend that he earned from the APC. ³⁹² Mr. Shandu insisted that his life began to change after he moved to Durban and started working at the APC:

Community where I come from they used to see me as worthless, a person who cannot do anything in life. After I joined the APC my life changed and I have met people who understand my situation and we are being assigned to social workers who are qualified and helpful. Everyone is treated equal and no one is above the other. APC has done good things for us and it is free of charge to belong to the APC. It has made us feel like normal people because previously we were considered unworthy, the people that must rely on grants. Now I can go anywhere. I have acquired so many skills in this organization. The organization had also began ABET (Adult Basic Education) where we can uplift ourselves because education is important. It has also recruited us to some of its learnership programmes and our brothers and sisters as we speak have attained those learnerships. 393

It is important to acknowledge the role that independent organizations such as APC have played in transforming the lives of people living with disabilities. Persons with disabilities have slowly been able to start shifting their negative mentalities because of stereotypes that have posed on them by their societies. They are also able to do something productive everyday like everyone in

³⁹² Interview of Lucky Shandu.

³⁹¹ Interview of Lucky Shandu.

³⁹³ Interview of Lucky Shandu.

South Africa. Mr. Shandu asserts that being a member of the APC has completely transform his life because having people who experience similar conditions has shifted his mind set in the sense that he is not alone and he can do things more independently now.³⁹⁴

During my interview with Mr. Shandu he discussed the issue of transport. He asserted that many people with physical disabilities at APC have problems with their legs, so it requires some time for a person to arrive at the workstation. Thus, fetching and transporting these people with an organized transport system would be an amicable solution but the issue revolves around the problem of budget. 395 Communities, mostly in rural areas, have fallen behind. He thinks that it is the duty of both government and APC to initiate campaigns that will educate people with better knowledge about how to deal with persons with disabilities. However he states that it is not a duty for these two entities alone but communities must be part of these initiatives too because persons with disabilities are part of communities and there should be a clear stand on how to treat each other.

Qinisani Biyase

Another important aspect, which perpetuates inequalities for physically disabled people in rural areas, is the lack of information. This is evident in the life of Qinisani Biyase, a 25 years old isiZulu speaking man who grew up in Mtubatuba in the province of KwaZulu-Natal. He studied at Mtubatuba High School and reached grade nine, which he never completed because of illness issues. Biyase came from a poor single parent family. As a child he remembered that his mother

³⁹⁴ Interview of Lucky Shandu.

³⁹⁵ Interview 1 of Lesley Dietrich.

worked long hours as a domestic worker in Newcastle and as children, he and his three siblings often stayed with their uncle for days at a time when she was at work.³⁹⁶

On one occasion during the school holidays in 2005 when he was doing grade 7, Mr. Biyase and his friends became involved in a fight with another group of boys. However, one of the boys from the other group brought a knobkerrie stick (*isikhwili*) to this fight, which he used to hit Mr. Biyase on the head. When he arrived at home, his uncle told him that the fight was not serious and that fighting and the injuries they caused showed that he was becoming a man. As the days went on, he developed a serious headache and his uncle called his mother. He was taken to the local clinic where they examined his head and they found that Mr. Biyase was bleeding internally. He remembered being examined, being injected with something, and given pills to take. He was sent home and told to come back if there were any changes. ³⁹⁷

Mr. Biyase's condition steadily got worse. After a few days, he was taken to the nearest public hospital, Ngwelezane Hospital. He stayed at the hospital for period of two months and after that, was discharged. After two weeks at home, both his eyes turned to a sideways position. Mr. Biyase was taken back to hospital but they said they could not help him due to the complexity of his brain injuries so he was transferred to Chief Albert Luthuli Hospital in Durban. After two days, he was discharged and his uncle suggested that he be taken to a traditional healer in Ntuzuma. The traditional healer gave him some medicine and also *gcaba*, which in English means "traditional body scarification". Mr. Biyase told me that he got healed for a short period of time and after that his tongue started swelling in his mouth. 398 "I struggled with eating and speaking after my tongue

³⁹⁶ Interview of Qinisani Biyase. Conducted by S. Nxumalo in Durban. 18 October 2016.

³⁹⁷ Interview of Qinisani Biyase.

³⁹⁸ Interview of Qinisani Biyase.

swelled up. It was a difficult condition for me because these things were happening while I was young." ³⁹⁹

As a result, he was not able to speak and the left hand side of his body became paralyzed. Moreover, he had to wear nappies as he could not control his bodily functions. As the situation worsened, he was taken back to Ngwelezane Hospital and from there they insisted they could not help him and he was transferred back to Albert Luthuli by aeroplane ambulance. He stayed at this hospital from 2006 until January 2008. On 26th of January, he remembered waking up in the mortuary because his nurses and doctors believed that he was dead. He was assisted by a man who was working at the mortuary who helped him out of the cold storage shelf and took him to the hospital ward. After a year, they transferred him back to Ngwelezane Hospital where he stayed for a further two weeks in 2009. They discharged him and gave him a wheelchair. He emerged from these experiences with a paralysis of his left side, which he lives with today. 400

Biyase's story highlights the negligence of some parents in rural areas, especially those with certain beliefs about injuries in relation to manhood, which end up compromising the lives of young people. The major factor that contributed to his physical disability were the beliefs of masculinity held by his uncle. In isiZulu speaking societies stick fighting was considered a key part of the passage from boyhood to manhood, even though it could, and often did, result in serious injuries for some boys. Perhaps this issue would have been avoided if Mr. Biyase had been taken immediately to hospital and acquired earlier treatment. However, his uncle believed that it was a minor injury on his journey to manhood, which would heal, on its own.

³⁹⁹ Interview of Qinisani Biyase.

⁴⁰⁰ Interview of Qinisani Biyase.

Mr. Biyase told me that he has lived a despondent life. From 2009, he enrolled in grade eight and passed it, even though his teachers insisted that he was too old. In 2010, he registered to study grade nine which he never completed. ⁴⁰¹ He claims that at school he had to use a wheelchair and sometimes crutches. And, when he used crutches learners would laugh at him. This affected him negatively because even when he saw other learners he would assume that they were gossiping about his condition. ⁴⁰² Mr. Biyase claims that people have not changed their attitudes towards people with disabilities because they still believe that the views of persons with disabilities are insignificant.

He joined the APC in 2016. He was told about the APC by a social worker who worked in his area. The social worker spoke with his family and they agreed. He told me that it was valuable to join the APC as people "were more understanding there" and he found that many clients were in a similar situation to him. Back at home, he did not have friends because people gossiped about him and his condition, and he preferred to be alone. Before joining the APC, he would spend his time watching television and sleeping. At the APC, he learnt how to make handcrafts, such as bags and hangers. He sees the democratic government and its policies as good, as well as the work done for persons living with disabilities who belong to the APC because the staff assisted him in his application for a disability grant, which was approved. 403

Some Concluding Thoughts

An important lesson from the policies of government is the conditions to qualify for a disability pension grants. The post-apartheid government has introduced a pension grant for persons with

⁴⁰¹ Interview of Qinisani Biyase.

⁴⁰² Interview of Qinisani Biyase.

⁴⁰³ Interview of Qinisani Biyase.

disabilities to curb poverty but it becomes problematic when one is used to receiving a grant and then it stops because a person in government makes the decision that the person receiving the grant no longer needs the grant and is able to seek employment. Firstly, the government needs to consider that many people have struggled with illnesses or disabilities since when they were young, which eventually led them to quit school. Secondly, when they have not received an adequate education, it is usually only in manual labour jobs that less educated people can get employment. Yet, if those individuals are less educated and physically disabled, employers do not want to employ them in physically challenging manual labour jobs. This means that these individuals have to remain dependent and accept the daily stereotypes that are posed by ablebodied people.

Furthermore, the government has not done enough to actively affiliate with private organizations to campaign and promote awareness about issues facing and affecting people with disabilities in South Africa. Local municipalities must be key players who take an active role in fighting for disabled people's rights but they have seemingly neglected matters of disabilities.

This chapter has raised important issues to consider in the post-apartheid period. It draws on some of the life story accounts and social experiences of a number of people who have lived with disabilities in recent years. These interviews have been invaluable in providing a glimpse into the complex and difficult experiences that people living with disabilities have had to endure in their lives. What struck me is that many of their stories emphasized a positive perspective when it came to my interviewees' perspectives on their association with the APC.

However, while it is essential to recognize that the APC has clearly played an important role in improving the lives of many people who have lived with disabilities, as a researcher, one has to

bring a critical lens to these comments too. Indeed, one should note that social workers who worked for the APC had referred all of the disabled people I interviewed to me, and these people were themselves members, if not employees of the APC at the time they were interviewed. Thus their association or involvement with the APC would have influenced their perspectives. The fact that all interviews were also conducted on the premises of the APC would have likely influenced their comments too.

Although the apartheid era has ended, people living with disabilities in democratic South Africa still experience the sting of negative stereotypes by people in their communities, they still experience discriminatory treatment (including abandonment and abuse), and limited lives because of inaccessible environments. This is particularly the case in rural areas. While the APC has been able to make a dent in these areas by the work it has done, there is still an enormous amount of work to do. For example, if the APC could raise more money to hire additional social workers in all of its branches that would mean more reach for this organization, especially for people in rural areas. This would then lead to more awareness about this organization and expand its clientele, which would then in turn help more people to learn skills and to become more independent. More extensive awareness campaigns would then also help to further undermine negative stereotypes about the contributions that are made in societies about people with disabilities. Highlighting just the positives of any organizational effort can lead to complacency in a world where people living with disabilities still need champions to fight for their cause.

CHAPTER SEVEN: CONCLUSION

This thesis has examined the broader history of service provision for people who lived with disabilities in the region of KwaZulu-Natal before the late 1930s when the CCA was formed, as well as in the years after this date. Many people were physically disabled as a result of working in the booming mining sector. Many unskilled Africans and skilled white miners worked under haphazard conditions, which led to injuries, while others contracted debilitating diseases like TB or silicosis, which caused physical impairments.

The unequal provision of health care facilities between the urban and rural "reserves" areas, but also between black and white South Africans because of segregation laws, have been decisive factors. Historically, this led to Africans with physical injuries being poorly cared for, while others who were not treated timeously for illness they developed, suffered through the development of physical impairments. Missionary doctors and nurses did the best they could in their rural clinics and hospitals for patients when government services were inadequate.

Polio outbreaks in South Africa during the early to mid-twentieth century also contributed to development of physical disabilities in South Africa because this disease weakened the body causing many to develop paralysis. Various wars, including the First and Second World Wars contributed to emotional and physical impairments for South African people through traumas they experienced too. Of course, as we have seen from analysing the lives of my interviewees, physical disabilities could also be obtained through engaging in everyday activities such as experiencing mishaps or accidents that happened at the work place, such as on farms or in factories. Some people also believed that their physical disabilities were caused by the wrath of their ancestors or because they were bewitched by someone using nefarious "mutis" to cause injury to their intended targets.

This thesis has focused on the formation and work of an important organization that was developed to assist people who lived with physical disabilities in South Africa. The Cripple Care Association, which became a national organization with representation in the country's different provinces, was first developed in the Transvaal in 1937. A large financial donation by the philanthropist Lord Nuffield to the CCA in 1939 led to the development of a number of different branches across South Africa that catered for white people. This included two Natal CCA branches, located in Pietermaritzburg and Durban.

Although the Natal CCA initially operated mainly to assist white physically disabled clientele, from the 1950s it shifted its concern, as did other CCA branches, to assist Coloured, Indian and African people too. This enabled Africans from the rural "reserves" to participate in programmes provided by the Cripple Care Association. This led to growing numbers of Africans living in both rural and urban areas, but also in Bantustans and townships, to become clients of CCA centres, such as Ematupeni Centre in Umlazi, Zimele Centre in KwaMashu, and Jabulani Centre in Empangeni.

The experiences of people who have lived with physical disabilities, especially African people, has been harsh because of conditions and unequal distribution of resources between white and black South Africans. People living in rural areas arguably experienced the worst access to resources and for many; there was no knowledge of the operation of CCA during the apartheid years. As a result, many rural Africans assumed that there was no organization that could assist people with physical disabilities during apartheid. Many of these people did not receive compensation for injuries suffered at their various work places, as most were highly exploited unskilled or manual labourers and did not receive disability grants from the apartheid government.

These injustices of apartheid made Africans with disabilities struggle to survive on a day-to-day basis and helped to keep many in abject poverty with no assistance for their conditions.

The democratic government after 1994 implemented policies that aimed to better the lives of people who lived with disabilities. This was witnessed by the passing of laws and development of an improved system of disability grants to people who qualified. These were important mechanisms to alleviate poverty for people living with disabilities in South Africa. The post-apartheid period also saw the establishment of the BEE initiative, which has tried to pull previously disadvantaged groups into businesses, including people with disabilities, and the establishment of the affirmative action policy, which gave opportunities to previously underprivileged groups in accessing employment. Furthermore, the government has played an active role in pressuring schools and universities to make their facilities more accommodating to cater for the needs of people with disabilities in South Africa. Finally, they have also tried to make health care facilities more widely and freely available to disabled people in government hospitals and clinics.

The role of the Association for the Physically Challenged has been significant in providing for the needs of many people who have lived with physical disabilities. People with physical disabilities have claimed that their lives changed after becoming clients in this organization. This is largely due to the availability of more qualified social workers, rehabilitation programmes, skills development workshops, and jobs that provide clients with supplementary income. This organization has also assisted their clients with their applications for disability grants. Furthermore, the APC has tried to shift the major stereotypes about people living with disabilities by providing them with jobs, which makes them more productive and thus helps to change perceptions in the minds of able-bodied people in their communities. After people have joined

APC, they feel the sense of belonging because they get to interact with people who understand their conditions and the organization is treating them with respect.

Continued Challenges Facing the People with Disabilities in the Twenty-First Century

Although the government has become more supportive in recent years, and they have been able to expand their services, as we have seen in previous chapters, while there have been some improvements in people's lives, problems still exist. People with disabilities still experience the burden of stereotypes developed by their family and community members. Many people with disabilities in rural areas still develop physical disabilities, which could be simply avoided by early identification of the symptoms by family members. APC organization is still less known in rural areas and many people with disabilities continue to rely on home-based caregivers for support.

Moreover, the APC still faces the issue of lack of sufficient funding for staff training and capacity building for their community based programmes. While the APC receives assistance from the government, which helps subsidize workshops, the organization has to continue carrying the burden of outsourcing some funding for a large part of its work and facilities. The APC remains a private entity, which sometimes experiences major shortages in some of its resources. 404

The Provincial Director of the APC, Lesley Dietrich told me in an interview that there is a lack of support from regional and local government structures to stimulate income generation projects. Furthermore, she has highlighted that there is no clear stand or support from the local municipalities in supporting projects for people with disabilities. Dietrich argues that this issue is

⁴⁰⁴ Interview 2 of Lesley Dietrich. Interview conducted through email by Nxumalo. 13 November 2016.

caused by a government in which people who were appointed to serve their constituents are not adequately trained about disability issues. She also claims that there is lack of interest by municipalities in supporting programmes that assist people living with disabilities, which leads to inadequate funding support. Municipalities are principal role players in their localities and it is disheartening to hear about their general apathy towards acquainting themselves about disability issues or assisting people. People who lived with disabilities in South Africa in the apartheid period were marginalized, and it is concerning to see that some leaders who were appointed to better such people's lives in recent years continue to turn a blind eye. During apartheid, the exclusion of African people with disabilities was as a result of race but today there is the problem of self-enrichment. Corruption in South Africa is enormous which has led to impoverishment amongst citizens of this country.

According to Lesley Dietrich people with disabilities still experience the issues of being denied access to quality education. She claims that many young people who have recently joined the organization do not have matric qualifications. 406 There is still much inaccessibility in public schools, particularly in under-resourced rural areas, for children with disabilities. Their schools fail to adequately accommodate their needs so this leads to a high dropout rate. The accessibility of public transportation for people with disabilities is a problem too. Currently the APC is struggling to provide transport that will deliver their clients to and from their workplaces. The APC also lacks enough functional computers and machinery, especially in township branches. 407

⁴⁰⁵ Interview 2 of Lesley Dietrich.

⁴⁰⁶ Interview 2 of Lesley Dietrich.

⁴⁰⁷ Interview 2 of Lesley Dietrich.

The Importance of this Research to me as an Author

I have learned that for Africans who have lived with disabilities in South Africa during the twentieth century, racism and economic inequalities greatly influenced their lives. The apartheid system played a large role in determining their positions as second-class citizens in the country of their birth, obstructed their efforts to better themselves through equal opportunities, and has led to unequal access to resources. Living with physical disabilities has also brought difficulties for men and women who have been unable to meet the criteria of their society's socially constructed gender ideals. This has led to feelings of emasculation amongst men and made women question their "womanliness" if they could not find a husband or bear child because of their disabilities.

However regardless of the influence that these and other discriminatory factors had on their lives, it is incorrect to view people who have lived and continue to live with disabilities as unproductive dependents. Through the development of training and skills workshops by the CCA/APC, a number of people have been able to overcome many hurdles and empower and support themselves. Recognizing the agency of those who have tried to help physically disabled people to improve the quality of their lives, but also the agency of disabled people who have worked to overcome their challenges, has been an important focus of this thesis.

I have also been exposed to policies, which were implemented by the democratic government in assisting people with disabilities. I presumed that every person that has a disability qualified for a government disability grant, however it was worrying to find out how some clients of the APC have made several applications but have had no success.

Another significant thing I have learnt is that societies are the ones that create stereotypes. These stereotypes produce barriers in the lives of people living with disabilities, and have made it

difficult to live fruitful lives as members of their communities. Looking at both the experiences of people with physical impairments in the apartheid and post-apartheid periods their communities have viewed them in relation to their disabilities. People were and are still defined in terms of their disabilities. The inability to walk, for example, in South Africa is linked to that person's capacity, or in this case, incapacity.

In South Africa, the individual model of incapacity is dominant. This model sees disability "as an irregularity, as an individual misfortune, something that occurs to ill-fated individuals on a more or less arbitrary basis." As a result, how disability is managed is based upon the notion that the "difficulty resides within the individual and must be overcome by the individual's personal exertions." According Oliver Sapey and Pam Thomas, focusing on this individual needs model for disabled people is wrong as it has led to a tendency to view disability only in those terms. Indeed, it focuses almost exclusively on attempts to modify an individual's impairments and return them to something that "approximates normal". As a result, the effects of the wider physical, attitudinal, and social environments of disabled people have been largely ignored or rarely changed to accommodate them, which has resulted in a maintenance of the status quo and kept people living with disabilities in their disadvantaged state within their societies. As a result, people living with disabilities continue to be an oppressed group and they have not attained equal access to education, transport, jobs and amenities.

⁴⁰⁸ Michael Oliver, Bob Sapey, and Pam Thomas. *Social work with disabled people*. (London: Palgrave Macmillan, 2012): 19.

⁴⁰⁹ Michael Oliver. *Understanding disability: From theory to practice*. (New York: St Martin's Press, 1996): 33.

⁴¹⁰ Oliver, Sapey, and Thomas. *Social work with disabled people*: 25.

⁴¹¹ Oliver, Sapey and Thomas. *Social work with disabled people*: 31.

⁴¹² Michael Oliver. *Understanding disability: From theory to practice:* 42.

In the South African context, some improvements have certainly been made for some people living with disabilities in recent years, but there is still much to be done to improve the quality of life of such people, but also to change how they are viewed and treated by able-bodied people in their societies.

It is also important to understand the complexities and contradictions that have emerged from labelling people with disabilities. This thesis has highlighted how labels for people with disabilities have changed over time. However, it has also considered the effects that labels have had on people's lives. The more careful labelling of people as "disabled" by lawmakers, the state and medical professionals has brought positives for such people, such as more recognition publicly of their rights or access to improved social grants. However, this greater recognition can also ironically lead to exploitative treatment (e.g. by carers who exploit the vulnerabilities of their charges to get access to their grants). Furthermore, greater recognition does not always bring improvements for people with disabilities. Many disabled people continue to experience being stigmatised or marginalised as minority groups in their communities because of such labels. Many medical doctors continue to perceive people with disabilities as ill, or as people who should get special attention and this often gives able-bodied people an impression those living with disabilities are weak or different. Thus, labels have the power to both help and hurt people.

A final point I would like to raise is the role that women have played historically in supporting people with disabilities in South Africa. Indeed, this research has shown that the development of care for disabled people was overwhelmingly female. My thesis has highlighted that most people I interviewed mentioned being cared for by women, such as their mothers, sisters, aunts, female friends and neighbours. Moreover, fighting for disabled people's rights, or efforts to improve their lives, have often been the work of women. This includes the many women who helped establish

and run the CCA/APC, the many social workers who visited and assisted people with disabilities, the women who helped mentor and care for their clients in the CCA/APC's various centres, and the many women who lobbied as activists to improve the policies and ultimately the lives of people with disabilities. In earlier, socially oppressive times for women in South Africa, this caring work provided the backbone of the social support system, and became one of the ways that some women made a mark for themselves in public life. Their struggles to work with, and to assist people with disabilities, has not been sufficiently studied and hopefully other researchers will someday turn their attention more extensively to these diverse array of women's important historical contributions.

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APPENDICES

APPENDIX 1

Daily Newspaper Article showing the Polio outbreak in 1970s on African people in rural areas



BHEKUYISE NGIDI, aged 12 years, post Polio cripple has never walked owing to fixed flexion deformity of both knees. He also has Sidiosis (Curvature of the Spine) as a result of Polio. He was brought in from a rural area to Port Shepstone Hospital where he was seen by the Orthopaedic Specialist and referred to King Edward VIII Hospital for extensive corrective measures and physiotherapy. He will eventually be able to walk with the aid of calipers, brace and crutches and hopes to attend school. He is a very bright cheerful child despite having no parents.

Source: APC Archive, Durban. Daily News Reporter. "Cripple and Polio outbreaks." *Daily News*, 9 August 1972.

 ${\bf APPENDIX~2}$ Picture of Joyce Le Brun, the founder of both Ematupeni and Zimele



Source: APC Archive, Durban. Joyce Le Brun. *From Pain to Purpose*. (Durban: Durban Cripple Care Association, 1972). This picture is taken from Joyce's Le Brun book.

APPENDIX 3 Picture Showing Ematupeni in the 1960s



Sources: Photograph from the APC Archive, Durban. NCC- A picture of the staff and client members who belonged to Ematupeni. 25 July 1968.

APPENDIX 4

Interview Questions for the Provincial Director of the APC

What is your name?

Where and when were you born?

Where did you grow up? Primary and secondary education?

Did apartheid laws have an effect on your life?

Early life, training and work life. Did you go to University? If yes, where?

Where and when did you receive your qualification?

What jobs have you had?

How did you become interested in disability issues?

How did you come to know about the APC?

Can you tell me anything about its history (e.g. when, why and how it was formed)?

When did you start working for the APC?

What type of physical disabilities did this organization cater for?

How did membership of this organization work when you first started working there? Basically, who could join this Association as a client?

Did this change over the years when you worked at this Association? How did the apartheid regime affect the funding of this Association?

Did African clients form a large part (the majority part?) of the APC's clientele when you joined, or in later years?

What about other "black" i.e. Indian and Coloured South Africans? Over the years, what type of work did you do at the APC? Please give examples of the work and/or projects undertaken as part of this Association's work.

Where did the funding for this Association come from, in terms of its operational costs, salaries, project start-up capital etc.?

Did this organization cater for men and women? Please elaborate.

Did this organization cater for people from different classes? Please elaborate. When did you became the Provincial Director at APC?

What influenced the Association to choose you?

How did your work change when you became the Director?

Other than the APC, what other disability organizations operated in Natal in the apartheid period? Do you think that disability issues, and provision of services for disabled people, have improved in the post-1994 dispensation? Please elaborate.

Thinking back over your many years working at this organization, what do you think its greatest strengths and weaknesses have been?

What influence has working for the Association had on her life?

APPENDIX 5

Interview Questions for Clients who belong(ed) to APC

What is your name?

Where and when you were born?

Where did you grow up? Your class background: working class, middle class, upper class family background?

When and how did you become physically disabled (i.e. born with your disability, or it developed as a consequence of an illness or an accident later in life)?

Primary and secondary schooling?

Did you attend disabled accessible institutions?

What difficulties did you experience as a disabled person in apartheid South Africa? Growing up, can you remember experiencing any obstacles based on your gender? Your race? Your class? Please elaborate.

When did you join the APC?

How long have you been a member?

Why did you join the APC?

Where there any other disability organizations you could (or did) join in Natal during the apartheid period?

Do you have to pay an annual membership fee to belong to this organization? If so, do you think the fees are expensive?

What work did the APC do for you, and for disabled people more generally? Please can you explain to me how APC services work?

Did the APC serve/assist African physically disabled people and other black South Africans when you joined the Association? What about in later years?

Have men and women been equally catered for through the services of this organization?

What about people from lower income families?

What sorts of stereotypes have you experienced as a disabled person?

Has this changed over time? If not, why not? If so, why?

What are some of the positives and negatives about being a client of the APC?

What influence has belonging to the Association had on your life? In your opinion, has the shift to the post-apartheid period influenced the provision of services for disabled people?

Has life in public become more or less accessible for you?

What about race, gender and class discriminations?

Is there a change in terms of superstations and perceptions of disabled people by those in democratic South African society?