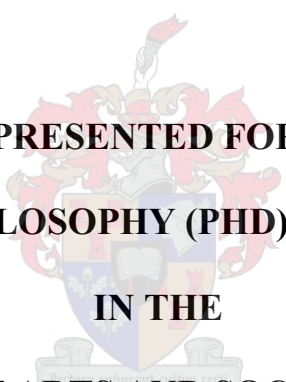


# **EXPERIENCES OF ADULTS WITH ACQUIRED PHYSICAL DISABILITIES OF SOCIAL WORK SUPPORT IN A SOUTH AFRICAN CONTEXT**

**by**

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**DISSERTATION PRESENTED FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY (PHD) IN SOCIAL WORK  
IN THE  
FACULTY OF ARTS AND SOCIAL SCIENCES**

The crest of Stellenbosch University is centered behind the text. It features a shield with a blue and gold design, topped by a red and white crest. The shield is flanked by two lions and sits on a base.

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**DECEMBER 2020**

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## ABSTRACT

Almost every person will experience a form of impairment or disability at some point in their lives. Different types of impairment could occur at any given moment. In a New York University Hospital study with persons who acquired paraplegia, a four-stage process similar to the stages of grief identified by Kübler-Ross was identified for person with disabilities coming to terms with their disability, these being shock, denial, anger and depression. This correlation could assist in understanding the adjustments persons who acquire a disability later in life must make as they ‘grieve’ the life prior to the disability onset. It is further argued that the social worker’s task is to help people with disabilities through these adjustment phases.

Taking this into account, the research question for this study was identified after a reviewing of previous research done on similar topics. The COVID-19 pandemic also influenced the research design and approach. Accordingly, this study stemmed from the research question: What are the experiences of adults with acquired physical disabilities with regards to social work support (especially in assisting them after they acquired the physical disability)?

A combination of descriptive and exploratory research was implemented to answer this research question. The research study made use of a qualitative approach with some quantitative elements in terms of the identifying particulars of participants. Qualitative research is seen as a valuable social work approach. It is helpful in researching social problems and vulnerable populations. Further it allows for the social work profession to learn from those they serve. Both of these aspects were true for this study as the qualitative research was done in part with a vulnerable service user group (adults with an acquired physical disability) regarding their experiences of social work services. This information derived from the perspectives of these participants can be utilised to plan future social work services to this group. Within this research approach both deductive and inductive reasoning were used. The literature review in this research study took place over three chapters aligned with the first three objectives of the study. During the literature review similar studies were explored and discussed, although, there were no studies available with the same researchable variables as this study. Despite this limitation, the literature review provided valuable insight on similar topics.

Due to the impact and restrictions of the COVID-19 pandemic, the three methods that were decided on for this research study, once it was restructured to be done remotely, included cell phone calls, WhatsApp or Zoom. The research project took place with two Cohorts. The first

Cohort included nineteen adults with acquired physical disabilities and the second five social workers who had experience working with persons with disabilities. While most participants were identified through purposive sampling some were included through snowball sampling. One participant from Cohort One also shared a story they had written on acquiring a disability which they offered to be used for the study. Another participant from Cohort Two did both a questionnaire interview (through e-mail) and an interview by means of Zoom. This essentially provided 26 sources with 24 participants.

From the literature review and the empirical data collected six themes were developed. These themes include: biological experiences of adults with an acquired physical disability according to the biopsychosocial and ICF model, psychological experiences of adults with an acquired disability, support services used by adults with an acquired disability according to the ecological perspective, support needs of adults with an acquired disability according to the ecological perspective, cultural experiences of adults with an acquired disability within their community as well as social work support services to persons with acquired physical disabilities aligned with policies in South Africa. The themes were further divided into sub-themes and categories.

The study provided conclusions and recommendations in the last chapter based on the findings of the empirical study. It was found that the participating organisation, provided services aligned with policies and the roles of the social worker. An overall bottom-up approach was suggested in service delivery and planning to adults with an acquired physical disability in terms of social work services. A few limitations to the study were discussed and recommendations for future studies made.

## OPSOMMING

Meeste mense sal een of ander tyd in hul lewe 'n vorm van gebrek of gestremdheid ervaar. Verskillende tipes gebreke kan op enige oomblik voorkom. In 'n New York Universiteitshospitaal studie met persone wat parapleë geword het, is 'n vier-fase proses soortgelyk aan die fases van rou wat deur Kübler-Ross geïdentifiseer is ontwikkel vir persone met gestremdhede wat tot aanvaarding moet kom van hul gestremdheid. Hierdie fases bestaan uit skok, ontkenning, woede en depressie. Hierdie ooreenkoms kan help om die aanpassing wat persone wat 'n gestremdheid later in hul lewe verkry te verstaan terwyl hulle rou oor die verlies van die lewe wat hulle gehad het voor die gestremdheid. Dit word verder gemotiveer dat dit die maatskaplike werker se taak is om persone met gestremdhede te help deur hierdie aanpassingsfases.

Met hierdie agtergrond in gedagte is die navorsingsvraag vir hierdie studie geïdentifiseer nadat vorige navorsing oor soortgelyke onderwerpe nagegaan is. Die COVID-19 pandemie het ook 'n invloed op die navorsingsontwerp en benadering gehad, wat later in hierdie opsomming verder bespreek sal word. Die studie ontstaan gevolglik uit die navorsingsvraag: Wat is die ondervindinge van volwassenes met 'n verkrygte fisiese gestremdheid in terme van maatskaplike werk ondersteuning (veral in die ondersteuning nadat hul die fisiese gestremdheid verkry het)?

Die navorsingstudie het gebruik gemaak van 'n kombinasie van beskrywende en verkennende navorsingsontwerpe. Daar is gebruik gemaak van 'n kwalitatiewe benadering met sommige elemente van 'n kwantitatiewe benadering ten opsigte van die identifiserende besonderhede van die deelnemers. Kwalitatiewe navorsing word gesien as 'n waardevolle maatskaplike werk benadering. Dit is behulpsaam in die navorsing van maatskaplike probleme en kwesbare bevolkingsgroepe, omdat dit minder indringend, deur die gebruik van 'n semi-gestruktureerde onderhoudskedule te werk gaan. Hierdie navorsing laat ook die maatskaplike professie toe om te leer van diegene aan wie hul dienste lewer. Beide van hierdie aspekte was op hierdie studie van toepassing siende dat die kwalitatiewe studie grotendeels plaasgevind het met 'n kwesbare bevolkingsgroep (volwassenes met 'n verkrygte fisiese gestremdheid) rakende hul ondervindings van maatskaplike dienste. Hierdie inligting wat uit die perspektiewe van die deelnemers verkry is, kan gebruik word om te help vir die beplanning van toekomstige maatskaplike dienste aan hierdie teikengroep. Die beredenering in hierdie navorsingstudie was

beide induktief en deduktief. Die literatuurstudie het oor drie hoofstukke plaasgevind ooreenstemmend met die eerste drie doelwitte van die studie. Gedurende die literatuurstudie, is soortgelyke studies verken en bespreek, alhoewel daar geen ander studies met dieselfde navorsingsveranderlikes soos hierdie studie bestaan het nie. Nietemin het die literatuurstudie geldige insig gelewer op soortgelyke onderwerpe.

Weens die impak en beperkinge van die COVID-19 pandemie, was die drie metodes wat gekies is vir hierdie studie, nadat dit geherstruktureer is om oor 'n afstand te gedoen te word selfoonoprope, WhatsApp en Zoom. Die navorsingsprojek het plaasgevind met twee Kohorte. Die eerste Kohort het negentien volwassenes met 'n verkrygte fisiese gestremdheid ingesluit terwyl die tweede uit vyf maatskaplike werkers met ondervinding in dienslewering aan persone met gestremdhede bestaan het. Deelnemers vir hierdie studie is grotendeels verkry deur doelgerigte steekproeftrekking en sommige deur sneeubal-proefneming. Een deelnemer van Kohort Een het 'n storie gedeel met die studie. 'n Ander deelnemer van Kohort Twee het beide 'n vraelys onderhoud (deur middel van e-pos) en 'n onderhoud deur Zoom gelewer. Dit het 26 bronne uit 24 deelnemers gelewer.

Uit die literatuurstudie en die empiriese data wat versamel is, is ses temas ontwikkel. Hierdie temas sluit in: biologiese ondervindinge van volwassenes met 'n verkrygte fisiese gestremdheid volgens die biopsigososiale en ICF modelle, sielkundige ondervindings van volwassene wat 'n fisiese gestremdheid verkry het volgens die biopsigososiale model en die fases van rou, maatskaplike/omgewingsondervindings van volwassene wat 'n fisiese gestremdheid verkry het volgens die ekologiese perspektief (Bronfenbrenner), ondersteuningsbehoefte van volwassenes met 'n verkrygte fisiese gestremdheid volgens die ekologiese perspektief (Bronfenbrnner), kulturele ondervindings van volwassene wat 'n fisiese gestremdheid verkry het en maatskaplike ondersteuningsdienste aan volwassenes met 'n verkrygte fisiese gestremdheid in terme van beleide in binne 'n Suid-Afrikaanse konteks. Hierdie temas is verder onderverdeel in sub-temas en kategorieë.

Die studie het gevolgtrekkings en aanbevelings gehad in die laaste hoofstuk wat gebaseer is op die bevindings van die empiriese studie. Dit is gevind dat die deelnemende organisasie dienste volgens die beleide en die rolle van 'n maatskaplike werker gelewer het. 'n Oorhoofse onder-na-bo benadering is voorgestel in dienslewering en beplanning aan volwassenes met 'n verkrygte fisiese gestremdheid in terme van maatskaplike werk dienste. 'n Paar beperkinge in die studie is bespreek en aanbevelings vir toekomstige studies is gemaak.

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“If I have seen further, it is by standing upon the shoulders of giants” – Sir Isaac Newtown



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## LIST OF ACRONYMS AND ABBREVIATIONS

A.D.	Anno domini (in the year of the Lord)
AASW	The Australian Association of Social Workers
ACPF	The African Child Policy Forum
ADLs	Activities of Daily Living
AIDS	Acquired immunodeficiency syndrome
B.C	Before Christ
CASE	Community Agency for Social Equity (RSA)
CBO(s)	Community-based Organisation(s)
CBR	Community-based Rehabilitation
CHC	Community Health Centres
COVID-19	Corona Virus Disease 2019
CRPP	United Nations City Resilience Profiling Programme
CSO(s)	Civil Society Organisation(s)
DALY	Disability-adjusted life years
DESC	Departmental Ethics Screening Committee (Stellenbosch University)
DIAUD	Disability Inclusive and Accessible Urban Development Network
DICAG	Disabled Children's Action Group (RSA)
DOH	Department of Health (RSA)
DPO(s)	Persons with disabilities organisation(s)
DPSA	Department of Public Service and Administration (RSA)
DSD	Department of Social Development (RSA)
DWCPD	Department of Women, Children and People with Disabilities (RSA)
FBO(s)	Faith-based Organisation(s)
GDoH	Gauteng Department of Health (RSA)
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
IASSW	International Association of Schools of Social Work
ICDH	International Classification of Impairments, Disabilities and Health
ICF	International Classification of Functioning, Disability and Health
ICSW	International Council on Social Welfare
IFSW	International Federation for Social Workers

INDS	Integrated National Disability Strategy (RSA)
MDG(s)	Millennium Development Goal(s)
MSF	Ministry of Social and Family Development (Singapore)
NASW	National Association of Social Work (USA)
NGO(s)	Non-governmental Organisation(s)
NHI	National Health Insurance (RSA)
NIDS	National Income Dynamics Study
NPO(s)	Non-profit Organisation(s)
ODP	Office of Deputy President (RSA)
OSDP	Office on the Status of Persons with Disability/-ies
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act (RSA)
PWD(s)	Person(s) with Disability/-ies
REC	Research Ethics Committee (Stellenbosch University)
RSA	Republic of South Africa
SACSSP	South African Council for Social Service Professions
SADA	South African Disability Alliance
SAHRC	South African Human Rights Commission
SARS	South African Revenue Service
SASSA	South African Social Security Agency
SCI	Spinal Cord Injury
SDG(s)	Sustainable Development Goal(s)
SIDA	Swedish International Development Cooperation Agency
TB	Tuberculosis
TBI	Traumatic Brain Injury
UK	United Kingdom
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDESA	United Nations Department of Economic and Social Affairs
UNDRR	United Nations Office for Disabled Risk Reduction
UNICEF	United Nations Children's Fund
UNISDR	United Nations Office for Disaster Risk Reduction
UPIAS	Union of the Physically Impaired Against Segregation (UK)
USA	United States of America
VOIP	Voice Over Internet Protocol
WHO	World Health Organisation

WPRPD	White Paper on the Rights of Persons with Disabilities
YLD	Years Lost due to Disability
YLDs	Years Lived with Disability
YLL	Years of life lost

## GLOSSARY

Activity limitation	Refers to difficulties a person may have in executing tasks or actions of daily living.
Commode	An adult potty chair and is made up of a frame equipped with a toilet seat and a removable bucket.
Continence	Relates to helping an individual achieve and maintain this control of their bladder or bowel functions.
Deafblindness	A unique and isolating sensory disability resulting from the combination of both hearing and vision loss or impairment.
Democracy	A form of government in which the supreme power is vested in the people and exercised directly by them or by their elected agents under a free electoral system.
Disability	A complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives.
Eudaimonism	An approach to ethics that focuses primarily on eudaimonia (generally understood as the highest human good).
Eugenics	A movement that is aimed at improving the genetic composition of the human race. Historically, eugenicists advocated selective breeding to achieve these goals.
Global South	Refer to the regions of Latin America, Asia, Africa, and Oceania. The use of the term Global South does not merely act as a metaphor for underdevelopment. It references an entire history of colonialism, neo-imperialism, and differential economic and social change through which large inequalities in living standards, life expectancy, and access to resources are maintained.
Impairment	A problem in body function or structure.
Lockdown	An emergency measure or condition in which people are temporarily prevented from entering or leaving a restricted area or building. During COVID-19 this included various levels of restriction in public areas with restrictions in terms of time and amount of people together.
Models	An organized set of guidelines and procedures, based on research and evidence-based practice which can offer solutions to problems. The blueprint for action as it generally describes what happens in practice based on underlying theory.
Neo-Liberalism	Neoliberalism, ideology and policy model that emphasizes the value of free market competition.
Normate	Refer to fantasy image of perfect bodily health, beauty, and functioning.
Pan-Africa(n)	The idea that peoples of African descent have common interests and should be unified.

Pandemic	An epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people.
Participation Restriction	Refer to the person not being able to experience full involvement in life situations.
Perspectives	A professional view used to assist social workers to examine and focus on a realm of social functioning, necessary to complete a thorough assessment.
Quadrupod	These walking aids have a walking stick-style shaft and a three or four point base. They are therefore freestanding and are more stable than standard walking sticks. Some quadrupods incorporate an extension above the handgrip that terminates in an elbow cuff, similar to the cuff found on elbow crutches.
Rehabilitation	A set of interventions designed to reduce disability and enhance functioning in individuals' interaction with their environment.
SCI	Damage to any part of the spinal cord or nerves at the end of the spinal canal (cauda equina) — often causes permanent changes in strength, sensation and other body functions below the site of the injury.
Social Work	A practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people.
Social Work Support	Social work support includes social work intervention, support services as well as connecting clients with other relevant resources in the community.
Social work theories	Attempts to explain how individuals, families, groups, organizations, communities, societies, and social movements develop and function.
Spinal TB	A very dangerous type of skeletal TB as it can be associated with neurologic deficit due to compression of adjacent neural structures and significant spinal deformity.
Traumatic Brain Injury	A blow to the head or a penetrating head injury that disrupts the normal function of the brain. TBI can result when the head suddenly and violently hits an object or when an object pierces the skull and enters brain tissue.

# **CHAPTER ONE**

## **INTRODUCTION**

### **1.1 PRELIMINARY STUDY AND RATIONALE**

Even though one in seven people have been identified to have a disability, it is still considered a minority issue. While at least a billion people have a disability, excluding their families that are also affected, the necessary support and recognition remains lacking (Shakespeare, 2018). It was argued by Barnes (2009), that persons with disabilities (PWDs) can be considered a minority group deserving of all the rights and respect that we grant to any other legitimate minority group as well.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) does not provide a specific definition of disability, but rather recognises disability as an evolving concept which “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations Department of Economic and Social Affairs, 2007:1). The World Report on Disability (World Health Organisation & World Bank, 2011) further emphasised how, over recent decades, many social and health science researchers have identified the role of social and physical barriers in disability. Within the South African context, The White Paper on the Rights of Persons with Disabilities (WPRPD) defines disability as “imposed by society when a person with a physical, psychosocial, intellectual, neurological and/or sensory impairment is denied access to full participation in all aspects of life, and when society fails to uphold the rights and specific needs of individuals with impairments” (Department of Social Development, 2016:17). This study focused on adults with an acquired disability which occurred after birth (PACER, 2004), for example through accidents, diseases and infections (Careerforce, 2015; Elliott, Kurylo & Rivera, 2002).

Various policies around the world have attempted to include PWDs into everyday society by addressing their specific needs. The UNCRPD addresses the needs and rights of PWDs in terms of active citizenship and opportunity, including employment, through policy (UNDESA, 2007). After the first democratic elections in South Africa in 1994, the new Constitution of the Republic of South Africa recognised the rights of all citizens, including PWDs (Howell, Chalklen & Alberts, 2006). It specifically refers to disability as “prohibited grounds for



discrimination” (Van Reenen & Combrinck, 2011:146). The WPRPD was established to update the 1997 White Paper on an Integrated National Disability Strategy (INDS), as well as to integrate the obligations UNCRPD and the Continental Plan of Action for the African Decade of Persons with Disabilities (both of which South Africa has signed) with South Africa’s legislation, policy frameworks and the National Development Plan 2030. Furthermore, on 29 April 2019, the South African Minister of Social Development, Susan Shabangu, signed the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities, to be submitted to Parliament for approval to ensure enforceability in South African law. South Africa became the third Signatory State of the Protocol next to Chad and Central Africa Republic (DisabilityRightsSA, 2019). Despite the changes in laws and policies, societal attitudes, advances in technology and access to society that provide PWDs with new opportunities to fully participate in society, they still face significant social and economic problems (Mackelprang, 2013; UNDESA, 2007).

The motivation for this study derived from Bogart’s (2014) emphasis on the crucial difference between congenital and acquired disability, identifying the need to focus on a specific onset of disability. In a New York University Hospital study (Weller & Miller, 1977) with persons who acquired paraplegia, a four-stage process similar to stages of grief identified by Kübler-Ross (1972) was identified for PWDs coming to terms with their disability, which includes shock, denial, anger and depression. This correlation could assist to understand the adjustments persons who acquire a disability later in life must make as they ‘grieve’ the life prior to the disability onset. The authors further argued that the social work task is to help people with disabilities through these adjustment phases. The term “social work support” within this study was mainly focused on reconstruction and aftercare services within the social work intervention levels, which is focused on the reintegration and support services to enhance self-reliance and optimal social functioning (DSD, 2006). For the purposes of this study, social work support could also include services such as assisting PWDs with access to resources, liaising with other service providers, identifying support needs, reducing stigmatisation of disability, etc.

The WPRPD (DSD, 2016) emphasises this support in Pillars 3 and 4 titled Supporting Sustainable Integrated Community Life and Promoting and Supporting Empowerment of Persons with Disabilities. This further relates to the Global definition of Social Work as “... a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people” (International

Federation for Social Workers, 2014). Particularly this definition's focus on "[p]rinciples of social justice, human rights, collective responsibility and respect for diversities" as "central to social work," as well as the specification that the practice is "[u]nderpinned by theories of social work, social sciences, humanities and indigenous knowledges" and "engages people and structures to address life challenges and enhance wellbeing" is relevant to the concept of empowering PWDs (IFSW, 2014). Despite these strides, society still faces many challenges related to disability, such as providing culturally competent services to clients with disabilities, advocating for non-discriminatory laws, policies, and practices, promoting client participation at different levels and finally, embracing PWDs (Mackelprang, 2013). The collaboration of social workers with PWDs and their families can assist with increasing access to opportunities and promoting social inclusion and community living (Ministry of Social and Family Development, 2018), which is what the WPRPD aims to work towards, aligned with the 2030 of the National Development Plan and the UNCRPD.

## **1.2 PROBLEM STATEMENT**

Many previous studies have discussed social work in relation to PWDs, but few have been complementary, emphasising how social workers often failed to recognise the potential of working with PWDs (Oliver, Sapey & Thomas, 2012). The role of social work has been criticised as being structured to enforce dependency, which is not aligned with the vision of the WPRPD as published by the Department of Social Development, which identifies "South Africa" as "[a] free and just society inclusive of all PWDs as equal citizens" (DSD, 2016:55). Furthermore, many studies focused on the perspectives of the service provider (social worker) rather than the service user (PWD), while even fewer studies narrowed it down to physical disabilities, more specifically the experiences of adults with acquired physical disabilities on social work support in South Africa. Within the Nexus system (2018) no studies were found that had a specific focus on how adults with acquired physical disabilities experienced social work support, specifically in terms of assisting them with integrating and becoming full citizens in society. The risk of this is that the real concerns regarding social work support with PWDs may never be fully identified and addressed. Knowledge of service users' perspectives is useful in monitoring the services for quality assurance (Department of Health, 2000). Accordingly, this study – whilst contributing to indigenous knowledge within the Global South – explored how adults with an acquired physical disability have experienced social work support within a South African context to determine whether social work support is aligned with the WPRPD.

### 1.3 RESEARCH QUESTION

A research question provides the researcher the opportunity to indicate a theoretical and methodological orientation (Given & Munhall, 2008) and directs research literature (Creswell & Poth, 2018; Maree, 2016). The study originated from the research question:

What are the experiences of adults with acquired physical disabilities with regards to social work support (especially in assisting them after they acquired the physical disability)?

### 1.4 THEORETICAL POINT OF DEPARTURE

As mentioned before, within the South African social work context, the WPRPD acts as a guiding document for social work support to PWDs. Understanding PWDs and their experiences is intricate, and various models have been used in similar research topics. Some of these models include the medical, biopsychosocial, ecological model (Bickensack, Chatterji, Badley & Ustun, 1999) which was used in this study to investigate the experiences of adults with acquired physical disabilities on social work support in a South African context. This will be discussed further in Chapter Three and Six.

The biopsychosocial model was introduced as a new model to the medical field in 1977 (Engel). Previously, the medical definition of disability had simply defined it as a state requiring medical care caused by some health condition (Parsons, 1975). Conversely, the biopsychosocial model was based on the systems theory (Adler, 2009) focusing on three components of an individual incorporated in his/her interpersonal relationships (Kaplan & Coogan, 2005; Routledge, 2005). The *bio* (biology) component focused on the genetic, biochemical and physical factors of a person, whereas the *psycho* (psychological) involved the developmental, psychological and psychopathological aspects and, finally, the *social* aspect family systems, diversity, governments, social justice and culture (Hatala, 2012). Relating to the social aspects of this model, Bronfenbrenner's ecological perspective considers the influence of the environment on the individual with a series of systems which fit into one another. With each aspect, the influence on the individual becomes more specified and concentrated (Bronfenbrenner, 1979).

According to Oliver and Sapey (2006), no single theoretical model specifically fits disability in social work. Due to the complexity of the concept of disability and social work, as well as

the different models used in previous research on disability-related topics, it is important to consider different models on disability, including the social model and the International Classification of Functioning, Disability and Health. However, this study was guided by the biopsychosocial and ecological models to gain better understanding of the experiences of adults with acquired physical disabilities on the social work support they received, especially with regards to community integration.

## **1.5 GOAL AND OBJECTIVES**

The goal of this study, guided by South African policies to support service delivery to persons with disabilities, was to understand the experiences of adults with acquired disabilities on social work support in South Africa. This was achieved by means of the following objectives:

- To provide an overview on the scope and nature of disability and to explore relevant South African policies and legislations which focus on support to persons with disabilities;
- To discuss different perspectives on and models of disability with specific focus on those relevant to the social work profession;
- To present a theoretical discussion on the social work profession and how social work support to persons, especially adults, with acquired physical disabilities have been perceived from previous, similar studies;
- To empirically investigate the experiences of adults with acquired physical disabilities on social work support in South Africa;
- To make recommendations to policy makers, organisations and social workers on how the social work support to adults with acquired physical disabilities can be further developed to assist with integration into society.

## **1.6 RESEARCH METHODOLOGY**

The research methodology, as presented below, entails the literature review, research approach, research design, sampling, instrument of data collection, and reflexivity.

### **1.6.1 Literature review**

A literature review serves many functions within qualitative research, such as gaining an understanding of the concerned issue, identifying similarities and differences between previous and current issues and identifying gaps or weaknesses in previous studies (Creswell, 2014; De Vos, Strydom, Fouche & Delport, 2011). The literature review in this research study took place over three chapters aligned with the first three objectives of the study (see 1.5).

### **1.6.2 Research approach**

This research study made use of a qualitative approach, which is seen as a valuable social work approach. An advantage of qualitative research is the extent to which the identified meanings accurately represent participants' perspectives on the research topic (Grove & Gray, 2019). However, some elements of quantitative research were also applied to the study in terms of the identifying particulars of participants. This provided an overview of the participants and confirmation of the inclusion criteria.

Additionally, this study used a combination of different reasoning approaches. Deductive reasoning was used by incorporating general findings from previous studies within the literature review and relating it to specific expectations of the study. On the other hand, where empirical findings omitted from the literature review were identified, inductive reasoning was used to relate specific findings with general reasoning (Maree, 2016; De Vos et al., 2011).

### **1.6.4 Research design**

This research study utilised a combination of descriptive and exploratory research to answer the research question (Grove & Gray, 2019). In the literature review chapters, descriptive research was used to provide a more intensive analysis and understanding for the research topic (Rubin & Babbie, 2005) before explorative research provided insight into the topic during the empirical study (Maree, 2016; De Vos et al., 2011).

### **1.6.5 Sampling**

The research project was done with two cohorts. The first consisted of nineteen adults with acquired physical disabilities, while the second included five social workers who had experience working with PWDs. The initial plan was to schedule face to face meetings with participants by contacting them through details received from the participating organisation's

different branches. To this end, the organisation had shared of contact details with the researcher with prior consent from the participants. However, due to the COVID-19 pandemic, participants were only contacted and interviewed electronically e.g. through cell phone calls, WhatsApp calls, voice notes or Zoom. Participants had a choice between these three methods where cell phone calls were used for calls mostly and only one participant had a WhatsApp call. Other participants who chose WhatsApp preferred to use the voice note or “live chat” (i.e. responding to questions continuously over a period of a few hours) option as they found it difficult to communicate through calls. All participants participated in their own personal capacity.

The planned method of sampling entailed both purposive sampling, where a clear definition of the population and intended sample is crucial (Creswell & Poth, 2018; Maree, 2016), and snowball sampling, where there is limited access to appropriate participants (Maree, 2016), as was the case due to the COVID-19 pandemic. An information pamphlet was used to give potential participants more information about the research study (See Addendum J and K) Identifying participants for sampling was done through identifying the concepts of universe, population and sample. In this categorisation, the universe includes all possible subjects that have the characteristics that the researcher is interested in for the study, while the population refers to the total set from which the individuals for the study are chosen and the sample to the subjects chosen to participate fully in the study (De Vos et al., 2011). Accordingly, the criteria for inclusion were as follows within the two cohorts of the empirical study:

#### ***1.6.5.1 Cohort One***

The universe for Cohort One included all adults with physical disabilities, whilst the population consisted of all adults with acquired physical disabilities in South Africa and the sample all adults with acquired physical disabilities that have received South African social work services. The motive for interviewing adults who have an acquired physical disability/s was to achieve a better understanding of the first-hand experiences they had of social work support services received to assist in community integration as an adult with physical disability/s with/without the ability to live on their own. The specific focus on adults who acquired a physical disability later in their life was aimed at gaining a better understanding of how social work support services have assisted them with adjusting into community life and their life with a disability, compared to their life prior to acquiring a physical disability. Based on a study done by Muller-Kluits in 2017, which found that family caregivers of persons with physical disabilities shared

similar concerns and needs despite their family members having different types of physical disabilities and being different age groups, this study also included participants with a variety of physical disabilities. The purpose of this was to explore the shared experiences and strengthen the transferability of the study.

The criteria for inclusion for Cohort One are that the participant must:

- be an adult (over 18 years old) with an acquired physical disability which they acquired after the age of 11 years old;
- have an acquired physical disability related to mobility impairment such as spinal cord injury, stroke or other forms of paralysis or amputation. Persons who have acquired a hearing impairment (or deafness) or visual impairment (or blindness) may be considered as a secondary group as part of snowball sampling;
- have had some exposure to social support services in terms of their disability (e.g. rehabilitation or aftercare);
- be able to communicate in English or Afrikaans;
- decide to participate in the research study out of free will.

The criteria for exclusion was for persons who acquired a physical disability due to aging e.g. elderly people who have experienced gradual vision-, hearing- or other impairments. The reason for this is that acquiring a disability due to aging is often a more gradual process as is the impact of the adjustments that have to be made, whereas the purpose of this study was to examine more immediate impact.

#### **1.6.5.2 Cohort Two**

The universe for Cohort Two included all social workers, whilst the population included all social workers that are registered and practicing in South Africa and the sample registered social workers in South Africa who have delivered support services (e.g. rehabilitation or aftercare) to persons with disabilities. This sample group was chosen due to social workers' unique psychosocial perspective, as well as their perspective on how they assist persons with acquired physical disabilities. This could be compared to data collected during Cohort One in that this cohort can provide recommendations on how to improve social work support services.

Accordingly, it can also indicate how to better align these recommendations to South African policies and legislation on support services to PWDs, such as the WPRPD.

The criteria for inclusion for Cohort Two included that the participant must:

- be registered with the South African Council for Social Service Professions (SACSSP);
- have experience of providing social work support to PWDs in a South African context within the last five years, including the relevant policies and legislation focused on service delivery to persons with disabilities;
- be able to understand and communicate in English or Afrikaans;
- decide to participate in the research study out of free will.

#### **1.6.6 Method/instrument of data collection**

Qualitative interviews are generally minimally structured, audio-recorded and transcribed. The data collection for this qualitative study was done by means of a semi-structured interview schedule, which is mainly used to grant lengthy, valuable explanations from participants to gain knowledge of the research topic (Creswell & Poth, 2018; Maree, 2016; Wasserman, Clair, & Wilson, 2013). For instance, a participant could be asked broad questions to deduce their opinion on how adults with acquired physical disabilities experienced the social work support they received. This study's interview schedule was done in English and Afrikaans (see Addendum F to I). It consisted of open-ended questions (Maree, 2016) allowing adaptability to the research topic (Given & Munhall, 2008), and gave participants the opportunity to answer honestly (Maree, 2016).

After consent from participants was obtained, this study made use of a voice recorder to audiotape the interviews (Maree, 2016). These interviews were then transcribed. Initially, the researcher planned make use of field notes made during interviews to assist with the analysis (Wasserman et al., 2013). However, due to the COVID-19 outbreak, participants were interviewed electronically or telephonically via cell phone, WhatsApp or Zoom. Preference for WhatsApp voice notes was given, as this would still provide audio proof of interview to be transcribed. This study made use of the denaturalistic approach to transcription (Oliver et al., 2005), which removes unique elements of speech such as pauses during telephonic and other



voice recorded interviews whilst cautioning to influence any understanding of what was shared and the conclusions that can be drawn as a result (see 1.6.6.).

### **1.6.7 Data quality verification**

De Vos et al. (2011) and Maree (2016) agree that credibility and authenticity, transferability, dependability and conformability must be considered when establishing the candour of the qualitative research study. Accordingly, member checking of at least one participant per cohort (Maree, 2016) was used to ensure credibility and authenticity (See Addendum M). This was achieved by confirming that the themes have been accurately identified and described and determining whether the participants' views and the researcher's representation of their insights are accurate (De Vos et al., 2011). To further aid credibility, the study used two heterogeneous sample groups (see 1.6.4) with different identifying particulars. As a result, the groups provided varied perspectives on the research topic, which may correlate with one another and/or literature review findings from previous studies to substantiate the transferability from one situation to another (De Vos et al., 2011; Maree, 2016).

Dependability refers to the research process (see 1.6.5) being logical, well-documented and audited (Maree, 2016; De Vos et al., 2011) which was explained to the participants in the Consent to Participate forms (See Addendum B to E). Conformability (Maree, 2016; De Vos et al., 2011) in this study was ensured by an independent coder to confirm the themes identified for this research study as objective (See Addendum M).

### **1.6.8 Reflexivity**

Reflexivity includes self-reflection that allows for understanding of how one's personal background, culture and experiences (Creswell, 2014) influence and construct the world and one's ideas, or, in the case of this study, the researcher's relationship with the research processes and outcomes (O'Leary, 2007). The research topic focused on the experiences of service users (PWDs) on the social work support they received. As a social worker and a PWD, the researcher had to remain objective and not guide participants to answer in a certain manner. A reflective report was done with detailed analysis of how the researcher strived to remain objective during the study (See Addendum Q).

## **1.7 DATA COLLECTION AND PROCESSING PROCEDURE**

The data collection and processing procedure for this study comprised of qualitative data collection and interpretation, and followed methodological congruence (Creswell & Poth, 2018). As a registered social worker with SACSSP, the researcher is trained in conducting interviews and has done so before. Interviews were conducted in English or Afrikaans. Participants that found it difficult to communicate verbally were given the opportunity to complete their interviews as a questionnaire. The researcher also has basic sign language skills that could be utilised during the interview process should the need occur.

### **1.7.1 Data collection**

The data for the empirical study was collected through means of semi-structured interview schedules (see 1.6.5) done with 24 participants in two cohorts (see 6.4). The themes from the interview schedules were guided by the themes identified in the literature review of previous research done on the topic. The combination of the literature review and empirical study formed the basis of the data used for this study (Maree, 2016; Creswell, 2014; De Vos et al., 2011) according to the descriptive and explorative design of the study (see 1.6.3).

### **1.7.2 Qualitative data analysis and interpretation**

Qualitative data analysis is a non-numerical analysis and interpretation of observations to discover underlying meanings and patterns of relationships (Babbie, 2007) to attribute to a social or human problem (Creswell, 2014). After conducting the interviews, the main discussion points (themes), as well as the differences and similarities between the different participants' answers, were identified, discussed and analysed further according to the research approach and design (see 1.6.2 and 1.6.3). The models of disability (see 1.4) guided the analysis of the data collected whilst utilising the WPRPD and other policies on social support to persons with disabilities to ensure the South African relevance to the analysis.

## **1.8 RESEARCH AREA**

The research study took place in South Africa and was mostly but not exclusively focused within the Western Cape. The South African context of this study served to consider geographical boundaries (within South Africa), cultural influences, policies and legislature that influences disability service delivery in the country. Further, the unique challenges that arise

within South Africa due to its history and its socio-political environment were taken into account.

South Africa's geographical boundaries are identified by nine different provinces, of which the Western Cape is one. Each of these provinces have their own governmental structure and set of policies in line with national legislature. Within these geographical boundaries, there are eleven official languages not counting unofficial languages and other cultures. Afrikaans and English are considered to be among the main languages in the Western Cape. On a political front, South Africa has experienced dramatic political changes in the past few decades, from the introduction of Apartheid in 1948, to the formation of a Republic in 1960, and finally, the ending of Apartheid and the first democratic election in 1994 (South African History, 2018). These political changes brought about many new policies and legislations to address the needs and rights of vulnerable groups in South Africa, including PWDs. The reason for this research area was to contribute to indigenous knowledge on disability, which considers the unique South African context and its correlating policies. The participating organisation from which purposive sampling originated delivers services to PWDs and their families within the Western Cape in different socio-economic settings.

## **1.9 ETHICAL CONSIDERATIONS**

For this research study to be performed, some ethical considerations were considered among these ethical clearance and ethical issues.

### **1.9.1 Ethical clearance**

The research study went through all the admissions- and ethical committees before commencing with research. Due to the COVID-19 pandemic and the restrictions on face-to-face research, an updated proposal was submitted to the research ethics committee (REC) before commencing with interviews through means of telephonic and electronic interviews.

Qualitative researchers often need to access intimate details of participants' lives, which might leave them feeling exposed (Drisko, 2013). For this reason, the study was categorised as a medium-risk study under the REC submission (See Addendum A), and the researcher had to be aware of participants' possible feelings and approach the interviews with the notion of not doing any harm to the participants. Accordingly, an empathetic, non-invasive approach was

followed during the interviews. All the participants of this study were given the option to be referred for debriefing to independent social workers (see 1.9.2.4 and Addendum L).

### **1.9.2 Ethical issues**

The codes of ethical conduct for research considered during the qualitative research study are mainly based on three major principles, these being justice, beneficence and respect (Israel & Hay, 2006; Fuchs & Macrina, 2005).

The research study enforced justice by treating all participants fairly and aimed to make recommendations on disability-related issues identified during the empirical study to bring about social change in society. Beneficence considers the risks to participants to minimise them (Antle & Regehr, 2003). The semi-structured interviews may have left participants feeling exposed (Drisko, 2013), and as a result, an empathetic, non-invasive approach was followed during the interviews to minimise this risk. Respect means that the autonomy and self-determination of those who participate in research must be protected (Anastas, 2013) and its relevance to the study is clear (Grove & Gray, 2019). It particularly applied to some of the other ethical issues that were discussed including: voluntary participation, informed consent, confidentiality, compensation, debriefing of participants and the publication of findings which involved not doing anything to harm participants' rights.

Due to the COVID-19 outbreak, interviews had to be scheduled and conducted electronically and/or telephonically using tools such as Zoom, cell phone calls, WhatsApp calls or voice notes (whichever was more accessible to the participant). Internet research ethics is a subdiscipline of many research disciplines, e.g. social sciences, arts and humanities, medical/biomedical, and hard sciences. Ethical frameworks such as consequentialism, utilitarianism, deontology and virtue ethics, have contributed to the ways in which ethical issues in internet research are considered and evaluated (Buchanan & Zimmer, 2018).

VoIP (Voice over Internet Protocol) technologies (e.g. Zoom and Skype) provide researchers with the ability to interview research participants using voice and video across the internet via a synchronous (real-time) connection. Such tools thus provide new possibilities by allowing researchers to contact participants worldwide in an efficient and affordable manner, thus increasing the variety of samples. However, it could affect rapport and non-verbal cues (Iacono et al., 2016). Some authors (King & Horrocks, 2010) also warned researchers on the use of video for interviews due to technical glitches in sound and video transmission. However, since

2010, the quality of VoIP technologies has vastly improved. Technologies such as Zoom could further assist with the accessibility for PWDs, who may be willing to participate in an interview although they find physical re-location difficult. It could also assist with building more sustainability to the research process by limiting the pollution caused by means of transportation to interviews (Iacono et al., 2016).

In terms of telephonic interviews, ethical considerations, as also applies to face-to-face interviews, included, limitations and analysis (Carr & Worth, 2001). WhatsApp would pose some of the same concerns as both telephonic and Zoom interviews. However, if WhatsApp voice notes were used, a recording of the interview would still need to be transcribed. The advantage posed by this particular medium is that both the participant and the researcher would have immediate access to a copy of the interview as a recording. Precautions were made to still do interviews in a confidential manner (i.e. where the researcher is in a secured venue), and further, to store all data securely.

#### ***1.9.2.1 Voluntary participation and informed consent***

Social workers must obtain participants' consent and should refrain from being too vague in aligning the research process (Creswell, 2014; Drisko, 2013). Possible participants can only decide to participate after being fully informed of what will be required of them as well as the possible risks involved during the research process (Anastas, 2013; Boothroyd & Best, 2003). Accordingly, once participants agreed to form part of the study, they signed a consent form, which was done in English and Afrikaans to accommodate their preferred language. Due to the COVID-19 restrictions these consent forms were sent electronically and where not possible to sign and sent back, participants confirmed verbally or in alternative writing format (see figure 5.2). Participants participated voluntarily, and no one was forced or persuaded to form part of the study (Creswell, 2014; Anastas, 2013; Drisko, 2013). The consent form explained voluntary participation (Addendum B to E).

#### ***1.9.2.2 Confidentiality***

Confidentiality is one of the core values of social work (Drisko, 2013), where participants should be given the reassurance that their information will be kept confidential and not be disclosed in any way that could publicly identify them (Given & Munhall, 2008).

During Cohort One interviews, some persons with disabilities might have needed assistance in giving consent or conducting the interview. This could have been done by reading the consent form aloud for the visually impaired or Blind, and using sign language or filled out questionnaire for persons that are hard of hearing or Deaf (Eckhardt & Anastas, 2007). To eliminate the risk of confidentiality, persons who are hard of hearing or Deaf would be considered in answering the interview as a questionnaire. Persons with special needs that would be interested in participating were not excluded from the research study, but special measures would have been taken to accommodate them and ensure that no ethical issues would be breached in the process. Should translators/interpreters have been required, they would have signed a non-disclosure agreement, however this was not necessary in this study.

Minimal identifying particulars would present in this study. Participants were informed that these identifying particulars, including signed consent forms and lists linking names to research codes (e.g. Cohort One Participant One) would be stored separately from the research data itself, which is identified only by a code number or pseudonym (Maree, 2016). Data stored electronically was password-protected (Anastas, 2013). Names of participants were, as far as possible, not mentioned during the audio-taped interviews. With the transcription of the interviews, names of the participants were also not provided, and only pseudonyms were used (Given & Munhall, 2008).

The following research-related records were kept in a safe and secure place: the REC-approved research proposal and all amendments, all informed consent documents, recruiting materials, continuing review reports, recordings, notes on adverse or unanticipated events, and all correspondence from the REC.

### ***1.9.2.3 Compensation***

To ensure the legitimacy and efficacy of the research study (De Vos et al., 2011), no participant was compensated for being part of the study. However, to ensure that participants did not have any transport costs, interviews were scheduled to transpire in a communal area of their choice, such as their office or home (Grove & Gray, 2019). Due to the outbreak of the COVID-19 pandemic in March 2020, interviews were done electronically/telephonically, which ensured minimal costs and maximum convenience to participants. The choice in interview medium also ensured that participants could have options that would suit their needs best.

#### **1.9.2.4    *Debriefing of participants***

It is suggested in social work qualitative research done with vulnerable groups (Boothroyd & Best, 2003) to refer any participant who seems distressed to an independent source for professional assistance to avoid dual roles (Lunt & Fouché, 2010; Landau, 2008; Congress, 2001). All the participants of this study participated through their own choice, which should minimise the need for debriefing. Should the need have been there for debriefing, participants would have been referred to a social worker identified in their area. This was, however, not necessary for any of the participants in this study, as none of them requested any debriefing. (See an example of the agreement to debriefing form in Addendum L)

#### **1.9.2.5    *Publication of findings***

The research study will only be published for academic or professional purposes. Participants' identities will not be disclosed in these publications. Should findings be published it would be done according to the REC guidelines.

### **1.10    IMPACT**

Social impact assessment is the process of analysing and managing the consequences of a study on society (Vanclay, 2002). The WPRPD and other similar global policies focus on “a free and just society inclusive of all PWDs as equal citizens” (DSD, 2016). The study investigated the experiences of adults with an acquired physical disability on social work support within a South African context, considering policy guidelines such as the WPRPD. Relevant recommendations based on findings could be made to policy makers, organisations and social workers in general to strengthen the implementation of this vision.

## **CHAPTER TWO**

### **OVERVIEW OF DISABILITY IN DIFFERENT CONTEXTS**

#### **2.1 INTRODUCTION**

In Chapter One, a summary was provided for the planned research study. Building on this groundwork, this chapter delineates the objectives of this study. While various definitions of disability exist, two common features stand out in most official definitions, these being that disability is a physical or mental characteristic seen as an impairment or dysfunction, as well as that it involves some personal or social limitation associated with that impairment (Wasserman, 2016). These features are present in older and newer definitions, including those of the WHO (2001; 1980), the UN Standard Rules on the Equalization of Opportunities for PWDs (1996), the United Kingdom (UK) Disability Discrimination Act (1995) and the Americans with Disabilities Act (1990). The Disability Discrimination Act (1995) was replaced by the Equality Act 2010 in England, Scotland and Wales whilst the Disability Discrimination Act 1995 still remains in Northern Ireland.

Aligned with the first objective, this chapter will provide an overview of disability in terms of definitions and types, disability trends and policies around the world. It will further discuss disability within the Global South with specific focus on South Africa. To this end, it explains some South African policies on disability, as well as the experiences of South African persons with acquired physical disabilities and the services they use.

#### **2.2 UNDERSTANDING DISABILITY**

Disability is an evolving concept (United Nations, 2006) which is complex, dynamic, multidimensional, and debated (WHO & World Bank, 2011) due different interpretations and perspectives of what falls under the umbrella of disability (South African Human Rights Commission, 2017).

##### **2.2.1 Defining disability**

Historically, the term “disability” has been used as a synonym for “inability” (Wasserman, 2016). The term “disabled” was often also termed in comparison with what is perceived to be



“normal”, in other words, not deviating or different from the common type or standard (Davis, 2006).

According to the International Classification of Functioning, Disability and Health (ICF), there are three dimensions in defining disability i.e. impairments, activity limitations and participation restrictions (DSD, Department of Women, Children and People with Disabilities and United Nations Children’s Fund, 2012). Although the WHO’s description of disability implies that both medical and societal factors can affect disability, it does not mention the impact of the actions of PWDs on disability (Levitt, 2017).

The WHO describes disability as “a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives” (WHO, 2017). During the UNCRPD in 2006, PWDs were defined as people with long-term physical, mental, intellectual or sensory impairments which could hinder their equal participation in society when interacting with other barriers (UN, 2006).

The split term dis/ability that is often used within the disability sector is used in acknowledgement of the terms disability and ability existing in relation to one another (Goodley, 2014). Terms such as “person with a disability” also became more standard than “disabled person” to encourage the principle of PWDs not being defined by their disability, but rather that the disability is a characteristic they live with (Mackelprang, 2013).

### **2.2.2 Types of disabilities**

Disability can be defined as functional difficulties in at least one of the following areas: sight, hearing, mobility and self-care, where an individual reported varying degrees difficulties in these functionings (Graham, Moodley, Ismail, Munsaka & Ross, 2014). Figure 2.1. below represents some of the main types of disabilities i.e. physical, mental, hearing and visual, with the concept of having a multiple disability indicating the presence of more than one of these types of disabilities. Although these are not the only types of disabilities, this representation provides a sufficient overview of the types of disabilities for the purpose of the study.

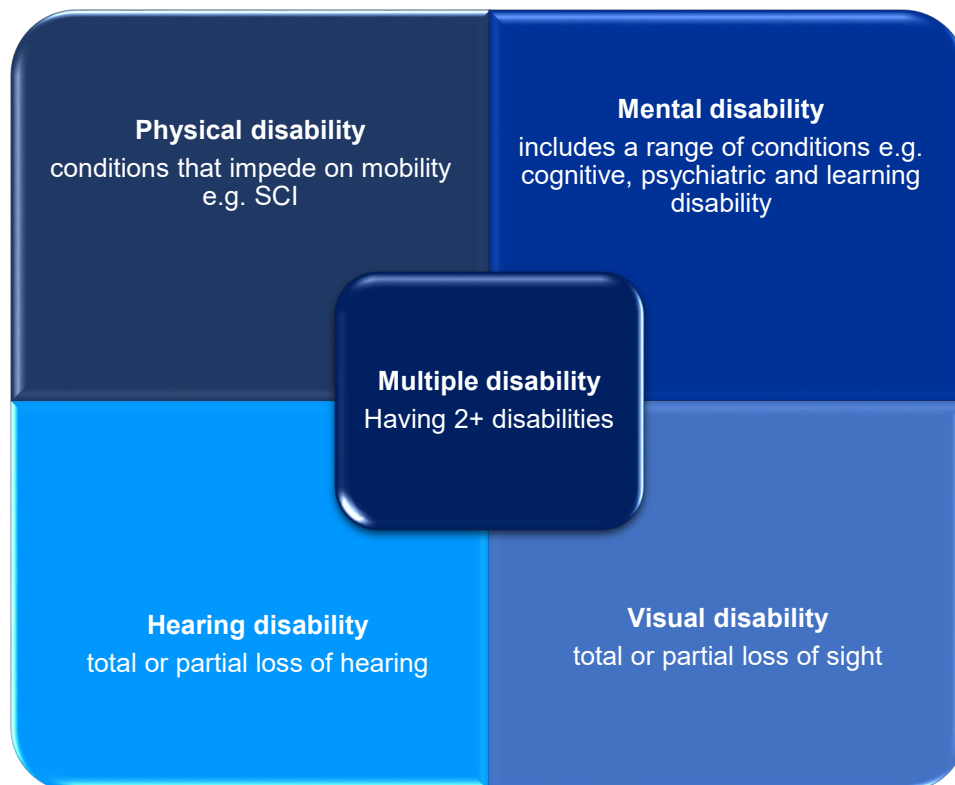


Figure 2.1: *Types of disabilities (SETA, 2006)*

This study will refer to physical disability as it is commonly defined, i.e. as forms of impairments that could impact on a person's physical capabilities such as being able to walk. It includes anatomical loss or musculoskeletal, neurological, respiratory or cardiovascular impairment (PACER, 2004).

A person could become disabled in different ways (Handicap International, 2009), typically in terms of two main types of onsets or causes of disability, these being congenital/hereditary or acquired/environmental. Bogart (2014) emphasises that there is a crucial difference between congenital and acquired disability, especially in terms of the way people incorporate their disability into their self-concept. A congenital disability occurs at birth as a result of either genetic or environmental influences (Careerforce, 2015; PACER, 2004; Elliott, Kurylo & Rivera, 2002). In this study, "acquired physical disability" refers to any physical disability that a person has acquired after birth, for example a spinal cord injury (SCI) or stroke (see sample criteria in Chapter One).

## 2.3 DISABILITY AROUND THE WORLD

As mentioned before, disability is a complex concept. The views and understandings of disability has changed over time, and also differs among different countries and cultural contexts. Understanding the development of the perceptions about disability and different global trends that influenced these views helps to understand the concept better.

### 2.3.1 Disability throughout history

Throughout history, societies have attempted to explain the place of disability in the social order. The table below provides a brief overview of how disability was viewed from as early as 12 000 B.C until today.

**Table 2.1: Disability Through History**

TIMELINE	ERA/CULTURE	BELIEF OF DISABILITY
<b>± 12 000 B.C</b>	Ancient Asians	Life with disability was viewed as substandard. <sup>1</sup>
<b>± 9 000 – 3000 B.C</b>	Neolithic tribes	Disability was believed to be caused by spirits. <sup>2</sup>
<b>± 2000 B.C</b>	Ancient Greeks	PWDs were not seen as human, and it was believed that they should be abandoned to die. <sup>3;4</sup>
<b>± 750 B.C</b>	Ancient Romans	Children with severe disabilities were left to die. Persons with disabilities were given assistance and expected to be appreciative and complacent. <sup>5</sup>
<b>± 600 B.C</b>	Ancient Zoroastrian	A perfect world without disabilities was envisioned. <sup>6</sup>
<b>± 500 – 1500 A.D.</b>	Middle Ages	PWDs were viewed as out of harmony with god or the natural order of the universe. <sup>6</sup>
<b>± 1600 – 1800 A.D.</b>	Enlightenment era	Those injured in war were given special consideration and support. <sup>6</sup>
<b>± 1800 – 1900 A.D.</b>	Victorian era	Social Darwinists advocated eugenics; wherein social engineering would discourage “undesirables” (such as PWDs) from reproducing, while promoting it for “desired classes” such as white, non-disabled, affluent people. <sup>7;8;9</sup>
<b>From 1900 A.D.</b>	Modern era	The intellectual elite advocated for the elimination of “undesirables” while advocating for the procreation of “desirables.” <sup>9</sup>

TIMELINE	ERA/CULTURE	BELIEF OF DISABILITY
1914 – 1918 A.D.		During World War I there were hundreds of thousands of veterans and civilians with disabilities in Europe and the United States. <sup>10</sup> With the increased survival rates of persons with congenital or acquired disabilities, the public responsibility to care for veterans disabled by wars, as well as technological advances led to an increased awareness and attention to “treating” PWDs. <sup>6</sup>
1940’s A.D.		Researchers (e.g. Roger Barker and Beatrice Wright) began demonstrating similarities between the experiences of PWDs and other vulnerable groups. <sup>6</sup>
1960’s A.D.		A riotous atmosphere was created relating to the Civil Rights movement, which lead to the formation of the social model that defined disability as a naturally occurring phenomenon adding to societal diversity. <sup>6</sup>
1970’s A.D.		The disability movement gained momentum and celebrated successes by uniting people with different types of disabilities and aligning with the Civil Rights movement. <sup>11</sup>

**Source:** (1) Miles, 2002; (2) Albrecht, 1992 (in Mackelprang, 2013) (3) DePoy and Gilson, 2004 (in Mackelprang, 2013) (4) Plato, 1991 (5) Morris, 1986 (6) Mackelprang, 2013 (7) Longmore, 1987 (8) Trattner, 1999 (9) Wiggam, 1924 (10) British Broadcasting Corporation, 1999 (in Mackelprang, 2013) (11) Fleisher and Zames, 2001

When considering the development of thoughts about disability throughout history, it can be deduced that disability was predominantly not seen as something with a positive outcome. Even during the turn of the twentieth century, the development of models and policies for understanding disability took several decades. Despite the major strides made in the perception of disability, these models still require improvement.

Having established a broad overview of the history of perceptions of disability, it is important to consider the development of ideas that influenced disability in twentieth century in more depth. Two ideologies stand out in particular, these being eugenics and neoliberalism.

### ***2.3.1.1 Eugenic influence on disability***

The aim of eugenics is to help society get rid of the human characteristics that are considered inferior (Watermeyer, Mckenzie & Swartz, 2019). It provided simplistic explanations for society’s ills, which manifested in justifying laws forbidding interracial marriage, authorising sterilisation of PWDs and propagating the institutionalisation of PWDs with degrading living

conditions (Mackelprang & Salsgiver; Longmore, 1987). In addition, Nazi Germany established the eugenic euthanasia project better known as the Holocaust (Watermeyer et al., 2019), which included the genocide of at least 75 000 PWDs (Mackelprang, 2013).

The explicit influence of eugenics on disability is that the ideology advocates for differentiation between congenital disabilities and acquired disabilities (Mackelprang, 2013). Traditionally, disability was seen as “shameful” (Mizrahi & Davis, 2008). However, World War I produced hundreds of thousands of veterans and civilians with disabilities in Europe and the United States, and responses to their needs reinforced and strengthened the concept of the “worthy poor” (British Broadcasting Corporation, 1999 in Mackelprang, 2013). Conversely, individuals with disability were considered to be genetically inferior and unworthy of procreating, or, in extreme cases, of living.

In modern society, it is believed that the Western world has moved past eugenics, and several agreements were established to protect people against eugenic movements like the Holocaust. Nonetheless, the idea of what constitutes ‘normal’ provides a template of the ideal citizen (Watermeyer et al., 2019). Usually, architects and designers focus on aesthetics rather than the practical use of buildings (Hamraie, 2012). In response to disability rights, the universal design concept provides an explicit critique and opposing approach to the exclusionary concept of the “normate” user (Watermeyer et al., 2019).

The term ‘normate’ is often used within disability studies to refer to a fantasy image of perfect bodily health, beauty, and functioning. It depicts an ideal everyone tries to reach, despite the seeming impossibility of living up to it. Garland-Thomson (2002) therefore argues that disability is a culturally bound category that should be considered alongside concepts such as race, class, ethnicity and gender.

### **2.3.1.2 *Neoliberalism on disability***

Neoliberalism views people as capable of making their own choices and harnessing the market to reach new forms of individualist economic power. In this sense, its emphasis on individual free will has gained the interest of many disability theorists, such as McRuer (2012). It encourages an affirmative disability politics of identity, capability, representative justice and the building of a new neoliberal workfare state (Watermeyer et al., 2019) for economic participation, which ensures equality comparable with so-called able-bodied citizens (Roulstone & Morgan, 2009). Still, although neoliberalism has promised economic mobility

through PWDs' non-discriminatory inclusion and participation within the labour market, the question of what types of jobs have become accessible for them remains (Watermeyer et al., 2019).

In addition to less accessibility to jobs for PWDs despite its promise of inclusion, another paradox exists within neoliberal governments (Evans, 2011; Sothern, 2007). This manifests in their reduction of welfare services and the individual's dependence on these services, while individual members of communities are still expected to take responsibility for their lives and aspirations with the support of civil society partnerships (Watermeyer et al., 2019). The UNCRPD (UN, 2006) and the Sustainable Development Goals (2015-2030) are thus limited by neoliberal strategies to withdraw or create governmental obligations, mechanisms and policies. This impacts economically poorer nations with different institutional contexts than first world countries. These include many countries in the Global South, such as South Africa (Watermeyer et al., 2019).

### **2.3.2 International trends in disability**

As mentioned before, the term disability is complex and multi-dimensional. Therefore, the measurement of the disability population of the world also becomes more complex, as different tools use different criteria to be considered. The World Report on Disability (WHO & World Bank, 2010) found that the global prevalence rate for the adults with a disability is 16% and 15% respectively, ranging from 11% in higher income countries to 18% in lower income countries. These statistics bring about the idea that PWDs may well represent the single largest minority on earth after women.

Studies conducted in developed countries such as Australia, the United States of America and Canada in the years 1998, 2001 and 2006 found that non-communicable diseases were associated with disability (WHO & World Bank, 2011). In 2010, the WHO estimated that the burden of non-communicable disease in South Africa was two to three times higher than that in developed countries (Mayosi, Flisher, Lalloo, Sitas, Tollman & Bradshaw, 2009).

Stroke, as an acquired disability, is the major cause of adult disability worldwide (Kwang-Hwa, Hung-Chou, Yennung, et al., 2012). Mayo, Wood-Dauphinee, Cote, Durcan and Carlton (2002) indicate that 50% of stroke survivors return to their communities to live with impairments that would need to be managed with the assistance of an able-bodied caregiver, often a family member (Kusambiza-Kiingi, Maleka & Ntsiea, 2017). Unfortunately, 34% to

52% of family members caring for stroke survivors experience depressive symptoms, with rates being higher in the first 90 days after the survivor's return to the community (Bartolucci, Elliott & Giger, 2004; Pohjasvaara, Vataja, Leppavuori, Kaste & Erkinjuntti, 2001; Kotila, Numminen, Waltimo & Kaste, 1998; Nieboer, Schulz, Matthews, Scheier, Ormel & Lindenberg, 1998). These findings are supported by later studies, where a negative correlation between community reintegration and levels of caregiver strain was found (Kusambiza-Kiingi, et al., 2017; Hillier & Inglis-Jassiem, 2010).

In addition to the adjustment of caring for a stroke survivor, previous studies have found that declines in social support are linked to family-caregiver adjustment during the period of the individual's reintegration into the community, which affects well-being and general health (Shewchuk, Richards & Elliott, 1998). Unfortunately, for many family caregivers of persons with chronic health conditions, social support deteriorates over time (Quittner, Glueckauf & Jackson, 1990). Nonetheless, health care providers can assist caregivers in obtaining and maintaining social support to sustain them in the challenges they face. This can be achieved by providing appropriate social support referrals and developing a proactive approach when interacting with caregivers (Grant, Elliott, Weaver, Glandon, Raper & Giger, 2006).

### **2.3.3 International policies on disability**

As indicated in the historical overview above, many global events have shaped the concept of disability. As the understanding of disability evolved, so did many policies around the world. Some of these policies include the Alma Ata Conference/Declaration, Millennium Development Goals (MDGs), Sustainable Development Goals (SDGs), Convention on the Rights of Persons with disabilities (UNCRPD), International Classification of Functioning, Disability and Health (ICF), World report on Disability and WHO Rehabilitation 2030. While in some cases these policies had a direct influence on disability-related concerns and service delivery, others played a more indirect role.

#### **2.3.3.1 *Alma Ata Conference/Declaration***

The Alma-Ata Conference (WHO, 1978) mobilised a "Primary Health Care Movement" to address "politically, socially and economically unacceptable health inequalities within all countries." Unfortunately, there are social disparities in the implementation of primary health services in most European countries, especially in terms of the utilisation of primary health services to ensure equal care needs (Van Doorslaer, Masseria & Koolman, 2006). The

declaration motivates for a continuing health care process and emphasises the importance of addressing the main health needs of people in the relevant community. Further, it specifies that primary health care should include promotive, preventive, curative, rehabilitative and palliative services (WHO, 1978).

With the passing of the 40th anniversary of the Declaration of Alma-Ata, it is essential to reflect on progress made, firstly in recognising the importance of rehabilitation, and secondly in integrating rehabilitation in primary health care. Where the rehabilitation workforce capacity is stronger, rehabilitation may be accessible at the primary care level, whilst, in comparison, where the rehabilitation workforce capacity is less developed, rehabilitation may sometimes be delivered by general health care providers. The countries around the world came together at the Global Conference on Primary Health Care to endorse the Declaration of Astana and to recommit in the strengthening of primary health care to achieve universal health coverage and the Sustainable Development Goals. Rehabilitation provided in primary health care has broader social benefits in that early intervention can reduce the prevalence and minimise the disabling effects of chronic conditions among adults and children (Bosch-Bayard, Llibre-Rodriguez, Fernández-Seco, Borrego-Calzadilla, Carrasco-García, Zayas-Llerena et al., 2016; Hubermann, Boychuck, Shevell & Majnemer, 2016; Nguyen, Lefevre-Colau, Poiraudau & Rannou, 2016).

### **2.3.3.2 *Millennium Development Goals (MDGs)***

In September 2001, the signed United Nations Millennium Declaration committed world leaders to combat poverty, hunger, disease, illiteracy, environmental degradation and discrimination. The United Nations MDGs were eight goals derived from this Declaration that all had specific targets and indicators. In a bid to implement positive changes where they were most needed, all 191 UN member states agreed to attempt achievement of these goals by the year 2015. Accordingly, the eight MDGs, as can be seen in Figure 2.2. below, include:

1. Eradicating extreme poverty and hunger;
2. Achieving universal primary education;
3. Promoting gender equality and empowering women;
4. Reducing child mortality;
5. Improving maternal health;
6. Combating HIV/AIDS, malaria, and other diseases;



7. Ensuring environmental sustainability; and
8. Developing a global partnership for development (WHO, 2000).



Figure 2.2: *Millennium Development Goals (UN, 2000)*

Since the MDGs were specifically designed to address the needs of the world's poorest and most marginalised population groups, they would not be achieved without the inclusion PWDs.

However, while great strides were made in recognising human diversity earlier in the twentieth century with efforts such as the Civil Rights Movement and the space it created for advocacy for other marginalised groups such as PWDs, the MDGs made no reference to PWDs. Despite this limitation, MDGs were relevant to and affected the lives of PWDs (UN, 2015) up until their termination at the end of 2015, although the accompanying guidelines, policies, programmes and conferences that form part of ongoing MDG efforts still fail to mention them specifically (UN, 2020a & b).

### 2.3.3.3 *Sustainable Development Goals (SDGs)*

The United Nations adopted 17 Sustainable Development Goals (SDGs) in 2015 as depicted in Figure 2.3 below. Based on the principle of “leaving no one behind,” the SDGs emphasise a holistic approach to achieving sustainable development for all (UN, 2015; Steenkamp, 2017). Accordingly, these 17 goals aim:

1. to end poverty in all its forms everywhere;
2. to end hunger, achieve food security and improved nutrition, and promote sustainable agriculture;
3. to ensure healthy lives and promote wellbeing for all at all ages;

4. to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all;
5. to achieve gender equality and empower all women and girls;
6. to ensure availability and sustainable management of water and sanitation for all;
7. to ensure access to affordable, reliable, sustainable and modern energy for all;
8. to promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all;
9. to build resilient infrastructure, promote inclusive and sustainable industrialisation and foster innovation;
10. to reduce inequality within and among countries;
11. to make cities and human settlements inclusive, safe, resilient and sustainable;
12. to ensure sustainable consumption and production patterns;
13. to take urgent action to combat climate change and its impacts;
14. to conserve and sustainably use the oceans, seas and marine resources for sustainable development;
15. to protect, restore and promote sustainable use of terrestrial ecosystems, sustainably manage forests, combat desertification, and halt and reverse land degradation and biodiversity loss;
16. to promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels, and lastly,
17. to strengthen the means of implementation and revitalise the Global Partnership for Sustainable Development (UN, 2015).



Figure 2.3: Sustainable Development Goals (UN, 2015). Diagram from *United in Diversity Creative Campus, Kura Kura, Bali (2016)*. Available at: <http://businesscommission.org/news/the-sdg-pyramid-of-happiness>

In contrast with the MDGs, which did not mention PWDs, the SDGs emphasise that people who are vulnerable – including PWDs of whom more than 80% live in poverty – must be empowered (UN, 2015). For instance, Social work support to PWDs and their families, could play a fundamental role in achieving SDG 3, namely to “[e]nsure healthy lives and promote well-being for all at all ages.” Other SDG’s where social work could also assist in service delivery to PWDs include SDGs 8 to 10 titled “promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all; build resilient infrastructure, promote inclusive and sustainable industrialisation and foster innovation; and reduce inequality within and among countries”.

Recommendations and conclusions argue that by addressing the needs of the family caregivers, the overall health and wellbeing of PWDs could be positively influenced in line with the SDGs.

#### **2.3.3.4 *Convention on the Rights of Persons with disabilities (UNCRPD)***

During the UNCRPD, South Africa was one of 155 countries that signed the convention (UNICEF, 2013). Although in Africa, Kenya, Uganda and Zambia have all ratified the UNCRPD, progress towards achieving the human rights of PWDs is still slow (Lang et al., 2017). In 2007, South Africa ratified the UNCRPD, thereby indicating the government’s commitment to protect the rights of its disabled citizens. The UNCRPD is the first legally binding international convention providing a clear understanding of governments’ responsibilities in addressing accessibility for PWDs to live independently and be able to fully participate in all aspects of life (Roomaney, 2017). It essentially aims to achieve the long-term goal for all schools, workplaces and services to be accessible to everyone (Watermeyer et al., 2019).

#### **2.3.3.5 *International Classification of Functioning, Disability and Health (ICF)***

The ICF covers all aspects of health and describes them in terms of health-related domains. The WHO encourages the application of the ICF internationally as a classification tool and a framework for social policy, research, education, and clinical practice (Rosenbaum & Stewart, 2004). This will be discussed more thoroughly in Chapter Three aligned with the biopsychosocial model of disability.

### 2.3.3.6 *World report on Disability*

The 2011 World Report on Disability provided the most comprehensive account of PWDs worldwide. It concluded that there are over one billion PWDs in the world (15%), of whom nearly “200 million experience considerable difficulties in functioning” (WHO & World Bank, 2011). The aim of the report is thus to provide governments and civil society with a comprehensive description of the importance of disability and an analysis of the responses provided. Further, it makes recommendations for action at national and international levels, and strives towards the vision of an inclusive world in which everyone is able to live a life of health, comfort, and dignity. It also suggests steps for all stakeholders – including governments, civil society organisations and disabled people’s organisations – to create enabling environments, develop rehabilitation and support services, ensure adequate social protection, create inclusive policies and programmes, and enforce standards and legislation to the benefit of PWDs (WHO & World Bank, 2011).

### 2.3.3.7 *WHO Rehabilitation 2030*

Rehabilitation is relevant to the needs of people with many health conditions including disability. The availability of accessible and affordable rehabilitation plays a fundamental role in achieving Sustainable Development Goal (SDG) 3, which is to “[e]nsure healthy lives and promote well-being for all at all ages” (WHO, 2017). Below is a figure illustrating 46 countries that contributed to the World Rehabilitation Call for Action 2030. Among these, only seven were from Africa, one of which was South Africa.

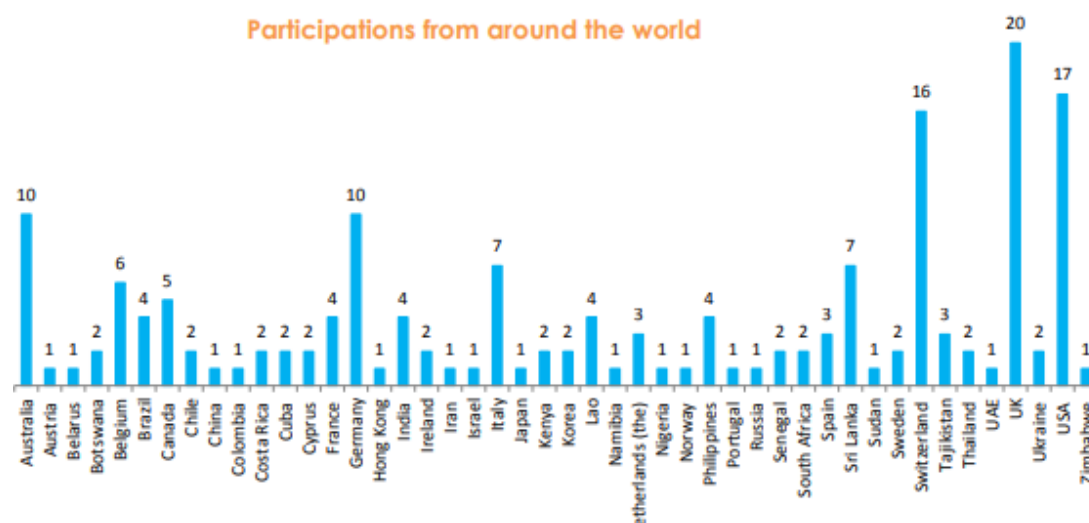


Figure 2.4: *Countries present at the establishment of Rehabilitation 2030 (WHO, 2017)*

The reason for the lack of African countries involved in the World Rehabilitation Call to Action 2030 may be attributed to the fact that strengthening and extending rehabilitation in countries is affected by certain barriers. These barriers include under-prioritisation by government amongst competing priorities, the absence of rehabilitation policies and planning at national and sub-national levels, as well as limited coordination between ministries of health and social affairs where both are involved in rehabilitation governance. Further, non-existent or inadequate funding, a dearth of evidence of met and unmet rehabilitation needs, insufficient numbers and skills of rehabilitation professionals, the absence of rehabilitation facilities and equipment, and finally, a lack of integration into health systems all play a role (WHO, 2017).

### **2.3.3.8 *Other policies on disability***

The principle of ‘design for all’ is one of the essential building blocks of the New Urban Agenda (Watermeyer et al., 2019) and many other policies around the world. Some of these include the Vienna Declaration of 1993 (UN, 1993), Habitat III, the initiative titled Good Practices of Accessible Urban Development: Making Urban Environments Inclusive and Fully Accessible to All (UN, 2016), the Paris Agreement of the United Nations Framework Convention on Climate Change (UN, 2015), the Brazilian Law for Inclusion (2015) and the Sendai Framework for Disaster Risk Reduction (United Nations Office for Disaster Risk Reduction, 2015). The “design for all” principle has also been pivotal in specific campaigns, including the Rockefeller Foundation’s 100 Resilient Cities project, the Making Cities Resilient campaign of the UN Office for Disaster Risk Reduction (UNISDR) and the City Resilience Action Planning Tool of the UN-Habitat City Resilience Profiling Programme or CRPP (Watermeyer et al., 2019). Adopting “design and access for all” strategies would assist cities to tackle spatial, social, and economic inequalities, as well as demographic changes such as an aging society. Including accessibility from the beginning means avoiding corrective and costly measures to remove barriers in the future (Disability Inclusive and Accessible Urban Development Network, 2016).

## **2.4 DISABILITY IN THE GLOBAL SOUTH**

In the Global South, countries have also put policies into place to assist PWDs. As one of the umbrella terms used to refer to regions outside Europe and North America, ‘Global South’ traditionally refers to the regions of Latin America, Asia, Africa, and Oceania. Many of these countries (though not all) are classified as low-income and often politically or culturally

marginalised, Although the term Global South is thus seen merely as a metaphor for underdevelopment at times, its meaning is far more complex. It references an entire history of colonialism, neo-imperialism, and differential economic and social change through which large inequalities in living standards, life expectancy, and access to resources are maintained (Dados & Connell, 2012).

Ultimately, for the greater part of colonial history in Africa, most people were not seen as full citizens of the countries in which they lived. Even in post-colonial Africa, many people are still struggling to be viewed as citizens with full rights. Within broader struggles, PWDs often compete with other minority groups (Watermeyer et al., 2019), adding to the struggle of who needs to be included in equality.

While many countries in the Global South such as Kenya, Uganda and Zambia have ratified the UNCRPD, progress towards achieving the human rights of PWDs is slow and frustrating in Africa, as in other settings (Lang et al., 2017). A report compiled in 2003 found that, even before the onset of the country's economic struggles, only 12.3% of PWDs in Zimbabwe received financial assistance of any kind (Eide et al., 2003). It has also been reported that the costs associated with the exclusion of a single group, including PWDs, from the labour force could lead to substantial losses. It is estimated that it could cost countries up to 7% of national Gross Domestic Product (GDP) and approximately 15-20% of the global market share due to inaccessible tourism (UNDESA, 2016). However, despite these difficulties, there have been glimmers of progress such as Uganda's 1995 constitution recognising the rights of PWDs at all levels and its 1996 Parliamentary Elections Statute specifying that PWDs should be included at the national level (Watermeyer et al., 2019).

Having focused primarily on other African countries in this introductory engagement with the plight of PWDs in the Global South, the rest of this section focuses on the situation of these individuals South Africa in more depth.

#### **2.4.1 South African trends in disability**

Koopman (2003) refers to the 1996 Census of South Africa estimating the prevalence of PWDs as 6.6%, while the Census of 2001 reported that 5% of the country's total population had a disability. In 2003, a District Health Survey was conducted by the DOH and the Medical Research Council, which reported that the overall disability prevalence for the population aged up to 19 years old was 5.3%. Likewise, Statistics South Africa (2005) indicated the prevalence

of PWDs in South Africa was approximately 5%. In 2011, the national census (StatsSA, 2014) estimated the national disability prevalence rate to be 7.5%, excluding children under the age of five years and persons with psychosocial and certain neurological disabilities. Still, this number could be higher, as it only represents 75% of the population at the time (38 million census participants of an estimated 51 million population). Redfern (2014) cited the General Household Survey from August 2012 (Statistics South Africa, 2013), which again indicated the overall prevalence of disability in the population to be 5.1%, with the majority of these cases being amongst adults. An analysis of the NIDS data, on the other hand, reveals a disability prevalence rate of 18%. This is similar to the global average prevalence rate for the adult population of almost 16% (WHO & World Bank, 2011), with lower income countries demonstrating higher prevalence rates. This being higher than the Census 2011 rate (Statistics South Africa, 2012) may be attributed to differences in the way the questions were asked and the inclusion of only adults in the National Income Dynamics Study (NIDS) analysis (Graham, 2014). The national disability prevalence increased slightly from 7.5% in Census 2011 to 7.7% in Community Survey 2016 (Statistic South Africa, 2016). In 2018, 4.4% of South Africans aged five years and older were classified as disabled (Statistics South Africa, 2018).

Most PWDs in South Africa are Black, as the ratio of Black citizens to White is a little over 10:1. In this statistical analysis, “Black” referred to all persons of colour, incorporating the three apartheid categories of “Black African,” “Coloured,” and “Asian,” which are still in use for purposes of affirmative action and economic redistribution (Watermeyer et al., 2019). The prevalence rate of disability also seems to be higher in females (Graham et al., 2014). The prevalence rate measures are deemed to be difficult due to the difference in sample groups, survey questions and interpretations of the term disability. It is estimated that by 2023 there will be a 30% increase in the number of first-time stroke sufferers (Wolfe, 2000).

#### **2.4.2 Influence of democracy on disability in South Africa**

From 1948 until democracy in 1994, apartheid policies rooted by colonial inequalities deliberately disadvantaged Black people in every aspect of civil life (Watermeyer et al., 2019). Under these policies, the majority of PWDs were also severely disadvantaged in terms of access to basic services. Not only were services focused towards white PWDs, but most were based in urban areas, which rendered them inaccessible to those from rural communities. Services were guided by the medical or charity model, where PWDs were perceived as sick or helpless



and in need of care. Consequently, many were denied opportunities and remained in the cycle of poverty and social exclusion (Philpott, 2004; Office of the Deputy President, 1997).

Since 1994, the challenge has been to address inequitable service provision from the past and change the medically based paradigm within which disability was viewed. There was a need to develop rights-based policies, address inequities in service provision and promote the inclusion of disabled children, which lead to the large-scale policy reforms of the late 1990s and early 2000s that emphasised access and equity (ACPF, 2011).

### **2.4.3 Influence of the South African National Health Insurance (NHI) on disability**

The NHI, as a form of universal health insurance, is the South African government's attempt at redressing the inequalities and ensuring accessibility to quality health service for everyone, and in so doing, decreasing the private health sector (Department of Health, 2020). Universal Health Coverage ensures that all individuals and communities receive the health services they need without financial adversity, including the full spectrum of essential, quality health services such as (health) promotion, (disease) prevention, treatment, rehabilitation, and palliative care (WHO, 2017).

As a health financing system, the NHI is designed to pool funds together to provide access to quality and affordable personal health services for all South Africans according to their health needs and regardless of their socio-economic circumstances. Although it is currently still being finalised, its planned implementation in South Africa is the year 2026. It will largely be funded from general taxes, and accordingly, people from lower socio-economic circumstances will not make any direct payment to the fund. Employers, on the other hand, will assist the NHI Fund by matching their employees' contributions. The NHI will offer all South Africans and legal residents' access to a defined package of comprehensive health services that will range from primary health care (PHC) to specialised tertiary and quaternary levels of care (Department of Health, 2020).

## **2.5 SOUTH AFRICAN POLICIES ON DISABILITY**

There are various South African policies to assist with disability. Table 2.2 below shows a summary of some of these policies.



**Table 2.2: Policies and legislation impacting on disability in South Africa**

<b>International conventions that place an obligation on the South African government to protect persons with disabilities</b>	
UN Convention on the rights of persons with disabilities	
<b>Legislation and policies that underlie the provision of disability services in South Africa</b>	
Constitution Integrated National Disability Strategy Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA) National Disability Policy Framework Disability framework for local government	
<b>Legislation and policies of key South African government departments</b>	
Health	White paper for the transformation of health services in SA Mental Health Act National Health Act Rehabilitation policy Free Healthcare policy Guidelines for provision of assistive devices
Social Development	White paper for Social Welfare Integrated national strategy on support services to children with disabilities Social Assistance Act White Paper on the Rights of Persons with Disabilities (2016)
Education	Education White Paper 5: Early childhood education: Meeting the challenge of early childhood development in South Africa Education White Paper 6: Special needs education: Building an inclusive education and training system

Adapted from The African Child Policy Forum (2011)

Some of these policies will be discussed more thoroughly below in terms of their contribution to service delivery to persons with disabilities in South Africa.

### 2.5.1 South African Constitution

The Constitution of the Republic of South Africa, hereafter referred to as ‘the Constitution’ (RSA, 1996), sets the foundation for any legal and policy framework. Section 9 states that the government may not unfairly discriminate against anyone on any grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth (RSA, 1996). Further, in conjunction with the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA), the framework places a complementary duty on the government to take active measures to promote the equality of PWDs (Roomaney, 2017). This act will be discussed in more depth later (see 2.5.4).

The Constitution recognises that PWDs have been discriminated against and that the equity for them requires redressing past inequity. This policy framework draws on the central principles of equity and non-discrimination, which are entrenched in various other policy documents relevant to PWDs. These policies include the Integrated National Disability Strategy (ODP, 1997), the Education White Paper 3 on the Transformation of the Higher Education System (DOE, 1997), the National Plan for Higher Education (DOE, 2001b), the Education White Paper 6 (DOE, 2001a), the Promotion of Equality and Prevention of Unfair Discrimination Act 4 (RSA, 2000), the Department of Public Service Administration's Batho Pele ('People First') principles (DPSA, 1997), the Disability Rights Charter (1991), the National DOH's Patient's Rights, the National Rehabilitation Policy, the Standardisation of the Provision of Assistive Devices in South Africa: Guidelines for Use in the Public Sector, and finally, Free Health Care for PWDs at the Hospital Level (Greyling, 2008).

### **2.5.2 Integrated National Disability Strategy (INDS)**

In South Africa, the White Paper on An Integrated National Disability Strategy (INDS) released by the Office on the Status of PWDs within the Office of the Deputy President in 1997 (ODP, 1997) shows the first official policy that adopted the social model (DWCPD, 2013). The INDS represented a paradigmatic shift away from the understanding of disability as purely a medical or welfare issue, instead arguing that it is society that must change through substantial changes to the physical environment. It covers disability issues such as integration of disability issues in all government development strategies, planning, processes and programmes. Further, it propagates an integrated and coordinated management system for planning, implementation and monitoring in all spheres of government. It aims to improve appropriate, accessible and affordable health services to enhance prevention of disability and ensure access to basic rehabilitation (ODP, 1997). It was strengthened by the passing of the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (RSA, 2000) and the compilation of the WPRPD, both of which will be discussed later.

### **2.5.3 White Paper for Social Welfare**

This policy document states that there must be social welfare policies and programmes which provide for social relief to ensure adequate economic and social protection during times of unemployment, ill-health, maternity, childrearing, widowhood, disability and old age. Under its statutes, social welfare services and programmes will aim to promote non-discrimination,

tolerance, mutual respect, diversity, and the inclusion of all groups in society including PWDs (DSD, 1997).

Section 3 of this policy focuses specifically on PWDs. Despite the document being written over 20 years ago, consequently containing statistics are not accurate anymore, some of its main points still relevant to current disability-related topics. Firstly, the document states that a national coordinated disability strategy will equalise opportunities in all spheres of social life, promote social integration and address poverty among PWDs. Secondly, it specifies that the Department of Social Welfare now known as the Department of Social Development (as it will subsequently be referred to) will liaise with other government departments to facilitate the access of PWDs to public buildings by reviewing national building regulations. Another relevant point it makes is that the Department of Social Development (DSD) will raise public awareness to facilitate the integration of PWDs into all spheres of social life. Lastly, it promises community-based support services and facilities that will offer PWDs and their family a wide range of opportunities and options to promote independent living and integration into community life. The policy thus emphasises community development, which is a pivotal for developmental social welfare and could also provide support to persons with physical disabilities (DSD, 1997) as aligned with the WPRPD (see 2.5.5).

#### **2.5.4 Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (PEPUDA)**

Another important policy in service delivery to PWDs is the Promotion of Equality and Prevention of Unfair Discrimination Act (RSA, 2000) mandated by section 9(4) of the Constitution. The act identifies the different ways in which discrimination is demonstrated in South Africa, and is focussed on preventing, prohibiting and eliminating unfair discrimination, hate speech and harassment. The act further addresses concerns of environmental accessibility and reasonable accommodation for PWDs in the workplace, and condemns unfair discrimination against them (ACPF, 2011).

Section 9 of PEPUDA prohibits unfair discrimination on the ground of disability. Firstly, it specifies that denying PWDs of any support necessary for their participation in society is illegal. Secondly, it forbids any breaching of the code of practice of the South African Bureau of Standards (SABS) that administer environmental accessibility. Finally, it proscribes failing

to eliminate obstacles which impact PWDs' ability to enjoy equal opportunities or failing to reasonably accommodate them (SAHRC, 2015).

### **2.5.5 White Paper on the Rights for Persons with Disabilities (WPRPD)**

The DSD launched the WPRPD in 2016. This policy updates South Africa's 1997 INDS (see 2.5.2). Further, it integrates the obligations of UNCRPD and the Continental Plan of Action for the African Decade of Persons with Disabilities, – both of which South Africa has signed – with South Africa's legislation, policy frameworks and the National Development Plan 2030. It also supports mainstreaming for realising the rights of PWDs and provides clarity on and guides the development of standard operating procedures for mainstreaming disability. The policy thus guides the self-representation of PWDs, as well as the review of all existing sectoral policies, programmes, budgets and reporting systems, and the development of new ones to align with Constitutional and international agreement obligations. In so doing, it stipulates norms and standards for removing discriminatory barriers for PWDs. Lastly, the policy provides a broad outline of the responsibilities and accountabilities of the different stakeholders involved in providing barrier-free, appropriate, effective, efficient and coordinated service delivery to PWDs (DSD, 2016).

The Vision of this WPRPD is that "South Africa" should be "[a] free and just society inclusive of all persons with disabilities as equal citizens," aligned with Vision 2030 of the National Development Plan, INDS (ODP, 1997) and the UNCRPD (1996). Further, its Mission is "[i]nclusive and Equitable Socio-Economic Development." The WPRPD applies to service providers such as oversight institutions, government institutions, the judiciary, the private sector, the media, law and policy makers, public servants, frontline staff, as well as representative organisations of PWDs (inclusive of parents' organisations) and non-governmental organisations. The main beneficiaries of the successful implementation of the WPRPD will be PWDs and their families as rights-holders (DSD, 2016). The table below shows the different pillars of the WPRPD and how it relates to the UNCRPD.

**Table 2.3: Pillars of the White Paper on the Rights of Persons with Disabilities related to the United Nations Convention on the Rights of Persons with Disabilities Articles**

PILLARS	RELEVANT UNCRRPD ARTICLE
Removing Barriers to Access and Participation	Article 9: Accessibility Article 11: Situations of risk and humanitarian emergencies Article 20: Personal Mobility Article 21: Freedom of Expression and opinion and access to information Article 30: Participation in cultural life, recreation, leisure and sport
Protecting the Rights of Persons at risk of Compounded Marginalisation	Article 10: Right to life Article 12: Equal recognition before the law Article 13: Access to justice Article 14: Liberty and security of the person Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment Article 16: Freedom from exploitation, violence and abuse Article 17: Protecting the integrity of the person Article 21: Freedom of expression and opinion, and access to information
Supporting Sustainable Integrated Community Life Independent Living	Article 8: Awareness Raising Article 11: Situations of risk and humanitarian emergencies Article 19: Living independently Article 20: Personal Mobility Article 23: Respect for the family Article 30: Participation in cultural life, recreation, leisure and sport
Promoting and Supporting Empowerment of PWDs	Article 13: Access to justice Article 24: Education Article 25: Health Article 26: Rehabilitation
Reducing Economic Vulnerability and Releasing Human Capital	Article 27: Work and Employment Article 28: Adequate standard of living and social protection
Strengthening the Representative Voice of PWDs	Article 29: Participation in political and public life Article 33: National implementation and monitoring
Building a Disability Equitable State Machinery	Article 4: General obligations Article 9: Accessibility Article 13: Access to Justice Article 20: Personal Mobility Article 24: Education Article 25: Health Article 26: Rehabilitation Article 33: National Implementation and Monitoring Article 35: Reports by States Parties
Promoting International Co-operation	Article 32: International Cooperation States Parties Article 40: Conference of States Parties
Monitoring and Evaluation	N/A

Source: DSD (2016)

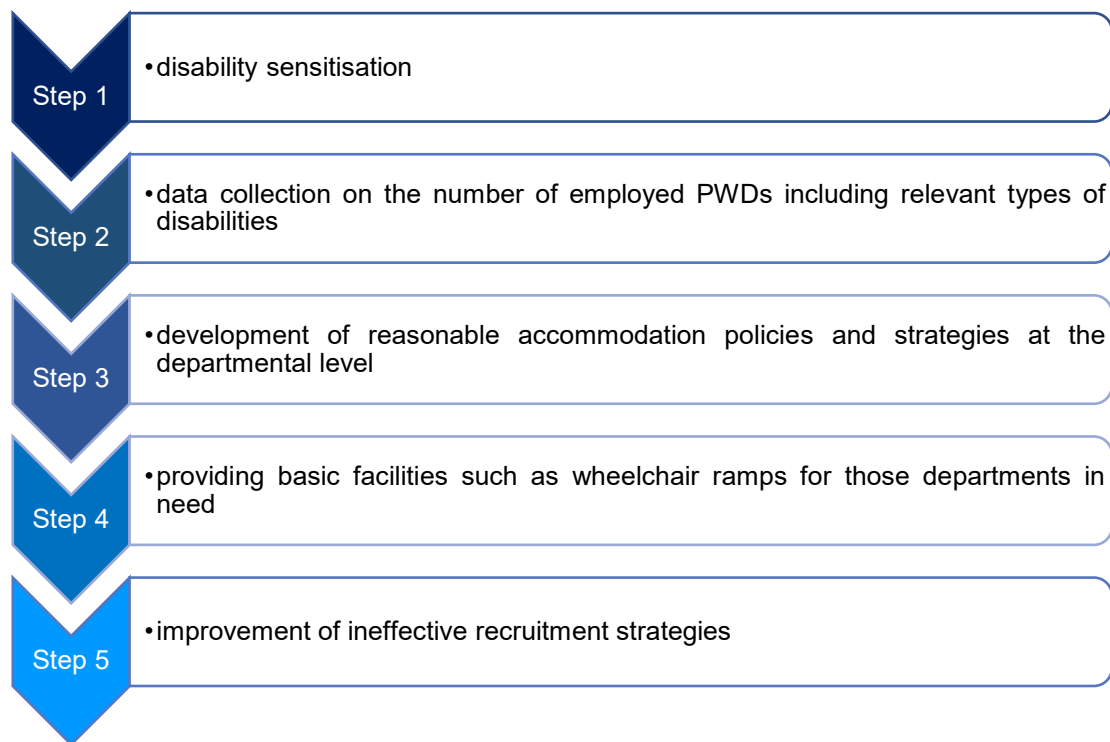
The breakdown of how the WPRPD, as a South African policy, relates to the international UNCRPD, indicates how the implementation of this policy would not just adhere to South African priorities, but also global priorities for services for PWDs.

### **2.5.6 Other policies on disability in South Africa**

The National Health Act regulates health services and establishes a national health system which aims to deliver efficient health services within the available resources. It further aims to guarantee all South Africans access to healthcare services and protect, respect, promote and fulfil the rights of basic nutrition and healthcare for vulnerable groups such as women, children, older persons and PWDs (ACPF, 2011).

Another health-related policy is the national rehabilitation policy, which aims “to improve accessibility to all rehabilitation services in order to facilitate the realisation of every citizen’s constitutional right to have access to health services [ ... ] and to serve as a vehicle to bring about equalisation of opportunities and enhance human rights for PWDs” (DOH, 2000).

In strategies for accommodating the needs of PWDs the Department of Public Service and Administration (DPSA) has developed a regulatory framework that aims to promote consistency across the public sector in terms of providing assistive devices, personal assistance and technology for public servants with disabilities. The DPSA proposed a five-step plan to address the situation in the public sector (SAHRC, 2015). This plan layout is demonstrated by Figure 2.5 below:



*Figure 2.5: The DPSA proposed a five-step plan to address the situation in the public sector (SAHRC, 2015)*

Social workers can play an important role in advocating for these steps to be taken in the community by doing disability sensitisation and ensuring that basic facilities and reasonable accommodation is provided for PWDs within the community.

A final example of national legislation that could have a significant impact in relieving some of the financial burdens experienced by PWDs is the South African Income Tax Act. This act was amended in 2008 to enable taxpayers to claim 33.3% of the qualifying out-of-pocket medical and disability-related expenses paid during the relevant financial year (SARS, 2016).

### **2.5.7 Policymaking on disability in South Africa**

Despite several policies addressing concerns within the disability sector, there are still some gaps, including the lack of a national policy on disability prevention. A 10-year review of the impact of government policies on PWDs reported that the DSD identified some concerns regarding the assessments social grants for adults and children with disabilities (DWCPD & UNICEF, 2012). These included the lack of uniformity of assessment tools across provinces, the lack of clarity regarding eligibility criteria for children, the subjective nature of assessment in determining eligibility, the necessity for training of assessors, a lack of awareness regarding

availability of grants and corruption around grant administration and payment processes (DWCPD & UNICEF, 2012).

Research on the effectiveness of disability policy implementation in South Africa has found that there is a lack of internal policies on disability. Further, policies are not aligned to implementation programmes, and policy requirements for disability mainstreaming are not aligned to performance management. Another concern that adds to the struggle of implementing effective disability policy includes a lack of monitoring tools and personnel with expertise and knowledge on disability issues. The definition of disability and the nature of PWDs' participation is also not adequately articulated, while there is a lack of budgetary allocations and civil servants responsible for implementing disability policies are ignorant. Finally, there procedural bottlenecks are prevalent (DWCPD & UNICEF, 2012).

The DWCPD and UNICEF (2012) found that some provinces had developed integrated provincial disability strategies, but without any budgetary allocations there had been no significant implementation of these strategies. In a South African context, McClain-Nhlapo, Watermeyer, & Schneider (2006) pointed out that legislation alone cannot guarantee that human rights are met, as it simply provides a framework of directives. There is also a history of PWDs being excluded in discussions about disability (Forber-Pratt & Aragon, 2013). For this reason, the “nothing about us without us” movement encourages PWDs to take responsibility for their own lives (Charlton, 1998).

The African Child Policy Forum (ACPF) is an independent, pan-African institution of policy research and dialogue on the African child. Its work is guided by the UN Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child and other relevant regional and international human rights frameworks. It aims to contribute to improved knowledge on children in Africa, monitor and report progress, identify policy options, provide a platform for dialogue, collaborate with governments, inter-governmental organisations and civil society in developing and implementing effective pro-child policies and programmes, and finally, to promote a common voice for children in and out of Africa (ACPF, 2011).

In 1998, the Office on the Status of Persons with Disability/-ies (OSDP) was established to coordinate and monitor the implementation of the INDS. It is aimed toward collaboration between different governmental bodies and departments, including NGOs, to promote the development of a disability-friendly environment (ACPF, 2011). After the ratification of the



UNCRPD, the OSDP published the national disability policy framework and accompanying guidelines (OSDP, 2008), which were intended to give a local interpretation of the UNCRPD and to outline practical steps towards creating an inclusive society. The framework aims to ensure that all disability programmes and objectives are mainstreamed into government planning, implementation and budget allocations, and to promote an inter-sectoral approach (ACPF, 2011).

The disability policy framework for local government 2009-2014 (RSA, 2009) aims to address the needs of PWDs. In so doing, it provides an enabling environment for municipalities, provincial and local government departments, as well as other role players in local government, proposing implementation structures and mechanisms for coordinating and monitoring disability services (ACPF, 2011). The South African Human Rights Commission (SAHRC) hosted a National Conference on the Rights of Children with Disabilities in October 2017, which aimed to strengthen the partnership between SAHRC, non-governmental organisations and government departments to ensure an inclusive society for children with disabilities. It also aimed to educate and empower parents and communities about their rights and how to enforce them (SAHRC, 2015).

During the COVID-19 pandemic, there was a general outcry both globally and on a national level for the consideration of people with disabilities in disaster management strategies (McKinney, McKinney & Swartz, 2020; Swingler, 2020). The International Disability Alliance (2020) stated that a global pandemic foregrounds the importance of accessibility measures for support services, and accordingly reiterated that governments must ensure all PWDs, including persons with deafblindness, are equally protected according to Article 11 of the UNCRPD. The pandemic also opened discussions for the WPRPD to be put forward into an act to protect PWDs (Western Cape Forum for Intellectual Disability, 2020).

In such times, PWDs' experiences can also influence curriculum changes that can lead to the development of an inclusive workforce. Taking this into account, policymakers and service providers across different sectors can deliver integrated programmes which address the diversity in South African society (Watermeyer et al., 2019).

## **2.6 PERSONS WITH ACQUIRED PHYSICAL DISABILITIES IN THE SOUTH AFRICAN CONTEXT**

Persons who acquire disabilities return to their community and have many different experiences in the process of reintegration into society. These could include mutual, spiritual and cultural experiences, or even feelings of stigmatisation. However, the use of support services could assist them with feelings of resilience. Consequently, both the experiences of PWDs in such situations and the support services delivered to them will be discussed in this context.

### **2.6.1 Experiences of adults with an acquired physical disability**

Globally, PWDs are marginalised and excluded from full participation in society (Kittay, Jennings & Wasunna, 2005). In South Africa, PWDs face multiple forms of discrimination, including lack of access to health care services, employment and education. Without social inclusion and reasonable accommodation of PWDs, equality cannot be achieved (SAHRC, 2015). The table below shows some of the support services according to specific needs for persons with disabilities and their families.

**Table 2.4: Types of assistance and support services for persons with disabilities and their families**

NEED	SPECIFICATION/EXAMPLE
<b>Community support and independent living</b>	Assistance with self-care, household care, mobility, leisure, and community participation
<b>Residential support services</b>	Independent housing and congregate living in group homes and institutional settings
<b>Respite services</b>	Short-term breaks for caregivers and people with disabilities
<b>Support in education or employment</b>	A classroom assistant for a child with a disability, or personal support in the workplace
<b>Communication support</b>	Sign-language interpreters
<b>Community access</b>	Day-care centres
<b>Information and advice services</b>	Professional support, peer support, advocacy, and supported decision-making
<b>Assistance animals</b>	Dogs trained to guide people with a visual impairment

**Source:** World Report on Disability (WHO and World Bank, 2011)

Specifically focusing on the needs of persons with physical disabilities, a 2012 study in Butterworth district in the Eastern Cape, South Africa, found some of the needs of persons with physical disabilities to include: accessibility of buildings, accessibility of transport, assistive devices, rehabilitation, employment, skills training and income generation, independence, social integration, caregivers, and other social services (Dingana, 2012).

### ***2.6.1.1 Mutual experiences of persons with acquired physical disability***

In South Africa, there are a wide range of policies advocating for the rights of PWDs. However, they are still considered to fare worse than their non-disabled counterparts. This suggests that, while policies are good, implementation may be failing PWDs in South Africa (Graham, et al., 2014). The question of full membership in a community is key to disability scholars and activists (Watermeyer et al., 2019). Morris (2005) identified self-determination, participation and contribution as important factors of citizenship for PWDs in the contemporary context.

When considering studies concerning the community integration of PWDs, a Hong Kong study by Pang, Eng & Miller (2007) found that only 11% of the participants considered themselves to be reintegrated into their communities. Further, a study done in Johannesburg, one of South Africa's capital cities, found that 57% of stroke survivors had moderate to full integration, and 21% had no community integration (Kusambiza-Kiingi et al., 2017). According to Mamabolo Mudzi, Stewart & Olorunju (2009), the average discharge date of a stroke survivor in Chris

Hani Baragwanath hospital in Johannesburg is after 12 days, in other words, often before the survivors reach functional independence. In South Africa there is also a shortage of post-discharge rehabilitation services for patients within public health care (government facilities). A South African study with persons with disabilities found that the primary needs of people with physical disabilities were housing, employment, skills“ development - emphasising training in those skills which could bring them an income, suitable public transport, accessibility of buildings and facilities, driving schools catering for people with physical disabilities, and Primary Health Care (Dingana, 2012). Some of these challenges will be discussed below.

#### *A. Lack of Employment*

The WPRPD (DSD, 2016) emphasises this support in Pillar 3 and 4 titled Supporting Sustainable Integrated Community Life and Promoting and Supporting Empowerment of Persons with Disabilities respectively. The collaboration of social workers with PWDs (and their families) can assist with increasing access to opportunities and promoting social inclusion and community living (MSF, 2018), which is what the WPRD, aligned with the 2030 National Development Plan and the UNCRPD, aims to work towards. It further states that the employment equity and work opportunity targets for PWDs should increase to a minimum of 7% by the year 2030 (SAHRC, 2015). The table below depicts the relation of PWDs compared to persons without disabilities in the workforce in South Africa.

**Table 2.5: Prevalence (%) of persons with disabilities (PWDs) in the workforce compared to persons with no disability**

	2016 (%)		2017 (%)		2018 (%)	
	PWDs	No Disability	PWDs	No Disability	PWDs	No Disability
Top Management	1,2	98,2	1,3	98,7	1,3	98,7
Senior Management	1,1	98,9	1,3	98,7	1,3	98,7
Professionally Qualified	0,9	99,1	1,3	98,7	1,1	98,9
Skilled	0,9	99,1	1,2	98,8	1,1	98,9
Semi-skilled	0,8	99,2	0,9	99,1	0,9	99,1
Unskilled	0,8	99,2	1	99	1,1	98,9

**Source:** Department of Labour (2019)

The table shows only a slight increase in employment of PWDs over the three-year period, despite the South African 2030 National Development Plan to include PWDs more into the labour market. However, as with many other statistical analysis studies on disability, these statistics might not be an accurate indication of reality, as it depends on the inclusion criteria for the term ‘disability’ and the sample size in terms of the population.

### *B. Financial concerns*

PWDs need to be financially independent by either being employed or receiving a social grant. One of the major impacts of disability is poverty caused by an increased financial burden on the family. There are South African studies that have also confirmed the connection between financial concern and disability. For instance, in some cases, person who acquired the disability may have been the breadwinner in the family (Dingana, 2012). Further, as mentioned before, many PWDs rely on families for caretaking. In such cases, the caregiver may also have had to stop working, which may result in increased financial strain (Muller-Kluits, 2017; Dingana, 2012). In many instances, the PWD will give up on benefiting from a service if they cannot afford it. Increased caregiving expenses such as the buying of disposable napkins or other medical and surgical supplies affects the household income and act as barriers to PWDs (Dingana, 2012).

### *C. Accessibility challenges*

As mentioned before, Article 9 of the UNCRPD concerns accessibility. Accessibility has different meanings and can be referred to as the right to use and obtain an equal benefit from the provision of goods, services, facilities, and accommodations generally available to the public without discrimination (Roomaney, 2017). In Thailand, to assist with accessibility, local architects organised workshops where the community suggested design options for walkways such as handrails at multiple heights, painting the handrails in bright colours to improve safety, and adding benches suitable for children as well as adults (Colenbrander & Archer, 2016). It is significantly more difficult for PWDs living in communities where disability is not understood as a social justice concern to feel securely entitled to demand full access of such a nature (Watermeyer et al., 2019).

The principle of ‘design for all’ is one of the essential building blocks of the New Urban Agenda (Watermeyer et al., 2019). The principles of universal design, as represented in Figure 2.6 below, is attributed to the Centre for Universal Design at North Carolina State University.

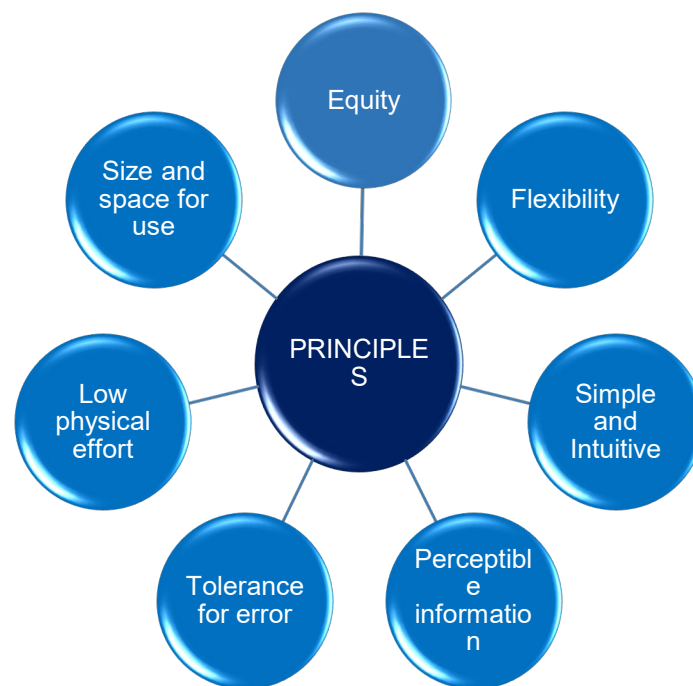


Figure 2.6: *Principles of Universal Design (UNDESA, 2016)*

As summarised in the figure, these principles include design that is useful and marketable to persons with diverse abilities (Equity), accommodates a wide range of individual preferences and abilities (Flexibility), is easy to understand, regardless of the user's experience, knowledge, language skills, or concentration level (Simple and Intuitive), communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities (Perceptible information), minimises hazards and the adverse consequences of accidental or unintended actions (Tolerance for error), can be used efficiently, comfortably and with a minimum of fatigue (Low physical effort) and provides appropriate size and space for approach, reach, manipulation, and use regardless of the user's body size, posture, or mobility (Size and space for use) (Watermeyer et al., 2019).

If South Africa could implement a design strategy such as the Principles of Universal Design, despite limited governmental capacity and fiscal resources, it would be able to contribute valuable lessons for the rollout of the Sustainable Development Goals and the New Urban Agenda for other countries, particularly in the Global South. Inaccessibility of buildings, or environments, are causes of dependency amongst people with disabilities. This includes both structural inaccessibility as well as availability of resources in rural areas such as was found in a study done in Butterworth district in the Eastern Cape, South Africa (Dingana, 2012).

There are also indications that, in the Global South, disability has been involved with shaping digital technology despite challenges of use, design, literacy, discrimination, market failure, lack of consumer power, and democratic deficit (Watermeyer et al., 2019).

#### *D. (Public) transport challenges*

In a study done with persons with physical disabilities in Butterworth, South Africa, it was found that the regular public transport was not suitable to be used by PWDs. For instance, climbing into a taxi was not possible for some people with physical disabilities, which meant that they had to be lifted into the vehicle. Further, some taxi drivers were impatient with people with physical disabilities, as they could not walk fast (Dingana, 2012). Likewise, taxis were not inaccessible to participants of this study. Similar challenges regarding public transport were also found in a study done in Cape Town with family caregivers of persons with physical disabilities (Muller-Kluits, 2017). This also impacted on PWDs ability to access services.

### **2.6.1.2 Cultural experiences of PWDs in the Global South**

There are different beliefs about disability. Studies in Zimbabwe and Uganda have found that disability is often seen as a “deficit” and the PWD as a “lesser person” (Visagie & Swartz, 2018). Neille and Penn (2015) explored the experiences of 30 PWDs living in rural Mpumalanga, South Africa, and found a prevalence of attitudinal barriers that lead to discrimination and deprivation, as well as psychological, physical and sexual abuse.

#### **2.6.1.3 Spiritual experiences**

The word ‘religion’ is not mentioned in the World Report on Disability (WHO & World Bank, 2010) despite evidence showing that many PWDs across in the Global South rely on their religion (Watermeyer et al., 2019). The relationship between religion and disability is complex, with religious beliefs often resulting in stereotypical thoughts regarding disabilities. For instance, the birth of a child with a disability may be seen either as a curse or a special gift from God. Patricia Bruce (2010) further argues that there is a strong belief in God as a healer in Africa (Watermeyer et al., 2019). Recent studies in Uganda, Ghana and South Africa found that PWDs describe their impairments as caused by misfortune, karma, ancestral punishment, witchcraft, or bad luck, the implication being that their condition shows a lack of favour from the relevant higher powers. Consequently, they associated disability with being sick, worthless,

and in need of charity and pity (Visagie & Swartz, 2018). In South Africa, Graham et al. (2014) found that most PWDs (91%) emphasised the importance of religious activities.

#### **2.6.1.4 Stigmatisation**

Hosain, Atkinson and Underwood (2011) conducted a study in rural Bangladesh which found that PWDs faced a great deal of cultural stigma, a lack of access to education and employment, as well as limitations to family life. Conversely, studies conducted in Sweden and Finland (Viemero & Krause, 1998) indicated that PWDs generally had better access to services and lower stigma associated with their disability. However despite the fact that PWDs receive better treatment in countries with more resources, modern media still portrays physical disability as a fate worse than death. This is demonstrated in movies such as the 2004 Academy Award-winning picture *Million Dollar Baby*, where the murder of a person with a severe disability is portrayed as heroic (Mackelprang, 2013), and the 2016 movie *Me Before You*, in which the PWD chooses euthanasia over living with his acquired disability. News headlines spread a similar message, such as the coverage of the Belgian Paralympian Marieke Vervoort's death by euthanasia in October 2019. Ultimately, stigmatisation can be prevented through early education, better inclusion of PWDs in society and the empowerment of PWDs as partners in removing the disability stigma (Buljevac, 2012). In South Africa, policies such as Chapter 5 of PEPUDA promotes equality but stigma continues to be a barrier for persons with disabilities (SAHRC, 2015).

#### **2.6.1.5 Resilience of PWDs**

Resilience refers to a universal capacity to prevent, minimise or overcome adversities. It could be a powerful personal factor which plays a pivotal role in the individual's quality of life (Aranguren, 2017). Quality of life experiences are not determined directly by disability, but rather how individuals negotiate their disability within certain contexts (Viemero & Krause, 1998). Ross and Deverell's 2010 study further states that experience, personality, social background and coping style are important factors to consider in understanding how disability is experienced (Graham et al., 2014).

The importance of resilience as a central developmental concept is frequently mentioned in the Paris Agreement of the United Nations Framework Convention on Climate Change (2015), the Sendai Framework for Disaster Risk Reduction (UNDDR, 2015), the SDGs (UN, 2015) and the New Urban Agenda agreed upon by Habitat III (UN Habitat, 2016). Likewise, campaigns



such as the Rockefeller Foundation's 100 Resilient Cities project, the Making Cities Resilient campaign of the UN Office for Disaster Risk Reduction and the City Resilience Action Planning Tool of the UN-Habitat City Resilience Profiling Programme emphasise this concept (Watermeyer et al., 2019).

#### ***2.6.1.6 Experiences of persons with disabilities during the COVID-19 pandemic***

Globally, 2% of the population experience combined hearing and vision impairments, namely deafblindness. In customary circumstances, hospitals provide services that help patients with deafblindness to communicate through specific support services. This might include tactile sign language, lip-reading and hand-held amplification devices among others. Even so, during the COVID-19 pandemic, where masks and gloves are compulsory, many of these services are hindered. For instance, these protective gears often hamper the ability to read lips. Due to lack of inclusive and accessible COVID-19 responses, persons with deafblindness are thus left behind (IDA, 2020).

The accessibility of mainstream media's coverage of the COVID-19 pandemic is quite extensive, but also inconsistent. For instance, while sign language interpreters on screen are often included at press conferences held by the government, live captioning (CART) is absent on most channels. Likewise, video illustrations or text are mostly not accessible for persons with deafblindness. Some text-based online media may be accessed through braille readers and/or synthetic voice, but only for those who are able to use assistive technology. With lockdown regulations, people around the world have switched to working remotely and use platforms such as Zoom, Go-to-Meeting or Skype to hold meetings. However, in the majority of cases, the hosts of virtual events and/or webinars fail to make these meetings accessible to PWDs by not having international sign interpretation and/or speech-to-text available (IDA, 2020).

The general lack of access to interpreter-guides often prohibits persons with deafblindness from accessing information. The global pandemic brings into focus how important accessibility measures and access to specific support services are, and how much more needs to be done to fully guarantee accessible information. Governments must ensure that persons with deafblindness are protected equally to other citizens according to Article 11 of the UNCRPD (2006).

## **2.6.2 Support services and disability**

Persons with disabilities, including adults with an acquired physical disability, often face difficulties in accessing services. The World Report on Disability made some recommendation on how to improve service delivery to PWDs. These recommendations involve the inclusion of PWDs in mainstream training opportunities, the provision of targeted support where mainstream opportunities are not available, the support of community-based rehabilitation to enhance the development of skills and enable PWDs to make a decent living, the promotion of micro-enterprises and self-employment for PWDs, the improvement of access to microfinance for PWDs through better outreach, accessible information and customised credit conditions, support of the development of networks that can campaign for the rights of PWDs, and finally, letting labour unions make disability issues such as reasonable accommodations part of their bargaining agendas (WHO & World Bank, 2011).

### **2.6.2.1 Health care and disability**

In 2016, the Gauteng Department of Health (GDoH) in South Africa terminated its contract with the Life Esidimeni facility to deinstitutionalise the care of patients. More than 1 000 mental health patients were moved from the facility to several (unprepared) NGOs. As a result, between 118 and 143 people lost their lives between March and December of 2016. It is claimed that the termination of the contract with Life Esidimeni was influenced by factors such as policy and legislative deliberations, which favoured community-based care over institutional care. The tragic events of the Life Esidimeni matter illustrates some of the obstacles that PWDs still face in South Africa, as well as their vulnerability and the apathetic social attitudes towards their wellbeing (SAHRC, 2015).

#### *A. Health care to persons with disability*

The South Africa government's vision is "an accessible, caring and high-quality health system" (DOH, 2007:11). The White Paper for The Transformation of The Health System in South Africa provides a comprehensive policy on all the department's core service delivery areas (ACPF, 2011) in achieving a more equitable, accessible and appropriate health system (DOH, 1997). Its legislative mandate steers the provision of free healthcare, enhanced accessibility and the adoption of a rights-based instead of a medically based approach to the management of disability (OSDP, 2008).

The South African health-care system is divided into public (government) health services and private health care services. Public health is funded through government taxes, whilst private health care is funded through health insurance or out-of-pocket payments. Both types of health care have their benefits and obstacles. Generally, the public health services are free to patients but overcrowded, as they see to a large proportion of the population with a limited number of resources in ratio to the number of patients, they deliver services to. However, the private health services are expensive as not everyone can afford health insurance, but have more resources available in terms of the number of patients they deliver services to (Ngubo & Muller, 2015).

Health professionals can assist caregivers to acquire and preserve social support to help them withstand the challenges they face. They can also aid by developing a proactive approach as they interact with caregivers (Grant, 2006). In 2001, South Africa adopted a comprehensive primary healthcare package that covered the continuum of primary health care services in terms of promotive, preventive, curative, rehabilitative and palliative care (ACPF, 2011) to meet the healthcare needs of each province with at least one community health centre (CHC) in each of the health districts. CHCs are, in most cases, the first medical point of contact for stroke survivors. Most stroke survivors are seen either once a week or once a month depending on the CHC patient load, with many CHCs in the Western Cape experiencing a lack of therapeutic services such as physiotherapy, occupational therapy and speech therapy (Rhoda, Mpofu & DeWeerd, 2009).

Rhoda et al. (2009) examined at the rehabilitation of stroke survivors at community health centres in the Western Cape and identified the limited rehabilitation services as a challenge. The framework of the South African health care system will likely change with the implementation of the NHI.

#### *B. Influence of the COVID-19 pandemic on health care to persons with disabilities*

Similarly horrifying to the Life Esidemeni happenings, a sinister practice has been identified during the COVID-19 pandemic where some doctors have been placing unlawful do-not-resuscitate (DNR) orders on the records of individuals with learning disabilities without prior consultation with the person's family or carers. Cases of this have been reported in both the U.S. and U.K, although this does not indicate that these are exclusive cases (Alexiou, 2020).

This has sparked discussion compared to Nazi-era eugenics within disability communities. The Nazis dismissed disabled people as 'useless eaters' and a drain on society, initialising forced

sterilisation of PWDs, ‘mercy killings’ by lethal injection, as well as the use of gas chambers and death camps. These extreme comparisons indicate the paradigm shift that many PWDs fear has taken hold across society since the onset of the COVID-19 pandemic as the world responds to it.

### **2.6.2.2    *Rehabilitation and disability***

Rehabilitation is a set of interventions designed to reduce disability and enhance functioning in individuals’ interaction with their environment. Rehabilitation is relevant to the needs of people with different health conditions, including those experiencing disability (WHO, 2017).

One such case study on how rehabilitation can contribute to healthy lives and wellbeing is that of a 49-year-old woman in Switzerland who was involved in a bicycle accident. As a result, she sustained multiple injuries, underwent many surgical procedures, and spent extensive time in hospital. When she was discharged, she continued rehabilitation with a community physiotherapist. The rehabilitation services helped her to manage her chronic pain, improve her movement, strength and balance, and has allowed her to return to work. She described the experience as gaining a “second life definitely worth living” (WHO, 2017).

In South Africa, some stroke survivors or other PWDs may receive private rehabilitation services, although the majority will receive treatment within the government sector (National Health Insurance Gazette, 2011). Singh (2008) noted that rehabilitation services often compete with other programmes within the health sector (e.g. curative programmes and HIV testing and counselling), which are often prioritised over it (Philpott, 2004). This limitation impacts on the accessibility of services (Dingana, 2012), as discussed earlier.

Social workers play a vital role in the multidisciplinary care model of rehabilitation, as will be discussed in Chapter Four. They conduct psychosocial assessments, psychosocial counselling, discharge planning, case management and psychosocial health education (Springer & Casey, 2013).

#### *A. General overview on rehabilitation to persons with disabilities*

The availability of accessible and affordable rehabilitation is important in achieving SDG 3. namely to “[e]nsure healthy lives and promote well-being for all at all ages” (WHO, 2017). It is also key in achieving the effective implementation of the Global strategy and action plan on

ageing and health (2016 to 2020), the Mental health action plan (2013 to 2020) and the Framework on integrated people-centred health services. Further, it serves as a contribution to the efforts of the Global Cooperation on Assistive Technology (GATE) initiative.

### *B. Community-based rehabilitation (CBR)*

The Community-based Rehabilitation (CBR) Guidelines (WHO, 2010) have adopted the principles of the UNCRPD, which summarised the process in three words, namely inclusion, empowerment, and sustainability (Watermeyer et al., 2019). Figure 2.7 below provides a visual representation of the guidelines as they relate to the UNCRPD key words.

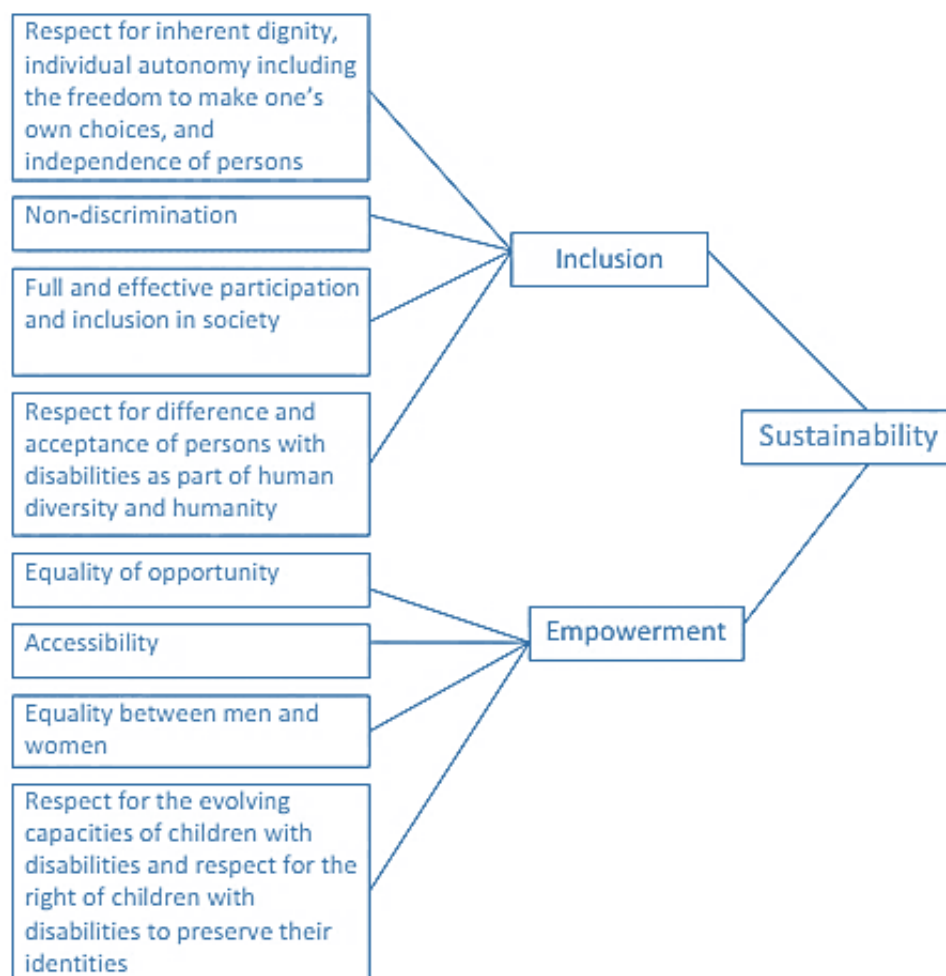


Figure 2.7: Principles of the UNCRPD and CBR Guidelines (Watermeyer et al., 2019)

The goal of the national rehabilitation policy is “[t]o improve accessibility to all rehabilitation services in order to facilitate the realisation of every citizen’s constitutional right to have access to health services [ ... ] and to serve as a vehicle to bring about equalisation of opportunities and enhance human rights for PWDs” (Department of Health, 2000:2). The policy suggests

CBR to enable PWDs in South Africa to achieve social integration, especially within health, education and social services (ACPF, 2011). CBR programmes on a local or international level by nongovernmental organisations (NGOs) have worked towards promoting disability-inclusive development and the elimination of barriers. Despite the development and implementation of more CBR programmes during the past two decades, one of the main criticisms is that the programmes' outcomes are not properly measured and evaluated (Watermeyer et al., 2019). Therefore, its contribution to PWDs cannot be determined.

### *C. Impact of COVID-19 pandemic on rehabilitation*

Recent study results suggest that the COVID-19 virus also affects the central nervous system (CNS). COVID-19 related neurological symptoms can be categorised into three groups i.e. neurological expressions (such as headache, dizziness, disturbances of state of consciousness, ataxia, epileptic manifestations and stroke), neuro-peripheral origin (including hypo-ageusia, hyposmia, neuralgia) and skeletal muscle damage, often associated with liver and kidney damage (Talan, 2020).

One recent study in Wuhan, China, reported neurologic appearances in 36.4% of sufferers, with more severe cases likely to have neurologic symptoms such as acute cerebrovascular diseases, impaired consciousness and skeletal muscle injury (Mao, Wang, Chen, He, Chang, Hong et al., 2020). Related cases of neurological syndromes were reported in Italy, with a significant increase in COVID-19-related numbers of vascular events, ischemic strokes, and thrombosis, likely due to the virus affecting clotting mechanisms. At the time of this paper being published, it was still unclear whether these neurologic syndromes are a direct cause of the virus entering the central nervous system, or an indirect response to the viral storm in their bodies (Talan, 2020).

It is also noted that, with the expected rise of COVID-19 cases, there could be increasing pressure to free up acute beds and transfer the patients to inpatient rehabilitation facilities including home rehabilitation, nursing home facilities and other long-term care providers. Patients may not be able to be directly transferred from hospital to these types of facilities due to the risk of transmitting disease (Khan & Amatya, 2020).

It is predicted that healthcare facilities will be overwhelmed, as many COVID-19 survivors will require rehabilitative care. Subacute care and rehabilitation facilities in many countries

currently lack the capacity and capability to safely treat patients with COVID-19 (Chang & Park, 2020; Koh & Hoenig, 2020).

### **2.6.2.3 Social services and disability**

Persons with disabilities and their families could make use of different social services. These could include, but are not limited to, non-governmental organisations, social grants, tax benefits, assistive devices and other community services. In terms of social support, upper middle-income and high-income countries often provide a combination of monetary programmes and a variety of social welfare services. However, in many developing countries, a significant number of monetary programmes are targeted at poor and vulnerable households, with only a fraction focusing on the provision of social welfare services to vulnerable groups, including individuals with disabilities or their families. In low-income communities, social welfare services are often the only resource. However, these are often limited, fragmented and very small, only reaching a small part of the needy population (WHO & World Bank, 2011).

#### *A. Non-governmental organisations*

NGOs have often stepped in where government services have failed to provide for communities' unique needs. They have the potential for innovation and specialisation whilst they could still partner with governments to deliver services (Fisher, 1997). They often act as vehicles for testing new types of service delivery and outcome evaluations. These practices cannot always be replicated widely, as some of the NGOs are small and have extremely focused targets (WHO & World Bank, 2011).

Many of these organisations will deliver services for a nominal fee, or even at no cost. On the other hand, a few companies deliver services such as residential services for a profit. Where PWDs or their families can afford to do so, they might employ personnel from these companies to assist with activities of daily living (WHO & World Bank, 2011). Disabled Persons Organisations (DPOs) can support PWDs to become aware of their rights, to live independently, and to develop their skills. This can be done through the following activities:

- Supporting children with disabilities and their families to ensure inclusive education
- Representing the views of PWDs to international, national, and local decision-makers and service providers

- Advocating for the rights of PWDs
- Contributing to the evaluation and monitoring of services
- Collaborating with researchers to contribute to service development
- Promoting public awareness and understanding by professionals about the rights of PWDs
- Conducting audits of environments, transport, and other systems and services to promote barrier removal (WHO and World Bank, 2011).

The social services to PWDs, especially in terms of social work services, will be discussed in Chapter Four.

### *B. Social Grants*

Graham (2014) indicated that 51% of people with disabilities in South Africa make use of social grants as a source of income. In 2015, the SASSA database indicated that 1 111 063 beneficiaries receive a disability grants, 127 139 children with disabilities receive care dependency grants and 115 256 social grant beneficiaries access grants-in-aid. The province of KwaZulu-Natal had the highest access to care dependency grants (28.7%), followed by the Eastern Cape (15.1%) and Gauteng (12.8%). KwaZulu-Natal also had the highest access to disability grants (25.5%), followed by the Eastern Cape (16.5%) and the Western Cape (14%). In addition, KwaZulu-Natal had the highest access to Grants-in-Aid (54.7%), followed by Limpopo (19.1%) and the Eastern Cape (14.4%) (DSD, 2016). Despite only 10% of PWDs indicating that they were receiving the disability grant, it had a noticeable impact on whether they lived below the poverty line (less than R502 (US\$52.84) per month in 2014). Whereas 78% of PWDs lived below the poverty line without the grant, this number only reduced to 69% where individuals received assistance from the grant (Graham et al., 2014).

### *C. Tax benefits*

Any taxpayer who has a disability, or whose spouse or child has a disability, is eligible for these claims. In accordance with the criteria set out in the ITR-DD form, eligibility for assistance is confirmed by a medical practitioner. There is, however, a requirement that taxpayers not be over the age of 65 years (Steenkamp, 2017; SARS, 2016).



The South African Revenue Service (SARS) defines physical impairment as “the restriction on the person’s ability to function or perform daily activities after maximum correction which is less than a ‘moderate to severe’ limitation” (SARS, 2016). SARS’ prescribed list of out-of-pocket medical and disability-related expenses include personal attendant care expenses, travel and other related expenses, insurance, maintenance, repairs and supplies, prosthetics, aids and other devices, services, continence products, service animals and alterations or modifications to assets acquired or to be acquired (SARS, 2012).

Despite all these attempts to assist PWDs, the application of the disability tax provisions remains problematic, as its interpretation is subjective and difficult to apply. Furthermore, SARS’ operational system design often creates a situation where many taxpayers must wait exceedingly long to receive their tax refunds (Steenkamp, 2017).

#### *D. Assistive devices*

Persons with physical disabilities may need to use various assistive devices, including a wheelchair, walking stick/frame, hearing aid and spectacles to make their adjustment in the community easier. Assistive devices could have a positive effect on movement of PWDs (DPSA, 2001). Statistics South Africa (StatsSA, 2014) reported that, in persons over the age of five years, the assistive aid that was used the most was spectacles, with 21.4% of the users being in South Africa and 2.8% in the Western Cape respectively. Other assistive devices include wheelchairs, walking sticks/frames or hearing aids, but were only used by about 2% to 3% of the population group in both South Africa and the Western Cape. Assistive devices allow for learning, employment and social participation and allow PWDs to participate as equal citizens of the society. Not only does the lack of assistive devices inhibit the PWD’s ability to be more independent and move around but it also impact on their families. A study in South Africa found that caregivers of people with physical disabilities felt that assistive devices would make their care-giving tasks easier (Dingana, 2012).

#### *E. Other community services*

Persons with disabilities may use different other community services. In a study done with family caregivers of persons with physical disabilities in Cape Town (Muller-Kluits, 2017), it was found other community services that persons with physical disabilities and family caregivers may also use include educational institutions and religious institutions.

## **2.7 CONCLUSION**

This Chapter provided a comprehensive overview of disability in terms of definitions and types, disability trends and policies around the world, disability in the Global South, South African policies on disability, as well as persons with acquired physical disabilities in a South African context in terms of their experiences and the services they use. Due to the lack of previous research on persons with acquired physical disabilities, referral to similar studies had to be made. This discussion assisted with understanding the complexity of disability in terms of its definition, as well as trends around the world, and more specifically in South Africa. The discussion on the different policies that have influenced disability service delivery provides a good insight into how justice (in terms of the social work definition) could be ensured for PWDs.

## **CHAPTER THREE**

### **MODELS AND PERSPECTIVES ON DISABILITY**

#### **3.1 INTRODUCTION**

In the previous chapter, disability was explained in terms of definitions, trends and policies. It became evident during this discussion that disability is a complex concept that cannot rely on one perspective for understanding. Similarly, it is important to note the different models that influence disability service delivery.

In accordance with the second objective of this study, this chapter will examine some of these different models and perspectives on disability. Models of disability aim to define disability, provide formative attributions and understand the source and cause of the disability (Smart, & Smart, 2014). The rationale of not only focusing on one specific model of disability is supported by Johnston (1997), who proposed a multi-factor perspective of disability. Accordingly, this chapter will include a discussion on the application of these different models within social work. More specifically, it will discuss how the models for this study were selected. A brief description of a model, theory and perspective will also be provided under this section (see 3.4.1). Not all of the models discussed in this chapter will be utilised for the study, but they are important to consider in determining how the understanding of disability developed. Further, they play an integral role in the approach to service delivery to PWDs and their families.

#### **3.2 MODELS AND PERSPECTIVES ON DISABILITY**

Levit (2017) argued that the effects of disability are influenced by a combination of society, the disabling condition and the actions of PWDs and other factors (such as the age of onset of the disability), and that these components can overlap. The impact of each component can also vary between geographical regions, from person to person, and over time in the same person. This motivates for a model that considers all of these aspects, or at least an understanding of different models of disability. To this end, some of the models, perspectives and theories that will be unpacked in this chapter include the medical model, social model, biopsychosocial model, capabilities approach (used as a model for this study), ecological perspective and finally, from a psychological point of view, the psychosocial theory and the grief model.

### **3.2.1 Medical model**

Disability has traditionally been understood in terms of the medical model (Watermeyer et al., 2006). The most commonly held belief within this model is that there is something wrong with PWDs in terms of a defect, deficiency, dysfunction, abnormality, failing or biomedical ‘problem’ located within the individual (Smart & Smart, 2014). In other words, this model regards disability as a health condition (Parsons, 1975) that should be prevented, treated, or cured (Mackelprang, 2013).

The implication of this view is thus that disability is believed to require sustained medical care because it is directly caused by disease, trauma, or other health conditions, while management of the disability is aimed at a “cure” (Disabled World, 2010). Within this model, experts are perceived to be in charge, while the PWD is expected to be passive and compliant (Smart & Smart, 2014). For this reason, the model does not consider the role that barrier-free environmental access can play in the independence and human dignity of PWDs, nor does it acknowledge their human, social, political and economic rights, their rights to full inclusion and integration into mainstream society, or their abilities (DSD, 2016). However, although the model has vast limitations, it is important for social workers to understand the historical misconceptions about disability it propagates.

The medical model has been criticised for several decades, especially within rehabilitation, as it may not assess the potential for improving function through collaboration with other professionals (Goodwill & Chamberlain, 1981). A turning point in the history of disability activism has been the development of the social model of disability (Watermeyer et al., 2019) after the dawn of the disability rights movement in the 1960’s (Mackelprang, 2013). In 1976, the Union of the Physical Impaired Against Segregation (UPIAS, 1976) described disability as something imposed through isolation and exclusion from full participation in society, often caused by societal barriers, environmental factors and economic barriers (Shakespeare, 2019; Forber-Pratt & Aragon, 2013). Yet, it is important to note that social analysis should not exclude medical or prosthetic interventions that may be appropriate and desirable.

### **3.2.2 Social model**

The social model of disability is built on the belief that disability, as a condition that “can range from mild to severe” and “be constant or episodic,” is primarily “dependent on [ ... ] environment,” with environment referring not only to “physical” location, but also to “cultural

and legal” milieu (Braithwaite & Mont, 2009:2). This perspective on the relationship between society and disability therefore plays a key role in disability inclusion (Goodley, 2013) by removing barriers within society. It requires a rethinking of the view of disability as caused by individual shortcomings to realise that limitations created by social barriers play a significant role (Barnes cited in Watson et al., 2013). Accordingly, Itzak Perlman the famous violinist stated that people with disabilities experience two problems, neither one due to the PWD themselves, these being a physical environment which is not accessible and the attitudes of people without disabilities toward PWDs (Smart & Smart, 2014).

Historically, as can be seen with the medical model, society focused on the disability and what was wrong with the person (Pillay, 2010). The birth of the disability rights movement has produced a contrasting approach to disability. The social model, which gained prominence in the UK in the 1980s, rejects medical views of disability. This model defines disability as a naturally occurring phenomenon that adds to societal diversity (Mackelprang, 2013). The World report on disability (WHO & World Bank, 2011) outlines the development of a social model of disability, largely through the efforts of PWDs themselves, in reaction to the medicalisation of disability by health professionals. This model has two main focuses, namely society’s shortcomings in terms of disability and abilities, and, by extension, PWDs’ own capabilities (Mbeki, 1997). It perceives disability as a social exclusion and oppression as opposed to a bodily defect, incapacity, or impairment (Watermeyer et al., 2019; Disabled World, 2010). Further, it considers disability to be owing to society’s failure to remove social, economic, and environmental barriers (Forber-Pratt & Aragon, 2013).

Taking this background into account, the social model does not accept labels, and emphasises the power of oppressed people (such as PWDs) in setting the agenda for effecting change (Oliver, 2013; Barnes, 1998). The model has led to many positive changes, such as accessible buildings and transport to include children with disabilities in sport in mainstream schools in some countries. However, in the past and today, most South African PWDs have been excluded from mainstream society (ODP, 1997) through prevention of access to social, political and economic rights (Vermaak, 2016).

The social model identifies three major types of discrimination i.e. institutional, environmental and attitudinal. Institutional discrimination occurs when, for example, there is no legislation for equal employment opportunities. Environmental discrimination, on the other hand, excludes PWDs from access, for instance when there is no ramp for a wheelchair user. Lastly,

attitudinal discrimination is expressed through fear, condescension or embarrassment, resulting in intentional or unintentional exclusion (Duncan & Watson, 2009). Technological discrimination can be identified as a possible fourth type of discrimination and occurs when, for instance, blind and deaf-blind persons do not have access to enabling computer technology (Graham et al., 2014). The social model of disability can play a role in the inclusion of all PWDs (Goodley, 2013) by removing societal barriers, but also by the effective action on the part of PWDs (Levit, 2017).

Despite its foregrounding of disability-related experiences, the social model should only be used to understand how the given circumstances apply to PWDs and not to command what these specific experiences should be (Oliver, Sapey & Thomas, 2012). As a result, the model inspired academics to focus on topics relevant to disability such as discrimination, the correlation between disability and industrial capitalism and cultural and social processes experienced by PWDs (Shakespeare, 2018). In addition, it could be valuable and informative when reflecting on the effect disability has on family life (Oliver & Sapey, 2012).

A key criticism of the social model is that it has limited considerations for the individual's experience of the body in relation to disability (Graham et al., 2014; Watermeyer & Swartz, 2008; Handley, 2003; Michailakis, 2003; Shakespeare & Watson, 2001). Similarly, to this limitation, it also fails to specify how varying PWDs' impairments interact with the environment, and by extension, how this results in different experiences of disability (Graham et al., 2014).

### **3.2.3 Biopsychosocial model**

Historically, disability was perceived to begin where health ended, the implication being that once you were disabled, you were in a separate category (WHO, 2002). However, according to the WHO, "[a] person's functioning and disability is conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas etc.) and contextual factors such as personal and environmental factors" (2000:6). Likewise, the biopsychosocial model (Engel, 1977), recognised that, as opposed to earlier more simplistic definitions, illness and ill-health are influenced by a combination of a person's biological, psychological and social components. By implication, it states that health is best understood through integration of all of these components (Sperry, 2006; Nicassio & Smith, 1995; Engel, 1977). As a result, it can be used to bridge the gap between the medical and social models by recognising both the nature

of impairment and the importance of environmental factors (McKenzie, Mji & Gcaza, 2014). Based on the systems theory (Adler, 2009), it focuses on three key components of the individual i.e. biological, psychological and social (Hatala, 2012). The biopsychosocial model is also used in the ICF in assessing a person's bodily functions, activity and participation, as well as the environmental and personal factors that could have an influence on their everyday life. For this reason, the WHO defines impairment as "a problem in body function or structure" (WHO, 2017). Activity limitation, on the other hand, refers to difficulties a person may have in executing tasks or actions of daily living. Both of these factors could influence participation restrictions, which is the term used to refer to the person not being able to experience full involvement in life situations (compared to a person without a disability). How the person experiences these limitations can be affected by contextual factors such as social attitudes, legal and social structures and internal personal factors (DWCPD & UNICEF, 2012).

The ICF integrates the two opposing models unpacked above, these being the medical model and social model (WHO & World Bank, 2011). The WHO (1980) published the International Classification of Impairments, Disabilities and Health (ICDH) that classified disabilities, impairments, and handicaps as internal problems. This was later replaced by the ICDH-2 or ICF model. This model suggests that disability originates from a health condition that gives rise to impairments, activity limitations and participation restrictions in relation to contextual factors. The ICF was the WHO's attempt to re-engineer the social model into a model that allows for disability and health status to be assessed by recognising both the nature of impairment and the importance of environmental (social) factors (Graham et al., 2014; McKenzie et al., 2014).

Within this model's explanation, impairment is a significant deviation or loss of normal body function or structure. Further, an activity limitation is a difficulty that an individual encounters when executing a task or action, and a participation restriction is a problem that an individual experience with regard to involvement in daily life situations. Contextual factors have two components i.e. environmental and personal factors. Environmental factors refer to the physical, social and attitudinal environment in which people live that facilitate or hinder functioning. By extension, personal factors could refer to the sociodemographic and socioeconomic characteristics. The ICF recognises that an individual may experience restricted participation in a major life area for many reasons, including personal factors. However, its classification does not include this area in that the assessment of these personal factors is left

to the discretion of the user of the classification (Rouquette, Badley, Falissard, Dub, Leplege & Coste, 2015; Bickenbach et al., 1999). The figure below illustrates a summary of the ICF model:

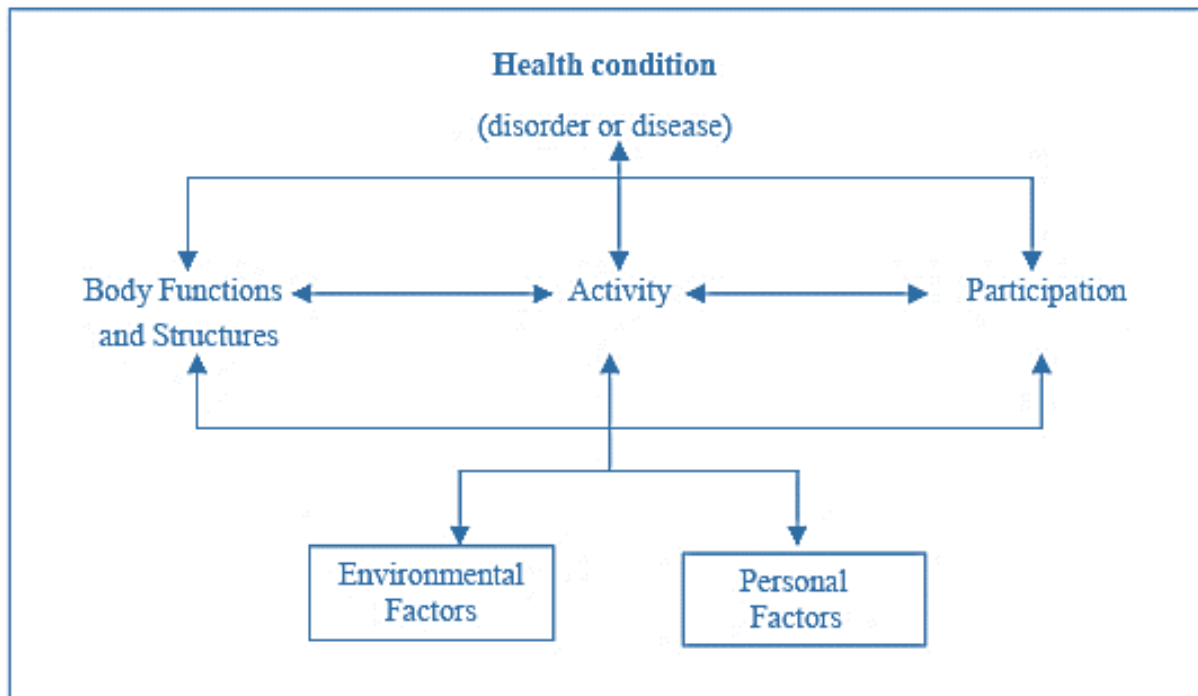


Figure 3.1: Summary of ICF model (WHO, 2001)

Ultimately, the ICF model acts as a multipurpose classification designed to serve various disciplines and different sectors. However, it serves merely as a classification system that can provide a standard for health and disability statistics across different sources of disability data (WHO & World Bank, 2011). It is an elaboration of Engel's biopsychosocial model, which added patients' psychological and social health concerns to the already successful biomedical model (Smith, Fortin, Dwamena & Frankel, 2013).

### 3.2.4 Capabilities approach

Another important model that has the potential to understanding disability is Amartya Sen's capability approach (Saleebey, 2007), which defines functionings and capabilities. For the purpose of this study, this approach will be used as a model, since it serves as the blueprint describing what happens in practice based on underlying theory (Shaw & Ow, 2020; Simons University, 2020). It aims to address a missing dimension in the ICF, where the importance of the individual's identity that is grounded in her/his beliefs, values and preferences is recognised (Sen, 1999).



Sen provided the framework for the capability approach in the 1980s and 1990s, but most of the latest research on this approach has been done by other researchers from different sectors, of which the most well-known is the philosopher Martha Nussbaum (Robeyns, 2005). The capabilities approach has shared perspectives with both the social and biopsychosocial models. Under Sen's description, functionings are described as activities (e.g. being able to play sport) and ideal states of persons (e.g. being physically fit), which can be general or specific. Capabilities (Sen, 1992), on the other hand, can be defined as opportunities to achieve functionings (Mitra, 2006). They rely on assets (e.g. human, social, educational and financial) available to the individual, as well as the social and political landscape which can either enhance or constrain capabilities (Graham et al., 2014). Building this groundwork, Nussbaum (Bussiere, Sicsic and Pelletier-fleury, 2016) identified ten central capabilities that represent a minimum standard of a fair life, these being:

1. bodily health
2. bodily integrity
3. senses
4. imagination and thought
5. emotions
6. practical reason
7. affiliation
8. other species
9. play, and
10. control over one's environment.

Sen's and Nussbaum's approaches are closely related, sharing some fundamental views and ideas (Robeyns, 2005). For instance, they agree that an individual's capabilities may be limited in many ways e.g. by living in poverty (Nussbaum, 2006; Sen, 1999), or by being faced with discrimination for having a disability (Graham et al., 2014).

The work of Amartya Sen (1999), and later that of Martha Nussbaum (2000), considered poverty from a capabilities perspective, which argues for the importance of individual functionings and capabilities (Sen, 1999) in evaluating human well-being/poverty or quality of life. Graham et al. (2014) likewise discussed poverty from a capabilities perspective, defining it as a multidimensional concern (including political, structural and other elements) and as a range of possible asset deprivations that impact on functionings.

Despite Sen (1999) himself not mentioning disability in his discussion of capabilities, others have used his framework to better conceptualise the bidirectional link between poverty and disability (Dubois & Trani, 2009; Mitra, 2006; Sharma, 2005). Utilising Sen's work, Mitra (2006) argued that the capabilities approach is a useful framework for analysing the lack of capability due to the opportunity restrictions PWDs encounter due to a variety of factors (Bussiere, 2016), especially within the economic environment (Mitra, 2006). It also has been argued that disability can be a deprivation of capabilities or functionings (Mitra, 2006; Burchardt, 2004).

Several other authors from different disciplines have used Sen's (1999) and Nussbaum's (2011) capability approaches to define disability (Le Fanu, 2014; Graham, Moodley & Selipsky, 2013; Morris, 2009; Saleeby, 2007; Mitra, 2006; Burchardt, 2004). Based on the model they established, disability can be defined as a reduced, or even a deprived capability originating from the person's impairment itself (actual disability) and their interaction with the environment (potential disability), which could limit opportunities for them (Graham et al., 2013; Dubois & Trani, 2009; Mitra, 2006; Burchardt, 2004). Some authors have also argued that this approach opens new views for policymaking because it focuses on the specifics of the disabling situation to consider equal opportunities, such as reducing the consequences of disability (Biggeri & Libanora., 2011; Biggeri, Bellanca, Bonfanit & Tanzj, 2011; Trani et al., 2011; Dubois & Trani, 2009).

Building on Sen's initial study, many researchers (Dubois & Trani, 2009; Mitra, 2006; Sharma, 2005) have used the capabilities approach to identify a bidirectional link between disability and poverty (Braithwaite & Mont, 2009). This manifests in the one condition potentially increasing the risk of the other (WHO, 2011), resulting in "a vicious cycle" (Yeo, 2005). They considered poverty to include issues of income and material assets, education, health, employment and social capital, all of which could be aggravated by disability (Braithwaite & Mont, 2009).

Taking this into account, Sen's (1999) capabilities approach thus offers an understanding of the ways in which poverty marginalises people and how disability could lead to capability limitations that prevent people from reaching specific functionings (Mitra, 2006). Further, considering the disability rights within Nussbaum's capability perspective, all people differ in their abilities to convert resources into functioning (Harnacke, 2013). She used the example of PWDs in part because they are often absent from more conventional concepts of justice (2006). For this reason, Harnacke (2013) believes that the Nussbaum's capability approach gives a

good basis to analyse disability. Reconceptualising disability through the capability approach makes it possible to overcome the dilemma of differentiation (Terzi, 2005). Both the capability approach (Mitra, 2006) and Bronfenbrenner's ecological model (Bronfenbrenner, 1979), which draws from the social model, considers the influence of the environment on the individual.

### **3.2.5 Ecological perspective**

Building from the social model, Bronfenbrenner's (1979) model of community levels or systems theory, later known as the ecological perspective (Germain, 1991; Meyer, 1983; Germain, 1976), proposed that there is a series of nested systems fitted into one another. It emphasises that all individuals develop within a context of environmental influences that have an effect on them (Harris & Graham, 2010). Therefore, this model not only identifies the social environment of the individual like the social model, but also acknowledges how the social environment influences the individual. Consequently, it identifies four levels within the community, namely micro-, meso-, exo- and macrosystem.

The microsystem consists of the immediate social environment (e.g. family), in other words, the most intimate and closest system to an individual (Parker, 2011). In this tier of the model, interactions refer to the face-to-face, long-term relationships (Donald, Lazarus & Lolwana, 1997), such as spouses, family members or very close friends. The mesosystem, on the other hand, refers to interconnections between two or more interactions outside the immediate environment, such as school and peer influences. The exosystem is the community context that may not be directly experienced by the individual, but which may influence the elements of the microsystem. It might include medical, educational and recreational resources, as well as the different channels that would influence the individual (Wait, Meyer & Loxton, 2005), such as the media, education systems, health services, parents' places of work, or community organisations (Donald et al., 1997). The macrosystem is the wider social, cultural, and legal context that encompasses all the other systems (Xu & Filler, 2008), including those in which the individual does not necessarily have direct contact.

Beyond the family and household, people may find support networks in their communities, either through informal arrangements such as neighbourhood friendships, or through more structured arrangements like religious organisations or community-based organisations (Graham, 2014). Efficient support services are determined by availability of appropriate assistive devices, the presence and willingness of family members to help, and the level to

which the environment facilitates participation of PWDs. People's environments have a great effect on the prevalence and extent of disability. Major environmental changes, such as natural disasters or conflict situations, affect the prevalence of disability, as these can create peoples' impairments and barriers in the physical environment. Examining PWDs' social-ecological world exposes their barriers or whether they are integrated into their social environments, which could also indicate people's perceptions of their interpersonal support availability (WHO & World Bank, 2011).

### **3.2.6 Psychosocial theory**

The previous models focused primarily on the medical and environmental characteristics of disability or some combination of these aspects, or in some cases, engaged with psychological elements. When considering a more in-depth psychological analysis in terms of acquired disability, one could consider the psychosocial theory (Erikson, 1982; 1968; 1964; 1963; 1959; 1958; 1950) to the end of understanding the impact of acquiring a disability in a specific life stage.

According to this theory, an individual's personality develops through means of a predetermined order of eight stages of psychosocial development, ranging from infancy to adulthood. The individual experiences a psychosocial crisis during each of the stages, which could influence their personality in a constructive or adverse manner. These crises are described as being psychosocial in nature because they involve psychological needs of the individual (i.e., psycho) conflicting with the needs of society (i.e. social) (Erikson, 1982; 1968; 1964; 1963; 1959; 1958; 1950). The theory further suggests that the successful completion of each stage results in a healthy personality and the acquisition of basic virtues. However, having a significant experience such as acquiring a disability during any of the stages could affect the outcome of the personality development.

In modern terms, the eight psychosocial crises can be referred to as developmental tasks. Developmental tasks are prevalent, universal psychological issues that individuals must confront and resolve to realise healthy development. Considering these developmental tasks guides an understanding for the psychological issues that are particularly prominent to individuals at different points in their lives (Syed & McLean, 2018). The table below provides a summary of these eight developmental tasks in terms of the different life stages noted by the psychosocial theory.

**Table 3.1: Different life stages according to Erikson's psychosocial theory**

STAGE	AGE	MAJOR QUESTION	VIRTUE	CONSTRUCTIVE OUTCOME	ADVERSE OUTCOME
<b>Trust vs Mistrust</b>	0-2 years	"Can I trust the world?"	Hope	A sense of trust in the world and the people who are supposed to care for them	Failure at this stage leads to a sense of distrust in the world and a belief that others are not dependable
<b>Autonomy vs Shame</b>	2-4 years	"Can I do things myself or must I rely on others?"	Will	A sense of independence and personal control	Feelings of doubt and shame over own abilities
<b>Initiative vs Guilt</b>	4-5 years	"Is it OK for me to do things?"	Purpose	A sense of purpose and the motivation to try new things	Feelings of guilt and a lack of initiative
<b>Industry vs Inferiority</b>	5 – 12 years	"How can I be good?"	Competence	Feelings of competence	Feelings of inferiority
<b>Identity vs Role Confusion</b>	12 – 19 years	"Who am I?"	Fidelity	Develop a strong sense of self	May not be sure of who they are
<b>Intimacy vs Isolation</b>	20 – 40 years	"Can I love and be loved?"	Love	Able to form lasting relationships	Can lead to feelings of loneliness and isolation
<b>Generativity vs Stagnation</b>	40 – 65 years	"What can I contribute to the world?"	Care	Feeling a sense of accomplishment	Feelings of being uninvolved with the world
<b>Integrity vs Despair</b>	65 years and older	"Was my life a good one?"	Wisdom	Looking back on life with a sense of satisfaction	Failure at this stage may lead to looking back at one's life with regret, sorrow and bitterness

Adapted from: Cherry (2018) (Available at: <https://www.explorepsychology.com/psychosocial-development-summary-chart/>)

It is important to understand the importance of balance within the psychosocial theory. Each of the eight crises consists of two opposing poles - a 'positive' (constructive) and a 'negative' (adverse) end. When individuals are engaged in the developmental tasks, they will have to find a sense of balance between these two poles. For instance, with the first stage categorised as Basic Trust, it is not considered adaptive to be all-trusting, since a sense of mistrust can serve individuals well in potentially dangerous situations (Syed & McLean, 2018).

### 3.2.7 Grief model

A person's disability is a triadic experience, involving the person who experiences the disability, the family that is affected by it, and the external environment where the disability is manifested. In most cases, persons who acquire a disability later in life are likely to experience the change as negative, with the process of adapting to it taking on similar stages to those associated with processing grief. More recently, as can be seen in the figure below, Ross and Deverell (2010) revised the five stages of grief identified by Kübler-Ross (1972) into nine phases that could relate to acquiring a disability:

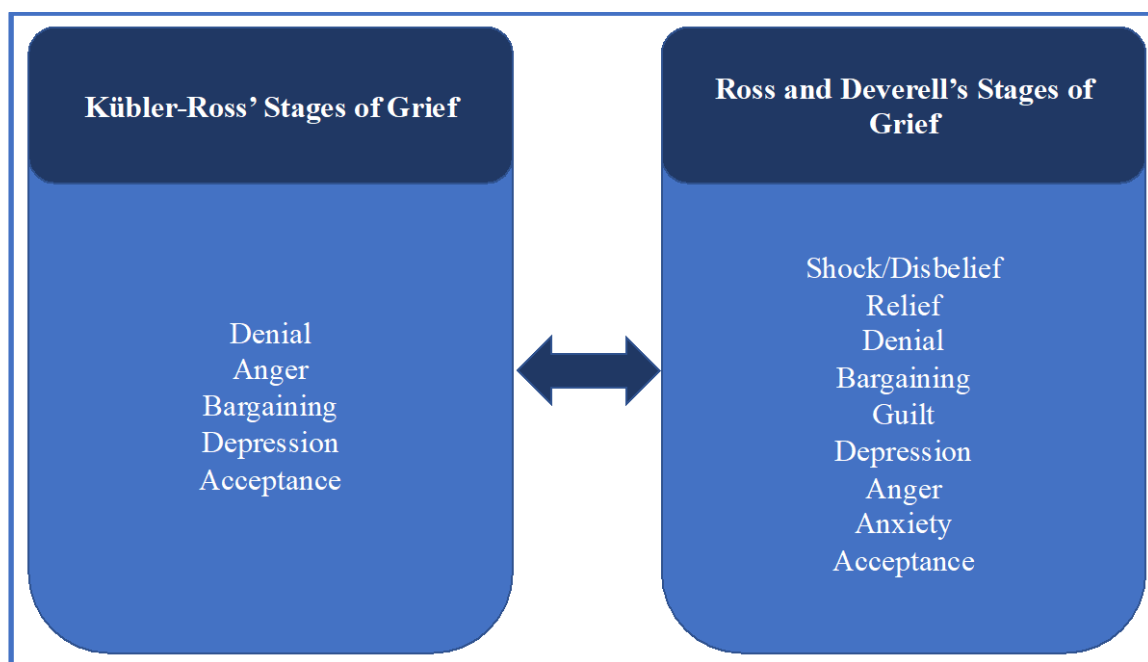


Figure 3.2: Comparison of phases of grief between Kübler-Ross (1972) and Ross and Deverell (2010)

According to Ross and Deverell (2010), one of the first reactions one has with the unexpected acquisition of a disability is a feeling of shock, numbness and disbelief. In cases where there has been a suspicion that something was wrong without a formal diagnosis, once the diagnosis is clear, there might be a feeling of relief from finally knowing the nature of the impairment, or from finding out that the disability is not as severe as expected. Conversely, denial could also be one of the first responses to a disability diagnosis, and a person may argue with the health professional or completely ignore the diagnosis and prescribed treatment. The bargaining phase is characterised by fantasy thinking, portrayed as bargaining with the self, God or therapists by making idealistic promises for a complete or significant improvement. People may also feel guilty about the cause of the disability. Guilt can be displayed in three

ways, namely through stories of what they believe caused the disability, a belief that the disability is a punishment and through the ‘just world’ hypothesis, namely that “[g]ood things happen to good people and bad things happen to bad people.” Reactive depression usually occurs during the grieving process, and is a normal and necessary part of mourning loss as long as it does not continue for too long. Anger can also reveal itself in different ways during the grieving process, for example by questioning why the impairment happened. Anxiety is usually displayed by caregivers in reaction to the question of how to balance the extra responsibility for the welfare of the PWD versus having an independent life of their own. The final phase, acceptance, which coincides with Kübler-Ross’s (1972) final stage of grief, can occur when the disability can also be seen as a positive outcome.

### **3.2.8 Other models and perspectives on disability**

There are other models and perspectives on disability which could also provide insight into different contexts. These include the Expert or Professional model, Tragedy Model/Welfare model, Moral model, Empowering model, Sustainable Livelihoods Framework, Strengths perspective and Ethnic-sensitive perspective.

#### ***3.2.8.1 Expert or Professional model***

This model has provided a traditional response to disability issues and could be viewed a subdivision of the medical model. Within its framework, professionals follow a process of identifying the impairment and its limitations (using the medical model) and taking the necessary action to improve the position of the disabled person (Disabled World, 2010).

#### ***3.2.8.2 Tragedy model /Welfare model***

Another branch of the medical model is the Tragedy and/or Charity Model of Disability, which views PWDs as victims of circumstance who deserve pity (Disabled World, 2010) and require hand-outs and care in separate institutions (Whitehead, 2004).

#### ***3.2.8.3 Moral model***

The Moral Model of Disability refers to the attitude that people are morally responsible for their own disability. For instance, the cause of the disability may be perceived as bad actions on the part of parents, the practice of witchcraft, or even karma within Indian religions (Disabled World, 2010). Similarly, as mentioned before, studies from African countries such



as Zimbabwe, Uganda and South Africa found that PWDs see their impairments as misfortune, karma, ancestral punishment, witchcraft, or bad luck (Visagie & Swartz, 2018).

#### 3.2.8.4 *Empowering model*

The Empowering Model motivates for PWDs and their families to decide the course of their treatment and what services they wish to utilise to achieve their own goals. In this context, professionals offer guidance and carry out the client's decisions (Disabled World, 2010).

#### 3.2.8.5 *Sustainable Livelihoods Framework*

The sustainable livelihoods framework, as depicted in Figure 3.3 below, considers how assets (natural, human, social, financial and physical), and political structures which facilitate asset accessibility, assist individuals to develop livelihood strategies to direct different vulnerability contexts. The interaction between the assets and the political context results in livelihood strategies which then produce livelihood outcomes such as increased income, health benefits and food security among others, and assist people to become more resilient to the vulnerability context (Graham et al., 2014).

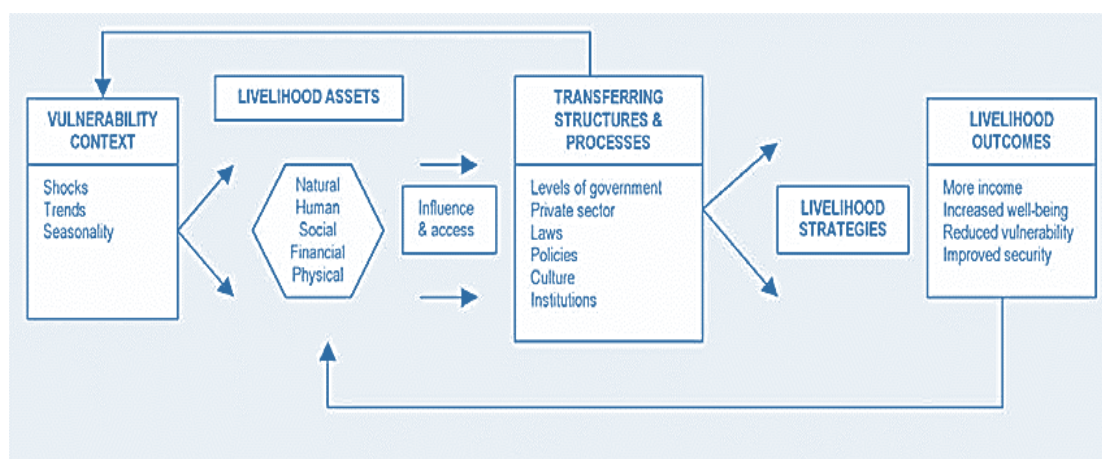


Figure 3.3: *The sustainable livelihoods framework (Rakodi, 2002)*

As can be seen from the figure, a person's environment plays a key role in ensuring they are able to sustain themselves. The importance of a person's environment was also addressed within the biopsychosocial model as well as the ecological perspective.



### **3.2.8.6 *Strengths perspective***

The strengths perspective was popularised by Dennis Saleebey (2005; 2002; 1997; 1992), after which social workers have been encouraged to refocus themselves into strengths-based, solution-focused, capacity building, asset creating, motivation enhancing, [and] empowerment specialists (McMillen, Morris & Sherraden, 2004). Saleebey (2002:20) believed the strengths perspective to be “a way of thinking” and “a distinctive lens for examining the world of practice,” wherein everything social workers do is focused on client strengths. The characteristics of the strengths perspective include its naturalistic, normative approach, its humanistic foundation and its central focus on relationships.

The strengths perspective has its philosophical roots in Aristotle’s teleological theory of human flourishing or eudaimonia. Eudaimonism believes that people should strive to reach their full potential through using their capabilities (Gray, 2011). Aristotle, and the strengths perspective thus support notions of freedom, self-determination, and responsibility. Eudaimonia only occurs due to individual choice and action, and consists in a person taking charge their own life to develop and maintain those virtues for which they are solely responsible (Rasmussen & Den Uyl, 1991)

Used amongst social workers, this perspective reminds professionals about their obligations to themselves and their clients by appreciating the people’s positive attributes and capabilities, along with their capacity for continued growth and enhanced well-being (Weick, Rapp, Sullivan & Kisthardt, 1989). The central focus on relationships in this perspective enhances their importance in social work.

### **3.2.8.7 *Ethnic-sensitive perspective***

This perspective ensures that the social worker is attentive to ethnic, cultural, and religious diversity among clients. It understands that the client’s social class, culture, ethnicity and religious beliefs have a significant impact on the service delivery they receive, and that the problems and effects of discrimination should be addressed in practice (Sheafor, Horejsi & Horejsi, 2000).

Cultural rights are human rights which aim for all cultures to enjoy conditions of equality, human dignity and non-discrimination in terms of language, cultural and artistic production, participation in cultural life, cultural heritage, intellectual property rights, author’s rights and

participation. On a global level, the UNCRPD places specific obligations on the government to promote, protect and uphold the cultural rights of PWDs and to combat the discrimination they experience due to negative perceptions in their communities (DSD, 2016).

In Southern Africa, as in many other countries, there are strong cultural beliefs about incapacity and invalidity (Munsaka & Charnley, 2013), particularly as these apply disability. For instance, it is believed in some Zimbabwean traditions that the mother of a disabled child “caused” the disability, generally through being unfaithful to her husband during pregnancy (Watermeyer et al., 2019). Similarly, a study done with twenty Zimbabweans found that psychological abuse, stigmatisation and prejudice had impacted on most PWDs in their communities (Munsaka & Charnley, 2013). The same rejection, exclusion, discrimination was also found in Uganda (Mulumba, Nantaba, Brolan, Ruano, Brooker & Hammonds, 2014). In Mpumalanga, South Africa, Neille and Penn (2015) explored the disability experience of 30 PWDs and found attitudinal barriers on the part of their communities that resulted in discrimination, deprivation and psychological, physical and sexual abuse. By taking these barriers to equality into account, Social workers can use the ethnic-sensitive perspective to better understand the cultural beliefs that may influence PWDs.

### **3.3 EXPERIENCES OF PERSONS WITH DISABILITIES ACCORDING TO DIFFERENT MODELS OF DISABILITY**

Scholars have tried for decades to understand and define disability. The complexity of the term has called for models of disability to consider the different aspects of the term. This, however, also poses a challenge in terms of conformity between definitions. Different models will thus be discussed below to cultivate a better understanding the term disability.

#### **3.3.1 Biological experiences of adults with an acquired physical disability according to the biopsychosocial and ICF models**

As mentioned earlier, the ICF represents the integration of the medical and social models to form a biopsychosocial model (Palmer & Harley, 2012; Bickenbach, 2011) including biological, psychological and social components. The table below indicates the difference between impairment, activity limitation and participation restriction as components within the ICF model using the example of a spinal injury.

**Table 3.2: Example of disability-related concepts within ICF**

HEALTH CONDITION	IMPAIRMENT	ACTIVITY LIMITATION	PARTICIPATION RESTRICTION
Spinal injury	Paralysis	Incapable of using (mainstream) public transport	Lack of accommodation in public transportation leads to no participation in (community) activities

**Adapted from source:** World Health Organization (2001)

One of the most common deficits that hinder a person's ability to complete their activities of daily living (ADLs) and community activities (Pang, Harris & Eng, 2006) is motor deficits (Langhorne, Coupar and Pollock 2009). A person's environment has a significant impact on the experience and extent of their disability. Inaccessible environments, policies and service delivery create disability by establishing barriers to participation and inclusion (WHO & World Bank, 2011). Amongst stroke survivors in a study done in Johannesburg, South Africa, at least 39% of stroke survivors reported problems with activity limitations and participation restrictions that are related to their community reintegration (Kusambiza-Kiingi et al., 2017; Pang et al., 2007). These restrictions impact on PWDs' ability to complete their activities of daily living (ADLs) (Langhorne, Coupar & Pollock, 2009). Accordingly, table 3.3. below provides some guidance on how the ICF could be utilised in different spheres of service delivery.

**Table 3.3: How the ICF can be utilised in different spheres and with different functions**

LEVEL	FUNCTION
Individual level	<ul style="list-style-type: none"> <li>• Individual assessment</li> <li>• Individual treatment planning</li> <li>• Treatment and other interventions' evaluation</li> <li>• Communication among health professionals</li> <li>• Self-evaluation by consumers</li> </ul>
Institutional level	<ul style="list-style-type: none"> <li>• Educational and training purposes</li> <li>• Quality improvement</li> <li>• Management and outcome evaluation</li> <li>• Managed care models of health care delivery</li> </ul>
Social level	<ul style="list-style-type: none"> <li>• Eligibility criteria for state entitlements e.g. social security benefits, disability pensions, workers' compensation and insurance</li> <li>• Social policy development e.g. legislative reviews, model legislation, regulations and guidelines, and definitions for anti-discrimination legislation</li> <li>• Needs assessments</li> <li>• Environmental assessment for universal design, implementation of mandated accessibility, identification of environmental facilitators and barriers, and changes to social policy</li> <li>• Economic analyses</li> <li>• Research uses</li> <li>• Intervention studies</li> <li>• Environment Factors Usages</li> </ul>

**Source:** World Health Organization (2002)

From the figures above, it can be seen how the ICF can utilise the biopsychosocial model in assessing a person's bodily functions, activity and participation, as well as the environmental and personal factors that could have an influence on their everyday life. Despite its potential for addressing the needs of PWDs, the biopsychosocial model has been critiqued for not being testable, being too general, not having a specified method for obtaining information from the PWD (Smith et al., 2013). Further, it has limited effect in terms of policy design, programme definition, development practice, promotion of participation and identification of barriers to inclusion (Graham et al., 2014).

### **3.3.2 Psychological experiences of adults with an acquired disability**

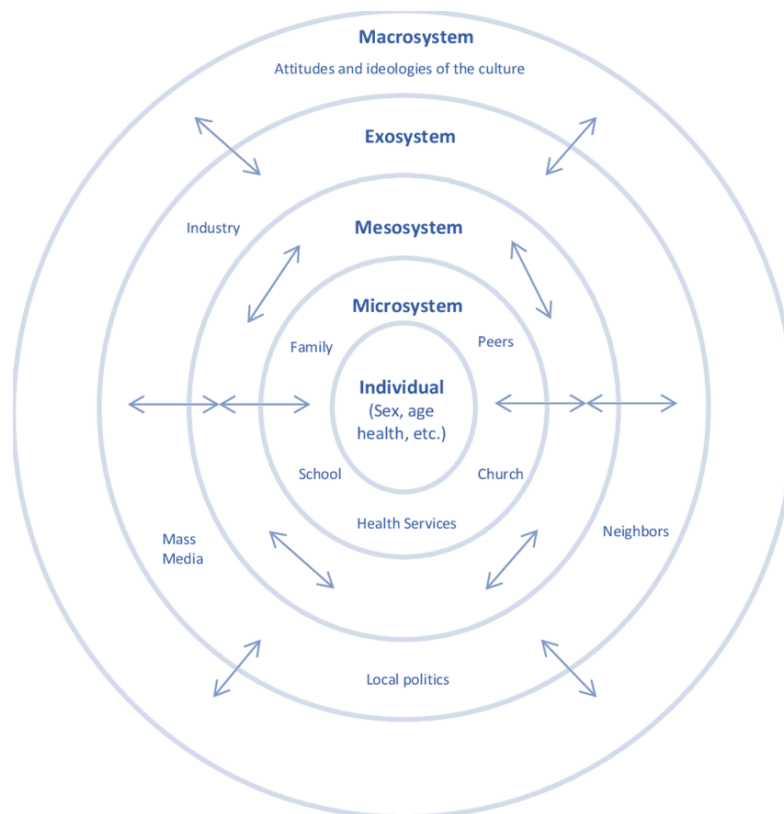
Persons with an acquired (physical) disability often have different psychological experiences when acquiring the disability. The two models that could assist with understanding these experiences include the psychosocial and grief models.

The psychosocial model provides an understanding of how acquiring a physical disability at a specific life stage could influence a person's psychosocial development. The theory describes the impact of social experience across eight stages of a person's lifespan (Ayinde, 2013). The grief model, on the other hand, provides insight on the different stages of grief a person may experience when having to come to terms with 'losing' the life they knew prior to acquiring the disability. Almost five decades ago, a study at a New York Hospital already identified a four-stage process by which newly disabled paraplegics come to terms with their disability. These stages include shock, denial, anger and depression (Weller & Miller, 1977). These stages are similar to the stages of grief identified by Kübler-Ross (1972) and later Ross and Deverell (2010) i.e. denial, anger, bargaining, depression and acceptance. This correlation is of importance because when a disability in a family occurs, an adjustment needs to be made and often the pre-disability life is "grieved".

Both these models could provide an understanding on how adults with an acquired physical disability experience the adjustment of life with a disability (grief model) as well as the psychological impact on personality development when acquiring a disability at a certain life stage (psychosocial theory).

### **3.3.3 Social experiences of adults with an acquired disability according the ecological perspective**

Social support has been known to contribute to the well-being of persons with acquired disabilities (Rintala, Young, Hart, Clearman & Fuhrer, 1992). It is defined as an exchange of resources between individuals to enhance their well-being (Müller, Peter, Cieza & Geyh, 2012). This service is crucial, since most individuals will be temporarily or permanently impaired at some point in life. Further, many non-disabled people take responsibility for supporting and caring for their relatives and friends with disabilities (Zola, 1989). Some of the crucial factors determining the need for support services are the availability of appropriate assistive devices, family members willing to provide assistance and the extent to which the environment facilitates participation of PWDs (Hanson, Neuman & Voris, 2003). However, social support often erodes over time for caregivers who assist family members with chronic health conditions (including disability) (Quittner et al., 1990). For this reason, better strategies for sustainably providing support for PWDs and family caregivers need to be established. To this end, the figure below shows a generic example of different social support that could be used by an individual according to the different systems within the ecological perspective.



*Figure 3.4: Generic example of how the ecological perspective can be used to identify different interactions of an individual (Woollett, 2016).*

From the figure above, the different subsystem can be identified as well as the support within each subsystem e.g. family and peers would be within the microsystem of this individual and would therefore portray the most intimate relationships. Then again, ideologies within a culture would have an indirect influence on the individual within the macrosystem. Social support has been associated with less pain-induced disability, lower levels of depressive symptoms and greater life satisfaction in people with spinal cord injury (SCI) (Widerstrom-Noga Felix, Cruz-Almeida & Turk, 2007). It can also act as a conjecturer of post-injury daily functioning and disability status (O'Hare, Wallis & Murphy, 2011; Wilcox, Kasl & Berkman, 1994).

The social ecological perspective extends beyond PWDs and their families (Kahana, Johnson, Hammond & Kercher, 1994) to include various other social institutions (Leiter, 2004). This includes the exchanges between people and their physical and social environments (Koopman, 2003). Social accommodations such as housing, transportation, and the built environment cater almost exclusively to non-PWDs' needs (Watermeyer et al., 2006), forcing PWDs to face inaccessible environments, practices, devices, and bureaucratic procedures that leave them experiencing alienation and the feeling that their communities have not been structure with

them in mind (Watermeyer, 2013). When looking at the social experiences of PWDs, it could be analysed further from two sides i.e. services (support) used and support needs still not met.

#### *A) Services used*

A survey of 1 505 PWDs in the United States of America found that 70% relied on family and friends for assistance with daily activities, and that only 8% used home-based care and personal assistants. In this study, 4 2% identified not being able to move in or out of a bed or a chair because no one was available to help, while 45% of participants worried that caring for them would become too much of a burden on the family and 23% feared going into a nursing home or other type of facility (Hanson, Neuman & Voris, 2003).

#### *B) Support needs*

Environmental factors such as access to buildings, climate, relationships with family, friends and health care workers, and societal attitudes all impact on the dimensions of disability experience. In addition, personal factors including age, race, gender, education, experience, personality, social background and coping style play a role (Ross & Deverell, 2010). The World Report on Disability (WHO & World Bank, 2011) highlighted inadequate policies and standards, negative attitudes, lack of provision of services, problems with service delivery, inadequate funding to implement policies and plans, lack of accessibility, inadequate consultation and involvement, and lack of rigorous data and evidence as barriers to participation for PWDs (Graham et al., 2014).

Taking these factors into account, PWDs may require a range of services that are not always met. Unmet needs for support may include personal care, access to aids and equipment, participation in education, employment, and social activities and modifications to the home or workplace (WHO & World Bank, 2011).

### **3.4 APPLICATION OF MODELS AND PERSPECTIVES ON DISABILITY AND SOCIAL WORK**

A practice framework should be consistent with the purpose, values and ethics of the profession, be possible to communicate to others, make sense to everyone, help the social worker analyse and understand highly complex and often chaotic situations, provide guidance and direction during the phases of change and rest on an empirical foundation (Sheafor et al.,

2000). Social work theory is most successful when it contains all three elements of perspective, theory and model (Payne, 1997).

### **3.4.1 Selecting practice frameworks in social work**

A practice framework is a set of beliefs and assumptions, such as models and perspectives, on conditions that influence people to change. It is used by social workers to facilitate desirable change (Sheafor, Horejsi & Horejsi, 2000). Social work theories are general explanations supported by evidence-based knowledge and may explain human behaviour (Simmons University, 2020).

Further, Social work theory attempts to explain how individuals, families, groups, organisations, communities, societies, and social movements develop and function. It could also be used to explain the cause (etiology) of a social problem and informs the social worker about what is considered normal and abnormal development through partially predictable stages. Finally, it could assist professionals in understanding the development and course of social problems as the starting point for a potential intervention to address those problems effectively (Garthwait, 2012)

A model is an organised set of guidelines and procedures based on research and evidence-based practice which can offer solutions to problems (Compton & Galaway 1994). It is therefore the operationalisation of theory and practice (Engelbrecht, 1999). In this light, it is often referred to as the blueprint for action, as it generally describes what happens in practice based on underlying theory (Shaw & Ow, 2020; Simons University, 2020). It further shows how to use a theory to create change (Simmons University, 2020).

A perspective is a professional view used to assist social workers in examining and focusing on a realm of social functioning necessary to complete a thorough assessment (Garthwait, 2012). It directs the social worker be more focused on certain factors when approaching a practical situation (Sheafor et al., 2000). Choosing a practice framework in social work could be done by using the guidelines suggested by Sheafor et al. (2000) used in this study.

Taking this background into account, the table below illustrates how different practice frameworks were considered for this study.



**Table 3.4: Application of guidelines for selecting a practice framework for this study**

	Ecological perspective	Strength perspective	Ethnic-sensitive perspective	Medical model	Social Model	ICF/ Biopsychosocial model	Capability approach	Grief model	Erikson's psychosocial theory
Acceptable for unit of intervention: Research	X	X	X	X	X	X	X	X	X
Acceptable for type of client: Persons with disabilities	X	X	X	X	X	X	X	X	X
Explanation of how and why change occurs: acquired disability experience	X	-	-	X	X	X	X	X	X
Role of social worker: Support and community integration	X	-	-	-	X	X	X	X	X
Understand professional relationship	X	-	-	-	X	X	X	X	X
Appropriate and supporting of beliefs: Current beliefs on disability	X	X	X	-	X	X	X	X	X
Not harmful	X	X	X	-	X	X	X	X	X
Supporting cultural differences	X	X	X	-	X	X	X	X	X
Effective application in understanding experiences of persons with disabilities on social work support	X	-	-	-	X	X	X	X	X

**Adapted from source:** Sheafor et al. (2000)

This table provided an analysis on how each model and perspective could contribute to the research study's overall aim by indicating which aspects each would be able to address. From the table's analysis, it was decided to mainly use the social model, ecological perspective, ICF/Biopsychosocial model, capability approach, grief model, and psychosocial theory as guiding models and perspectives for this study as these would be able to provide a more comprehensive understanding within the disability and social work context of the research study.

### 3.4.2 Social model for service delivery to adults with acquired physical disabilities

The social model recognises the impact of the social context of where PWDs live on their full participation, inclusion and acceptance into mainstream society, and recognises that disability is a social construct that is caused by the interaction of impairments with environmental barriers. It focuses on the abilities of PWDs, respecting their diversity and aiming to address the social barriers that result in discrimination. It further promotes broader systemic and attitudinal changes in society, as well as the mainstreaming of disability. Lastly, it reinforces the importance of being part of the transformation processes aimed at improving the quality of life of PWDs (DSD, 2016). These are all points of importance for social workers working with persons with acquired physical disabilities in assisting them with community or societal integration.

Taking the role of social workers in the plight of PWDs into account, the figure below indicates an example of how the social model could assist with understanding service delivery to PWDs in terms of stigmatisation, cultural and religious beliefs as well as inaccessibility.

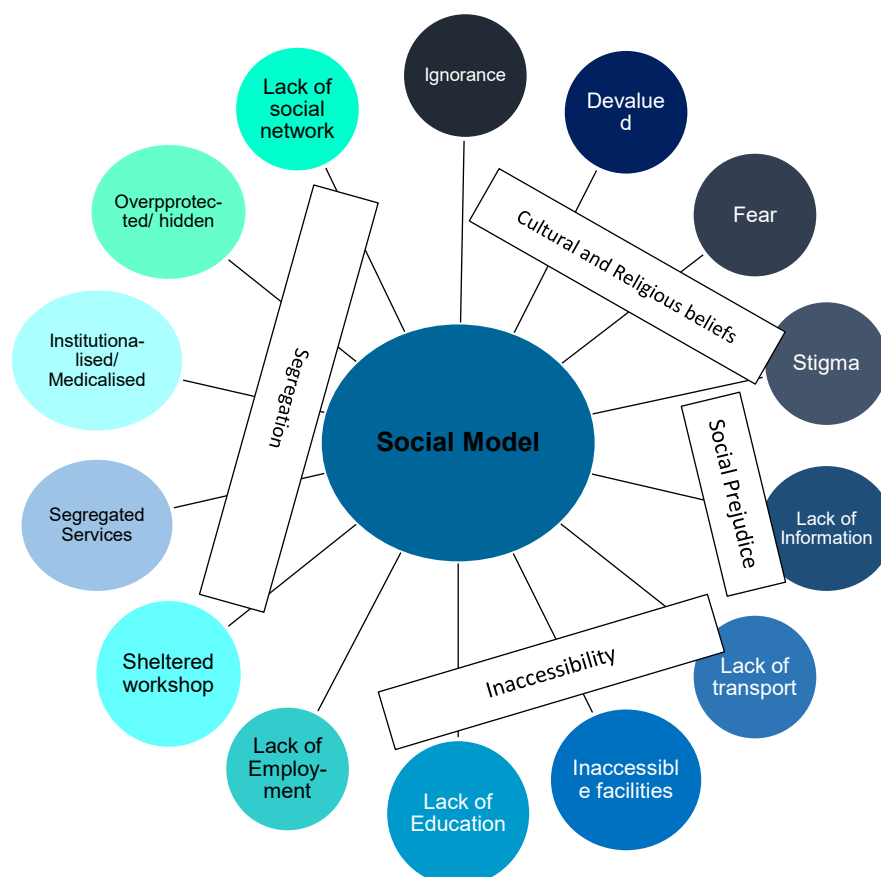
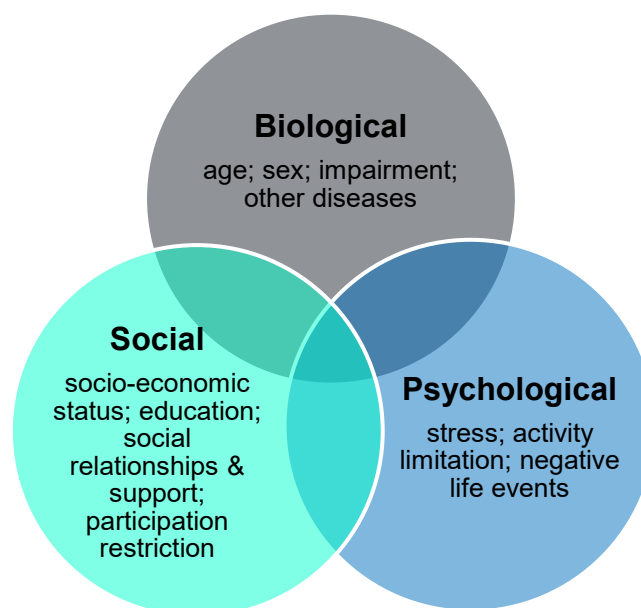


Figure 3.5: Social Model Adapted from Habtewold, Islam, Radje et al., 2016 (available at <https://www.miusa.org/resource/tipsheet/disabilitymodels>)

Ultimately, the social model opens a new line of enquiry and widens the focus from only examining the individual to also including social and cultural processes. Within social work research, Michael Oliver's principle of emancipatory research emphasises the importance of embracing a social model approach, which also commits to social change and working closely with DPOs (Shakespeare, 2018).

### 3.4.3 Biopsychosocial model in terms of the ICF for service delivery to adults with acquired physical disabilities

As mentioned earlier, the biopsychosocial model – which focuses on biological, psychological and social aspects of the individual – was introduced as an updated model to the medical model (Parsons, 1975) to also include some aspects of the social model based on the systems theory (Adler, 2009). The figure below illustrates an example of how the biopsychosocial model could be used to identify the different aspects that influence an individual.



**Figure 3.6:** *Biopsychosocial Model (Adapted from Habtewold, T.D., Islam, M.A., Radie, Y.T. et al., 2016)*

Social workers utilise the biopsychosocial model because it acknowledges individual needs while also acknowledging that social work interventions are linked to either biological, psychological or social problems (Silence, 2016). People are increasingly being (made) aware of their disabled identities through the global spread of disability diagnoses as well as the world-wide texts associated with the WHO's ICF (WHO, 2001), which renders the concept of disability more the complex. While this makes a single theoretical model difficult to fit within

disability services in social work (Oliver & Sapey, 2006), the biopsychosocial model does address some of the concerns highlighted in the social model.

The biopsychosocial model is further used in the International Classification of Functioning, Disability and Health (ICF) in evaluating a person's body functions, activity, participation as well as the environmental and personal factors that could have an influence on their everyday life. As established previously, the ICF integrates two opposing models i.e. medical model and social model, which suggests that disability originates from a health condition that gives rise to impairments, activity limitations and participation restrictions in relation to contextual factors (WHO & World Bank, 2011). The figure below shows an example of the utilisation of this model in a person with osteoarthritis, rheumatoid arthritis or functional musculoskeletal condition.

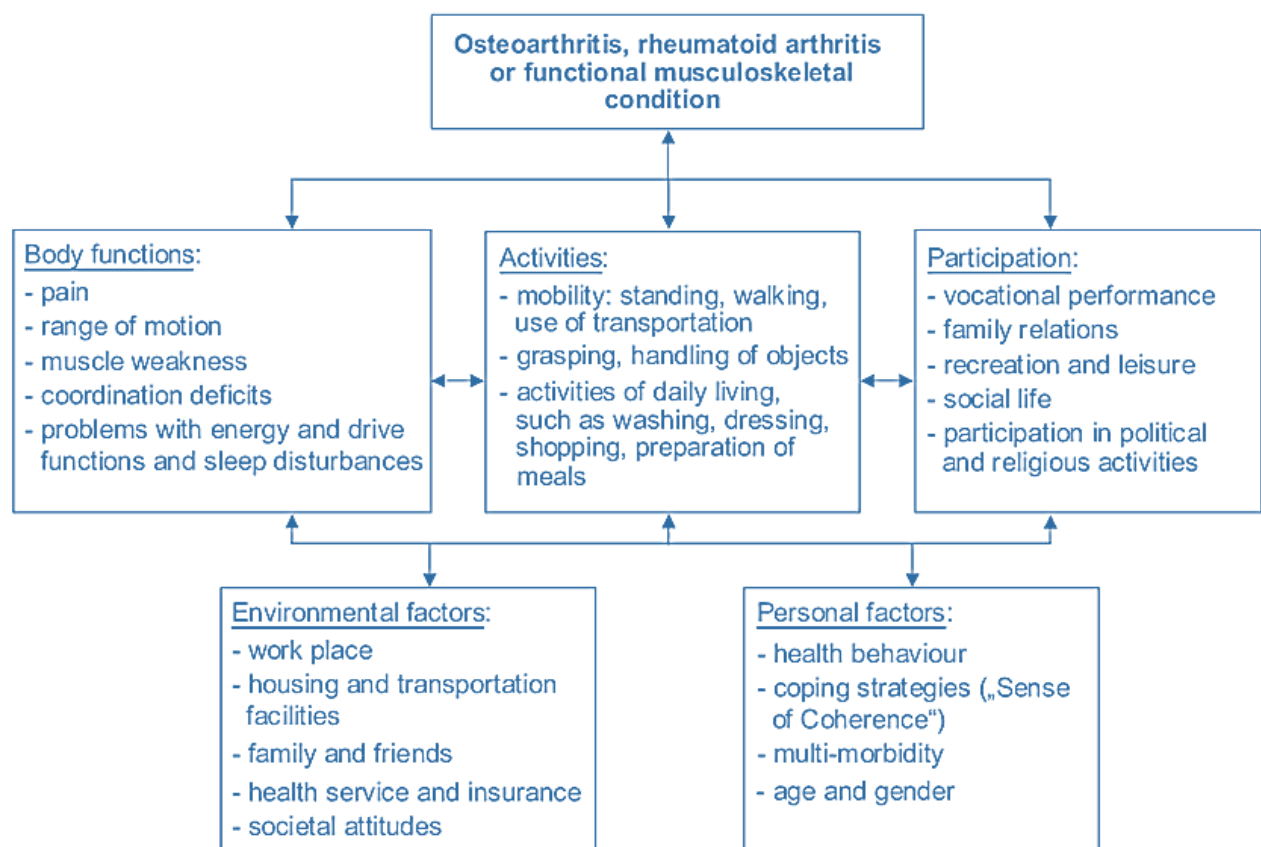


Figure 3.7: Example of utilising the ICF model in persons with osteoarthritis, rheumatoid arthritis or functional musculoskeletal syndrome (Source: Gutenbrunner, Ward & Chamberlain, 2007)

Ultimately, this model provides an understanding of how an individual's impairment can be influenced by their environment and create participation restrictions. This understanding will

assist social workers to be able to advocate for the reasonable accommodation and universal design to assist PWDs.

### 3.4.4 Ecological perspective in terms of service delivery to adults with acquired physical disabilities

The ecological perspective has been adapted in many ways to identify different aspects of people's socio-ecological context. As mentioned before, according to this model, there are four systems that are nested within each other to indicate the different interactions in an individual's social environment i.e. micro-, meso-, exo- and macrosystem.

In a study done with in Cape Town, South Africa, with family caregivers of persons with physical disabilities (Muller-Kluits, 2017), both the support services used, and the unmet support needs according to the ecological perspective were identified. The support needs that were identified, utilising the ecological perspective in this study can be seen in the figure below:

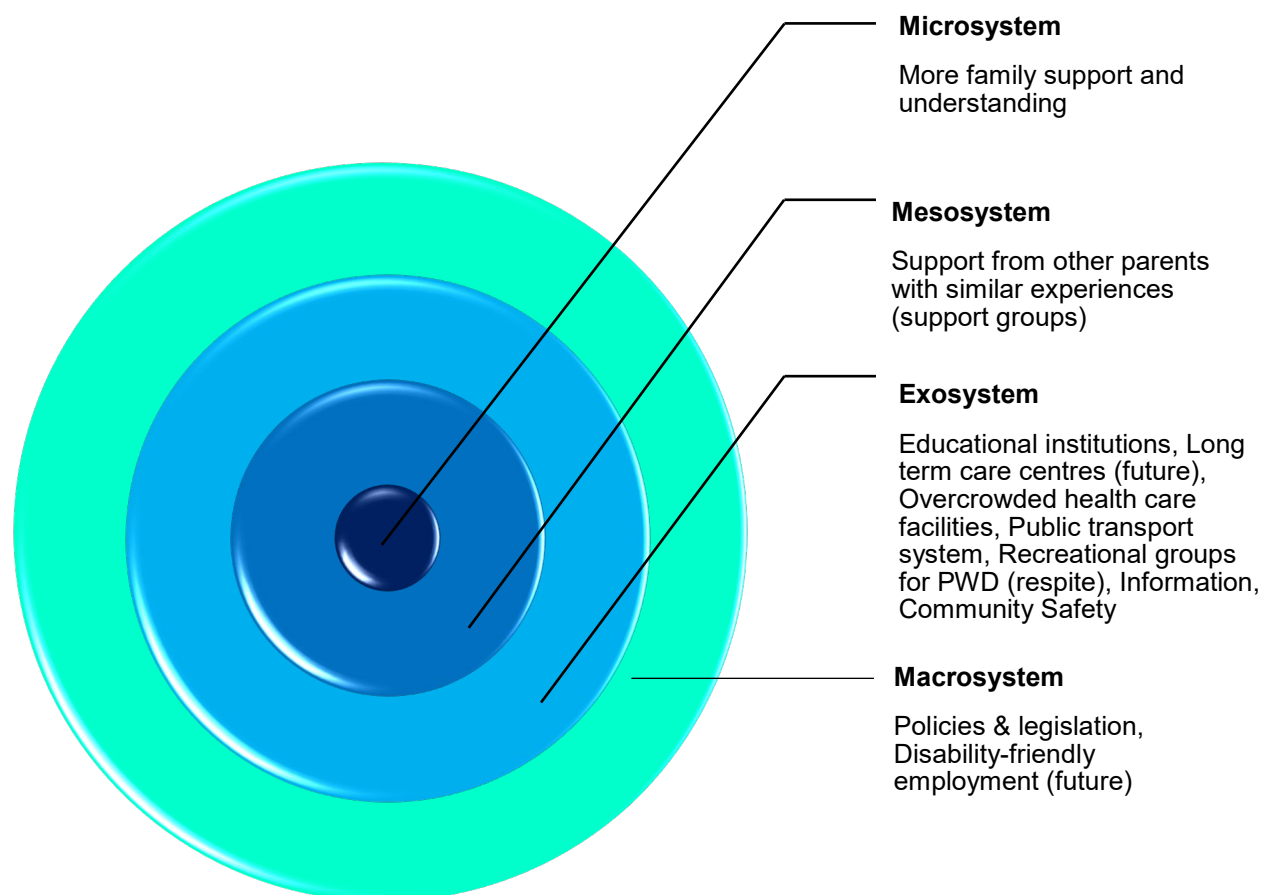


Figure 3.8: Support needs of family caregivers of persons with physical disabilities (Muller-Kluits, 2017)

Although these were needs identified for family caregivers of persons with physical disabilities, it could be used as a guide for the needs of this study as well. The correlation between family caregivers of PWDs as well as persons with acquired disabilities in the requirement to “adjust” to a new lifestyle in many cases brings forth a potential discussion for similar needs that may arise due to similar experiences.

As social workers work on individual, familial and community levels, this model could provide a good guide to understanding the PWD in relation to their (social) environment. Social workers could utilise this perspective in identifying services used, as well as identifying the support needs across the different societal levels.

### 3.4.5 Capabilities approach in terms of service delivery to adults with acquired physical disabilities

It has already been discussed how the capabilities approach could be utilised to show the influence of disability in terms of community integration. Both the ICF and this model uses a biopsychosocial approach in understanding disability (Saleeby, 2007). The figure below depicts the assessment of an individual in terms of their personal characteristics, commodities, environment and functionings:

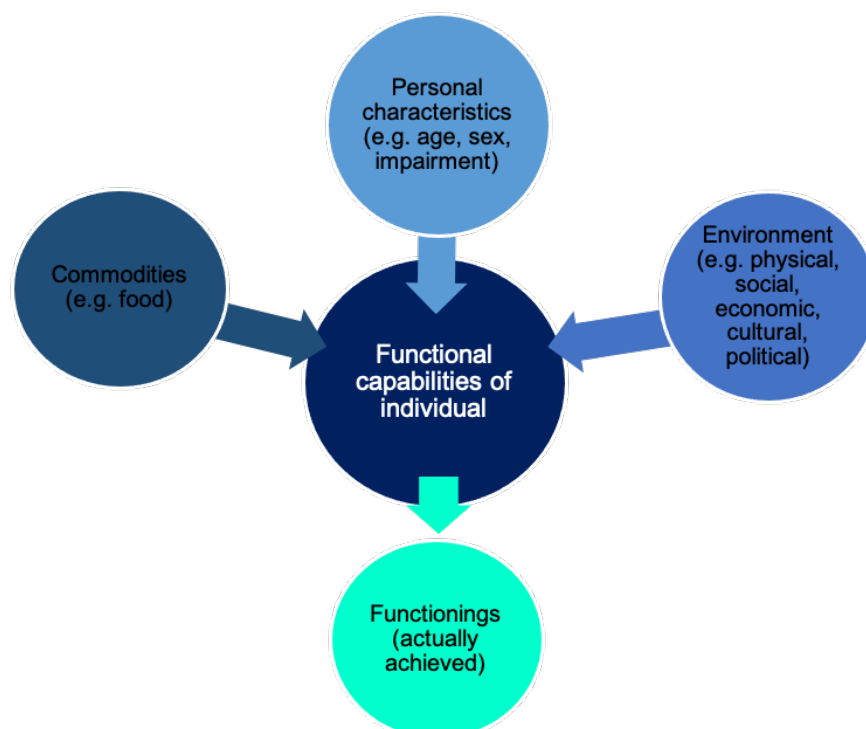


Figure 3.9: Example of utilising the capabilities approach in evaluating an individual (Adapted from Mitra, 2006)

In a study on poverty and disability in Johannesburg, it was found that support from family or household members played a key role in PWDs' ability to cope (Graham et al., 2010). It is however important to note that social networks do not automatically provide support (Graham, 2014). Collective networks can only enhance capabilities where members of the networks collaborate (Dubois & Trani, 2009). Recognising the marginalisation processes and addressing it with appropriate policy and programmatic interventions will see outcome changes for both those who are poor and those living with a disability. Another focus of the capabilities approach is what people have access to that can enhance capabilities and functioning, including social assets, access to employment, access to services, and material (non-income) assets (Graham et al., 2014).

In short, this approach helps social workers to understand PWDs' capabilities by considering the personal characteristics, commodities and environmental factors that impact them. It is also of importance to understand the bi-directional link between disability and poverty (as discussed earlier in this chapter). Social workers, aligned with the WPRPD's Pillar 5, aim to reduce economic vulnerability of PWDs. This approach assists social workers to better identify barriers to achieving this goal to also achieve Pillar 3 (Supporting Sustainable Integrated Community Life) and Pillar 4 (Promoting and Supporting Empowerment of PWDs) of the WPRPD.

#### **3.4.6 Model of grief in terms of service delivery to adults with acquired physical disabilities**

When a person acquires a disability later in life, they might mourn the loss of the life they had prior to the disability, as established previously. This could be comparable to the stages of grief identified by Kübler-Ross. The figure below shows a portrayal of how the five stages of grief can be used in terms of understanding the psychological aspects of a person who acquires a disability later in life.

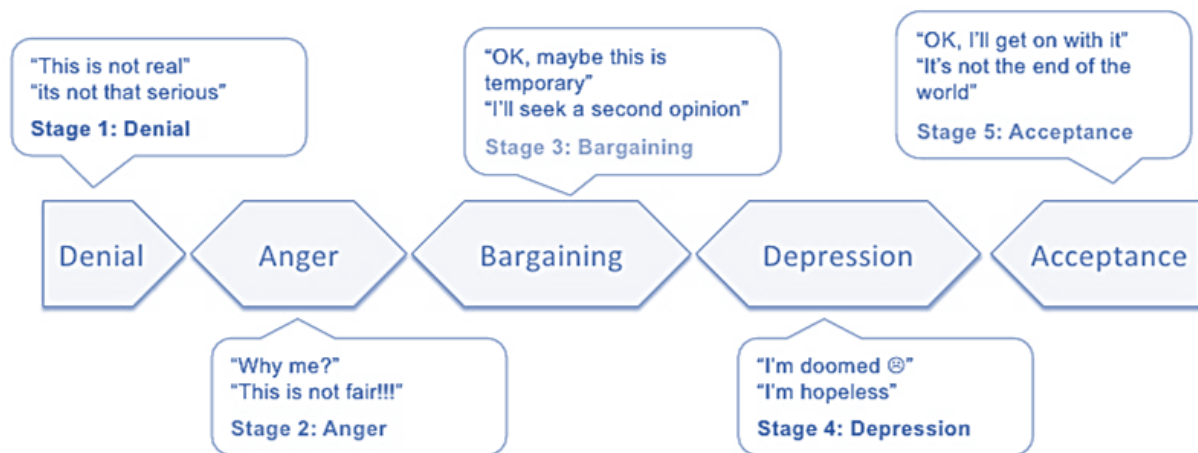


Figure 3.10: Kübler-Ross' Model of grief and disability (Tang, 2012)

Social workers play an important role in assisting PWDs and their families in working through these feelings in the different stages. Albrecht (in Mackelprang, 2013) argued that individuals must work through all of these stages to be fully socialised as the goals with policies such as the WPRPD (2016) and the UNCRPD (2006), to name a few. Understanding how the person with an acquired physical disability may go through the phases of grief and 'mourning' the loss of their life prior to the disability could assist social workers in providing efficient emotional support and empowerment opportunities in achieving Pillar 4 (Promoting and Supporting Empowerment of PWDs) of the WPRPD.

### 3.4.7 Psychosocial theory in terms of service delivery to adults with acquired physical disabilities

Jordan and Tseris (2018) noted that Erikson's theory has been common use for psychologists, social workers and other human service professionals. They also argued that it is necessary to include disability in theorisations of how people develop across their life course to challenge inherent beliefs about difference. Similarly, the WPRPD advocates for a 'life cycle' approach when providing socio-economic services to PWDs, which leads to a complementary element of being "person centred or people centred" (WPRPD, 2016).

Some attitudinal barriers confronting children (and adults) with a physical disability during different life stages have been documented (National Collaborative on Workforce and Disability, 1999), including inferiority, pity, spread effect, stereotypes, and fear (Ayinde, 2013). When a person is impaired in a specific function, some people believe that the individual is a "second-class citizen" or inferior. However, many PWDs have skills that render the



impairment unnoticeable in the workplace. Still, the Spread Effect occurs when people assume that an individual's disability negatively affects other senses, abilities or personality traits, or that the total person is impaired. As a result, any PWDs may experience stereotypes. Society often sees the PWDs as passive. This type of prejudice can set too high or low standard for individuals who are mere humans. Society often feels sorry for PWDs, which may lead to patronising or pitying attitudes. Most PWDs do not want pity and charity but rather equal opportunity to earn their own way and live independently. Lastly, there are often also people in society who are afraid that they will do or say the wrong thing around a PWD. They therefore avert their own discomfort by avoiding the individual completely (Ayinde, 2013).

As social workers, this theory could be useful in understanding the impact of certain experiences could have on a person's psychosocial development, such as acquiring a disability at a specific life stage. It is also beneficial to note the attitudinal barriers they may face during this specific life stage.

### **3.5 CONCLUSION**

Although a multi-factor model of disability as Johnston (1997) suggested may not be possible yet to incorporate all the different models and perspectives of disability, this chapter provided a good overview of these different insights on disability. As part of social work training, knowledge of different models and perspectives guides social work practice. Despite the complexity of disability making it difficult to decide on a model to utilise within the sector, its complexity also provides an opportunity, not only to have a singular perspective, but also to incorporate different perspectives to provide a comprehensive understanding of disability in context.

## **CHAPTER FOUR**

### **SOCIAL WORK AND DISABILITY**

#### **4.1 INTRODUCTION**

In accordance with the third objective of this study, this chapter will present a theoretical discussion of the social work profession and how social work support to persons with acquired physical disabilities, especially adults, have been perceived from previous, similar studies. As an introduction to this chapter, the definition of social work as a profession will be provided, followed by a discussion on the scope of practice and roles of a social worker. This will be followed by an overview of social work service delivery to PWDs across different sectors including health, rehabilitation, NGOs and family preservation sectors. From the discussion regarding the policies guiding service delivery to PWDs in Chapter Two, an explanation of the role of social work aligned with some of these policies will be provided. The application of social work roles in service delivery to PWDs, will also be discussed, especially in terms of the COVID-19 pandemic. Lastly, the chapter will unpack some of the challenges faces by social workers in the disability sector.

#### **4.2 SOCIAL WORK PROFESSION**

Social workers can play a vital role in delivering services to PWDs. To understand this role, the definition, scope and roles of the profession needs to be discussed.

##### **4.2.1 Definition of social work**

The global definition for social work contextualises the profession's broad service parameters, stating that it "is a practice-based profession and an academic discipline that promotes social change and development, social cohesion and the empowerment and liberation of people," along with "[p]rinciples of social justice, human rights, collective responsibility and respect for diversities (International Association of Schools of Social Work, 2014:1). It also identifies the practice as "[u]nderpinned by theories of social work, social sciences, humanities and indigenous knowledge" that "engages people and structures to address life challenges and enhance wellbeing" (International Association of Schools of Social Work, 2014:1).

Apart from the Global definition of social work, various other authors have attempted to define the practice as an academic discipline, and the application of an eclectic knowledge base, professional values and a wide range of skills to target individual, familial, group, organisational or community systems for change (Kirst-Ashman, 2013; Teigiser, 2009; Kirst-Ashman & Hullm, 1997; Bogo & Taylor, 1990). In terms of generalist social work, Balinsky (as cited in Morales, Sheafor & Scott, 2012) stated that the complexity of human problems requires a broadly oriented practitioner with a versatile repertoire of methods and skills capable of interacting in any one of a number of systems (Silence, 2016).

#### **4.2.2 Scope of practice in social work**

The International Association of Schools of Social Work (IASSW, 2014) notes that the social work profession's main tasks include promoting social change, social development, social cohesion and the empowerment and liberation of people (Silence, 2016). Its values are based on respect for the equality, worth and the dignity of all people (Wolpert, 2005), while its purpose is to enhance people's problem-solving and coping abilities. Consequently, its objectives are to assist individuals, families, communities who are socially disadvantaged, as well as to enhance their social functioning and prevent breakdown (Silence, 2016). Developed from ideals of humanitarianism and democracy, the values of social work are based on respect for everyone's equality, worth and dignity (Wolpert, 2005).

During their undergraduate training, social workers receive generalist training (Silence, 2016) to master knowledge, values and skills to empower service users. Further, to improve its quality, they are trained to evaluate service outcomes by using the problem-solving process, critical thinking skills and strength-based perspective (Williams, Crayton & Agha, 2014). Once they are employed, however, they are often expected to function within a specialised field such as health without the essential support and supervision from a social work supervisor (Silence, 2016). Especially when working within such interprofessional teams (Godden, 2012), they are faced with difficulties, since people's problems are complex and require a range of skills and methods to be addressed effectively. Further, since social workers often work with in the non-profit, non-governmental sector under the auspices of the Department of Social Development, new graduates may lack the necessary support due to lack of resources. The baccalaureate-level social work programs' objective should thus be to have graduate students who are competent in working with different populations in distinct settings (Beytell, 2014; Morales, Sheafor & Scott, 2012).

### **4.2.3 Roles of social work**

Engelbrecht (1999) identified some intervention roles performed by the South African social worker, which will simply be listed for the purpose of this study to provide space for a more thorough engagement with disability. Accordingly, these roles include counsellor, broker, public relation manager, marketer, manager, expert, leader, enabler, facilitator, motivator, researcher, educator, negotiator, mediator, advocate, activist, agitator and professional person (Engelbrecht, 1999).

## **4.3 SOCIAL WORK PROFESSION AND DISABILITY SERVICE DELIVERY ACROSS DIFFERENT SECTORS**

The social work profession has a strong history of responsibility to work with and advocate for vulnerable groups in society, such as PWDs, in terms of equity and social justice. Throughout the history of the practice, social workers have worked in the disability sector at both the micro and macro levels (Mackelprang, 2013; Stainton, Chenoweth & Bigby, 2010). Some of the earliest settings for social work practice include institutions for the ‘mentally retarded,’ as such facilities were referred to at the time. As can be seen with such classifications, the response to disability has historically been to allocate PWDs to separate homes, schools and workplaces. As a result, the only opportunity for employment for PWDs often included sheltered workshops (Watermeyer et al., 2019).

Social workers are important role players in delivering services to people with disabilities. A study done by Graham et al. (2010), for instance, found that 31% of PWDs identified a social worker as one of the main sources of social support available to them (Graham et al., 2010). They also indicated that they were more aware of social workers than of other service providers such as home-based carers, community rehabilitation workers and rehabilitation therapists (Lorenzo & Cramm, 2012).

### **4.3.1 Social work in the health sector**

As mentioned above, social workers are trained generically (South African Council for Social Service Professions, 2007; Patford, 1999), but are expected to provide a service within the specialised field of health. Research conducted in 27 health facilities in New York described the role of the social worker in the medical profession as that of a jack-of-all-trades (Mizharhi & Rizzo, 2008).

#### **4.3.1.1 *Function of medical social work***

The South African Council for Social Service Professions (2007) states that social workers in the health sector assess the psychosocial functioning of patients and families, intervening by linking patients and families to support community services where needed. They have an important role to play in the health sector, as they help patients and families deal with the impact of illness and treatment (Silence, 2016) by providing supportive counselling and psychotherapy. As established before, social workers' roles and responsibilities within the health sector might thus differ depending on the level or specific focus of care (Beytell, 2014).

Hospital social workers practice in specialised environments and are often assigned to specific medical units that are based on diagnosis, age or gender (Gibelman, 2005). Within tertiary medical settings, social workers conduct psycho-social assessments and make recommendations to medical experts, who in turn make life or death decisions with regards to patients needing procedures such as heart and liver transplants based on the social workers' findings (O'Donoghue, 2012). In addition, social workers may make diagnostic assessments (Caputi & Heiss, 1984) and recommend patient treatment programmes (Wolpert, 2005; Lourens, 1995; Wolock & Schlesinger, 1986; Patchner & Wattenberg, 1985) to the multi-disciplinary team. They also need expertise regarding health conditions to be fully effective within this sector of service (Silence, 2016). In terms of the service to the patient, they help patients and their families to understand a particular illness by working through the emotions of a diagnosis and providing counselling about the treatment decisions that need to be made (NASW Centre for Workforce Studies & Social Work Practice, 2011). Social workers also educate patients, assist in navigating the health care setting and provide the connection between the hospital and community sectors (Judd & Sheffield, 2010; Crisp, 2000). In some cases, they may report directly to medically trained staff, while in others they make decisions more independently (Department of Health, 2012; Continuous NHS Healthcare, 2011; Scott, 1980).

#### **4.3.1.2 *Social work function within a multi-professional team***

The term interdisciplinary refers to a group of professionals from different disciplines sharing a common purpose by embracing different professional perspectives to guide their decision making. It requires active communication and role identification based on their expertise and commitment to collaboration (Abramson & Bronstein, 2004). Within social work practice and

health care settings, client service delivery is virtually impossible without collaboration with professionals from other disciplines (Bronstein, 2003).

In South Africa, social workers forms part of the multi-disciplinary teams in the Department of Health (Silence, 2016) and play an integral role in the interdisciplinary hospital teams of doctors, nurses and other allied health professionals to ensure awareness of the social and emotional aspects of a patient's illness (National Association of Social Work (NASW), 2011). The social worker's involvement in the interdisciplinary team makes a positive difference (Black, 2005), as they must often advocate for the rights of patients even when the rest of the health team disagrees with them (Silence, 2016). Interdisciplinary teams which consist social workers have been reported to have increased attention to patients' wishes (Black, 2005) and to improving patient and family involvement in ethical decision-making processes in their health care situations (Joseph & Conrad, 1989).

#### **4.3.2 Social work in rehabilitation**

Rehabilitation is described as "a set of measures that assist[s] individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (WHO & World Bank, 2011). It is a complex, multidimensional approach in health care using an interdisciplinary model of specialised services. The comprehensive treatment team includes medical specialists and therapists specialising in physical therapy, occupational therapy, speech therapy, cognitive therapy, psychology, and recreational therapy. Social workers play an important role within these treatment team in terms of care coordination, discharge planning, and community reintegration (Springer & Casey, 2013).

Similar to their role within the health sector, social workers are also invaluable within the rehabilitation team by merit of their providing services to PWDs. They are thus a vital group in the multidisciplinary care model of rehabilitation. They conduct psychosocial assessments, psychosocial counselling, discharge planning, case management and psychosocial health education (Springer & Casey, 2013) using their knowledge of theories such as the social model, biopsychosocial perspective and the ecological perspective in understanding how the individuals interact with their environment (Sape, 2003; Sapezinskiene, 2000; Miley, O'Melia & Dubois, 1995).

#### **4.3.2.1 *Social work support with patient recovery programmes***

Social workers could play a vital role in the rehabilitation team of persons with physical disabilities by providing information and reassurance, along with developing problem-solving skills and exploring meaning and appraisals. Further, they are involved in facilitating access to necessary resources through interventions such as advice, referral, and advocacy that assist both the PWDs and their families (Dorsett, 2010).

#### **4.3.2.2 *Social work support with community integration***

Globally, PWDs are marginalised and excluded from full participation in society. In South Africa, they face multiple forms of discrimination in various areas, including with respect to access to health care services, employment and education. True equality cannot be achieved without sincere social inclusion and reasonable accommodation of PWDs (SAHRC, 2015). Although there is a wide range of policies focused on disability inclusion, the implementation fails PWDs (Graham et al., 2014), as they are still considered to be in a less privileged category than their non-disabled counterparts, represented typically amongst the poor and unemployed (Community Agency for Social Enquiry, 1999; 2005; Statistics South Africa, 2007). Previous studies have also shown that PWDs rarely benefit from mainstream education, while only a small number few have access special education schools (Wilson & Selipsky, 2010).

Throughout history, full citizenship rights and recognition have been denied to people in various contexts. The question of who may and may not be considered a full member of a community is a pivotal one to disability scholars and activists (Watermeyer et al., 2019), since PWDs have mostly been considered less important than their able-bodied counterparts within their communities, and thereby denied full recognition of their humanity (Kittay et al., 2005).

Taking this into account, Morris (2005) identified self-determination, participation and contribution as important in understanding citizenship for PWDs in the contemporary context. Self-determination refers to an individual's capacity for free choice, which would grant the exercise of autonomy attributed to full citizenship. Participation, on the other hand, includes political involvement, which accompanies the broader concept of community participation. Finally, PWDs have emphasised the value of their contribution to economic and social life in foregrounding anti-discrimination legislation along with the resources required for a reasonable quality of life.

Also related to the unmet needs of PWDs and the social work support that stems from these, disability mainstreaming is centred around ensuring that disability, as a norm and undeniable principle, is a focal point of all development initiatives, policies, budgets, plans and programmes that address their individual needs. Generally, mainstreaming requires universal design to ensure that a wide range of people, in this case particularly PWDs, can use it without it having to be adapted for a specific individual (DSD, 2016). Therefore, when applied to disability, this occurs on two inter-related levels. Firstly, it categorises disability as an inherent part of a programme or project, the implication being that PWDs should be included as beneficiaries or target groups. Secondly, mainstreaming ensures that budget allocations provide for reasonable accommodation measures required to ensure universal access to services (DSD, 2016). Accordingly, the figure below shows the four pillars for mainstreaming disability to ensure that PWDs can participate fully into society, these being rights, empowerment, equality and results.

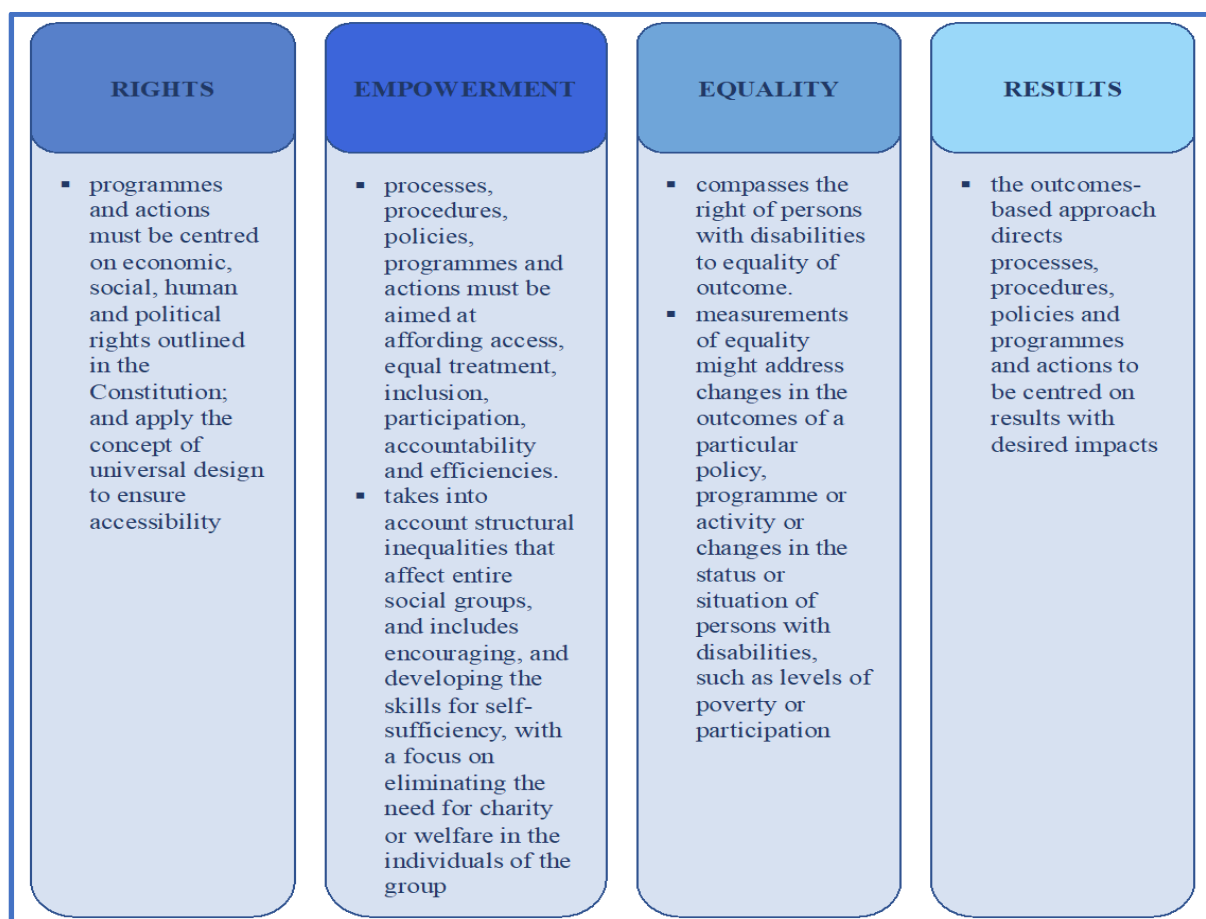


Figure 4.1: Four pillars that guide the mainstreaming of PWDs (DSD, 2016)



As mentioned before, South Africa has many policies in place to cater for the rights and equality of PWDs. For instance, a while a Hong Kong study by Pang et al. (2007) found that only 11% of the participants considered themselves reintegrated into their communities, a comparative study done in Johannesburg, South Africa found that a considerably greater amount of participants, in this case 28%, considered themselves fully integrated (Kusambiza-Kiingi, Maleka & Ntsiea, 2017). Removing the barriers to access and participation requires dimensions such as changing attitudes and behaviour, access to the built environment, transport, information and communication, universal design and access and reasonable accommodation measures (DSD, 2016), to be addressed.

Despite the strides made in the reintegration of PWDs in South Africa, implementation of these policies is still lacking. In a study done by Kusambiza-Kiingi et al. (2017), 58% of the stroke survivors had moderate to full integration and 21% had no community integration, which could be attributed to participants having low levels of functional ability at the time of discharge from the hospital. As already stated, the average stay of a survivor of stroke in Chris Hani Baragwanath, a government hospital in South Africa, is 12 days, which could mean that patients are discharged before they reach functional independence (Mamabolo et al., 2009). To ensure community reintegration, stroke survivors need to be discharged with a plan for continued intervention in their home or as a rehabilitation outpatient (Mayo et al., 2000). However, in South Africa there is a shortage of post-discharge rehabilitation services for patients who use government facilities. Only 20 of the 39 community health centres situated in various districts within the Western Cape offered rehabilitation services, whilst only half offered occupational therapy services (Rhoda et al., 2009).

#### **4.3.2.3    *Social work support to the (family) caregiver***

By supporting the (family) caregiver, the social worker could contribute to their social support, which, in turn, would have a positive impact on the caregivers' well-being (Broodryk, 2014). In chapter two, it was discussed that many PWDs rely on families for rehabilitation once discharged from hospital. By supporting both the PWD and the (family) caregiver, the social worker could thus positively contribute to the patient's recovery.

#### **4.3.3    Social work in the non-profit (organisational) sector**

Many PWDs worldwide would not receive education and be excluded from employment and other forms of social participation without the work of organisations such as faith-based

organisations (Watermeyer et al., 2019). Different organisations exist in supporting PWDs. Some of these organisations and their services will be discussed below.

#### 4.3.3.1 *Background of the non-profit (organisational) sector*

Since the time of Ancient Greece, governments had disability-related pensions for those returning from the wars (Stainton et al., 2010). Early poverty laws included provision for the ‘infirm’, and for the licensing of ‘beggars’ with a range of impairments. During late medieval times, charity houses were often home to so-called ‘idiots and cripples’. More recently, institutional provisions have been considered as a default welfare system for many PWDs (Stainton et al., 2010). After the disability inclusion movement, organisations such as special needs schools and local non-governmental organisations (NGOs) became important resource centres for households with a PWD, particularly where the disability was severe and difficult to manage. Today, these organisations provide additional training, peer groups of support and advice for households (Graham et al., 2014). To understand the non-profit sector, the figure below briefly illustrates the different organisations within a South African context for clarity.

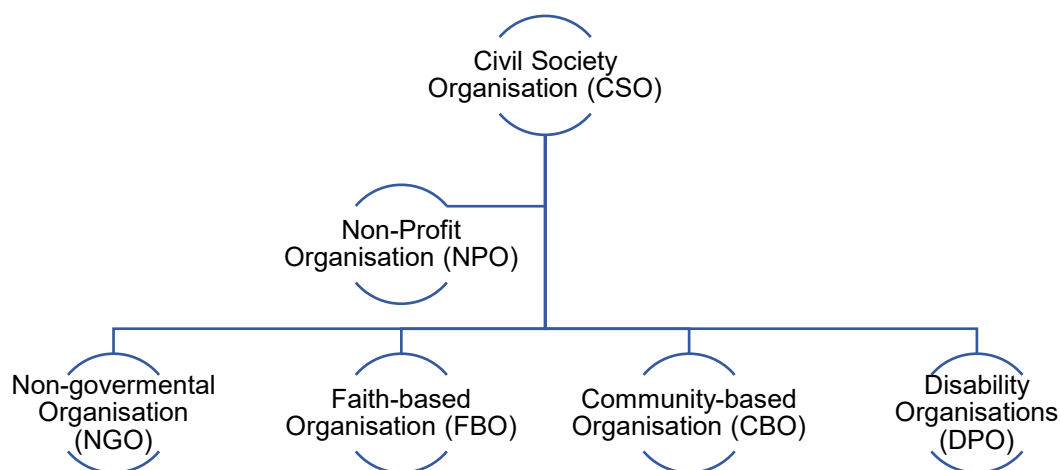


Figure 4.2: *Different types of organisations structure (Adapted from Ryklief, 2012)*

For PWDs in the Global South, and more specifically Southern Africa, there are substantial inequities in service provision and opportunities for participation. Their needs are often met by NGOs more than government services. In communities where resources are sparse, the only access that PWDs may have to services such as schooling and employment may be through

faith-based organisations or other types of NGOs (Swartz 2013; Mall & Swartz 2012a, 2012b). Without these organisations, many PWDs worldwide would receive no education at all and would be excluded from employment and other forms of social participation (Watermeyer et al., 2019).

#### ***4.3.3.2 Services delivered to persons with disabilities and their families within organisations***

South Africa has been commended for its inclusive approach to disability (Visagie, 2018). In the country, the NGO sector and social work is regulated predominantly by the Department of Social Development with the vision of “A self-reliant society” (DSD, 2015). The South African Disability Alliance (SADA) consists of representatives of national organisations that represent disability in the country. This organisation, previously known as the South African Federal Council on Disability, represents approximately 8% of the country’s population (ACPF, 2011).

The SADA national organisations include, but are not limited to, Autism South Africa; BlindSA; Cheshire Homes; Disabled Children’s Action Group (DICAG); Down Syndrome South Africa; Epilepsy South Africa; Muscular Dystrophy Foundation of South Africa; National Council for People with Physical Disabilities in South Africa; Occupational Therapy Association South Africa; QuadPara Association of South Africa; South Africa Association of Audiologists; South African Federation for Mental Health; South African National Council for the Blind; South Africa National Deaf Association; Stroke Survivor Foundation; and Uhambo Foundation (SADA, 2020).

In addition to the members of SADA, there are numerous local and provincial NGOs working in the disability sector (ACPF, 2011), categorised as either disability service organisations (organisations providing services within the disability sector) or PWDs’ organisations (DPOs) (Thomas, 2005). DPOs are considered as organisations consisting of PWDs or parents of children with disabilities who have the responsibility to provide capacity building through leadership, mentorship and training programmes in schools, higher education sector, protective workshops, residential and other facilities (DSD 2009). NGOs in the disability sector, however, are burdened by the lack of effective and efficient coordination amongst the sector (ACPF, 2011; Nkeli & Associates, 2008). This could be due to the limited platform ensuring that there is coordination and exchange of information and ideas between government and civil society organisations. This, in turn, has impacted on the effective implementation of disability

programme(s) by civil society and government that would improve the quality of life of people with disabilities (ACPF, 2011). PWDs have been using DPOs for supporting their rights to live independently, developing their skills, including them in education, representing them on different platforms, evaluating and monitoring services, collaborating with researchers to contribute to service development, promoting public awareness and understanding and finally, conducting audits of environments, transport and other systems and services to remove barriers (WHO & World Bank, 2011).

In a study done in Uganda, Kenya and Zambia, along with African developing countries in the Global South such as South Africa, several support services were identified that were used by PWDs. These support services included assistance from a DPO/NGO, government scheme, or individual benefactor, with some participants identifying that they received no support. This shows that, while most participants made use of the assistance of an organisation, a significant number of them did not have access to any form of assistance. Taking this into account, the figure below shows some of the services PWDs made use of within organisations.

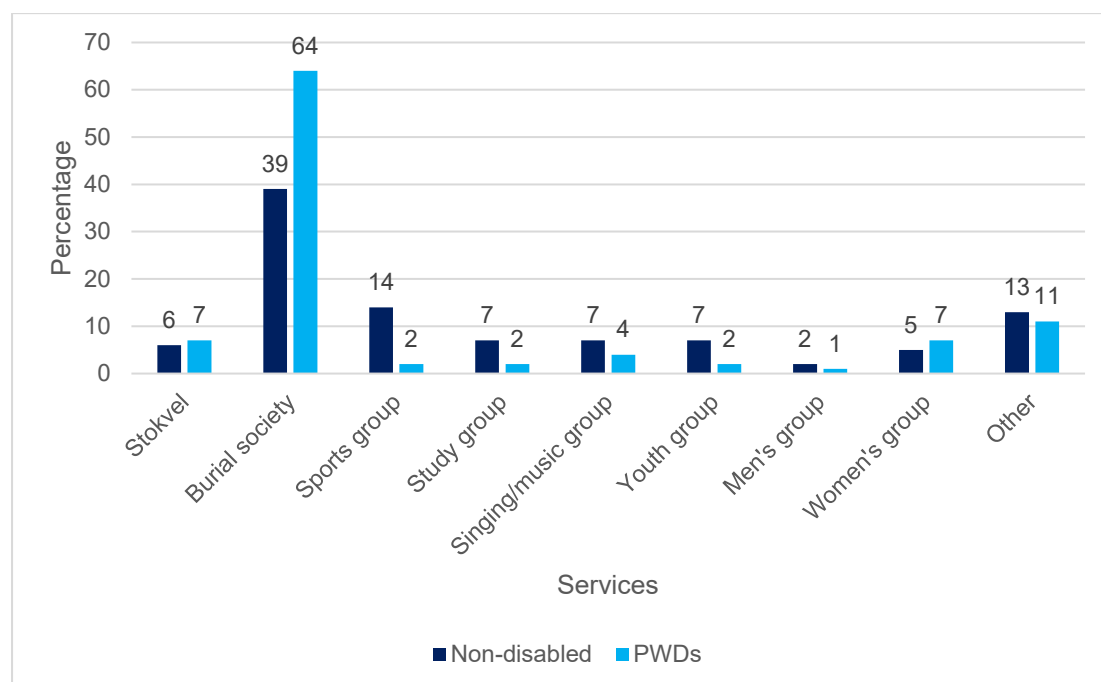


Figure 4.3: Participation in community organisations (Graham et al., 2014)

DPOs play an essential role in improving the implementation and monitoring of the WPRPD by supporting the empowerment of their members and communities through human rights education campaigns (DSD, 2016). NGOs working in the disability sector have expressed great concerns regarding accessing government funding. For this reason, governmental structures

such as the Department of Social Development have shown concern for NGOs' lack of administrative capacity, skills for financial management and writing of business plans (DSD, DWCPD and UNICEF, 2012).

#### **4.3.4 Social work support in terms of family preservation services**

Within social work interventions, family preservation is considered the primary model when providing child and family services where children are abused and neglected. The aim of this type of intervention is to prevent the statutory removal of children through improving the functioning of the family by strengthening family bonds and the use of resources (Al, Stams, Bek, Damen, Asscher & Van der Laan, 2012; Ryan & Shuerman, 2004; Tracy, 1995). Some of the family preservation services to PWDs and their families include care for the PWD, support to the family and resource development (Strydom, 2015). These family preservation services are usually rendered to families where there is the risk for child abuse and neglect and not to PWD. These support services could also be considered valuable to adults with an acquired physical disability and their families.

##### ***4.3.4.1 Care for person with disability***

As stated before, most PWDs rely on family caregivers. One of the methods suggested to ensure family preservation services is to empower family members through training programmes to better manage the care required. Another method could include expanding knowledge of disabilities to improve families' handling skills (Strydom, 2015) through educational services (Mullins et al., 2011; Martens, 2009). These are both aligned with the aims of family preservation (Tracy, 1995) i.e. the strengthening of families' coping skills to ensure effective caregiving. Although the primary focus of family preservation is on keeping the child within the family, alternative care could sometimes be in the best interest of the PWD (Strydom, 2015).

##### ***4.3.4.2 Support to family of person with disability***

Besides educating families more on gaining knowledge about the disability, families caring for PWDs could also be supported through counselling (Strydom, 2015; Mullins et al., 2011; Juby & Rycraft, 2004; Cash & Berry, 2003). This ensures the extension of the family's skills with regard to managing the PWD, as well as strengthening the family bonds as a component of family preservation (Tracy, 1995).

#### **4.3.4.3    *Resource development within community***

Families must be empowered during family preservation programmes to make use of resources in the community (Tracy, 1995). This could be done through means of developing possible alternative care methods for the family of the PWD, such as delivery of home-care or day-care facilities for PWDs (Strydom, 2015). Home-based care is also emphasised in South African policy documents (RSA, 1997; RSA, Western Cape Department of Social Development, n.d. in Strydom, 2015).

#### **4.3.5    *Social work support services to persons with acquired physical disabilities aligned with policies in South Africa***

As mentioned earlier in this chapter, social workers have a responsibility to advocate for social policies and practices that provide the same opportunities for PWDs as people without disabilities (Mackelprang, 2013). As discussed in Chapter Two, there are a number of policies and legislation that guide service delivery to PWDs. However, within a South African context, social work service delivery to PWDs is mainly be guided by the RSA Constitution and the WPRPD.

##### **4.3.5.1    *RSA Constitution***

Section 9 of the Constitution prohibits unfair discrimination on the basis of disability. It further allows for positive measures to be taken to promote the achievement of equality for categories of persons previously disadvantaged by unfair discrimination, in this case PWDs (RSA, 1996). This guides the social work role as advocate to ensure justice for PWDs, in accordance with the global definition of social work.

##### **4.3.5.2    *White Paper on the Rights of Persons with Disabilities***

In terms of an applicable policy framework for PWDs in South Africa, the Department of Social Development launched the WPRPD in 2016. With the implementation of the WPRPD, PWD should be afforded the opportunity to enjoy their full political, human, social and economic rights aligned with all other people in South Africa. They should also be able to participate fully and equally in mainstream social and economic life, and be given the right to live and work in safe and accessible environments free from discrimination, harassment and persecution (DSD, 2016).

Within Pillar 3 of the WPRPD, State Parties are required to recognise the right of PWDs to live in the community with equal choices. Firstly, this can be done through ensuring that they can choose their place of residence and where and with whom they live and are not required to live in a specific living arrangement. Secondly, State Parties can ensure that PWDs have access to a range of residential and other community support services, including personal assistance necessary to support living and inclusion in the community. Finally, equality can be attained by ensuring that community services and facilities for the general population are available on an equal basis to PWDs and are responsive to their needs. Appropriate measures must also be taken to eliminate discrimination against PWDs in family matters e.g. the right to make a choice to marry, as well as the right to decide freely and responsibly on the number and spacing of their children and to regulate their fertility on an equal basis with others. In this light, Pillar 3 of the WPRPD can be achieved through building supporting families and socially organised communities and neighbourhoods, human settlements/neighbourhoods and community-based services accessibility, and protection during situations of risk and disaster (DSD, 2016).

Similar to previous studies, the WPRPD reports that, under Pillar 4, the focus areas that aim to strengthen economic independence and a dignified life for PWDs through empowerment includes early childhood development, lifelong education and training, social integration support, access to lifestyle support, supported decision-making; and strengthening recourse mechanisms. On the other hand, the factors which contribute to dependency and disempowerment among PWDs include social isolation, unresponsive services and systems, poverty and abuse (DSD, 2016).

Further, Pillar 5 focuses on reducing economic vulnerability of PWDs through addressing disability, poverty, development and human rights; access to decent work and work opportunities; PWDs as owners of the economy; and reducing the cost of disability for PWDs and their families. The government, through the South African Social Security Agency (SASSA), provides different taxpayer-funded social security grants, including a disability and care dependency grant to assist with minimising economic vulnerability for PWDs and their families (Steenkamp, 2017).

Finally, Pillar 6 identifies five focus areas that require attention to strengthen the voice of PWDs i.e. strengthening access and participation through self-representation; recognition of DPOs (inclusive of parents organisations); strengthening the diversity and capacity of DPOs

and self-advocacy programmes; public participation and consultation; and self-representation in public life (DSD, 2016).

#### **4.3.6 Application of social work roles in service delivery to persons with disabilities**

As mentioned earlier, some of the intervention roles performed by the South African social worker include that of counsellor, broker, public relation manager, marketer, manager, expert, leader, enabler, facilitator, motivator, researcher, educator, negotiator, mediator, advocate, activist, agitator and professional person (Engelbrecht, 1999).

##### **4.3.6.1 *General roles for service delivery to adults with an acquired disability and their families***

It could be argued that some of the most pivotal social work roles include that of broker, enabler and educator. An educator, for instance, is expected to provide information, educate and provide preventive care, while a broker is supposed to mediate, defend and advocate on behalf of the client and be a case manager. Finally, an enabler has to consult and work as a clinical social worker. These roles could be used to analyse the experiences of PWDs based on the quality of service they receive from the social worker (e.g. in-patient rehabilitation, and rehabilitation in an ambulatory or a sanatorium etc.) (Sape, 2003; Sapezinskiene, 2000; Miley, O'Melia & Dubois, 1995).

In terms of services delivered to PWDs, especially adults with an acquired physical disability, other roles to take note of could include that of counsellor, public relations officer, manager, facilitator, motivator, researcher and advocate. As a counsellor, the social worker can guide the client towards modifying behaviour, empowerment and the acquisition of skills to cope with problem situations. The social worker could also act as a facilitator in expediting the process of social change by means of bringing people together through communication structures, stimulating activities, developing and channelling resources, and ensuring access to expertise. As a motivator, he/she could encourage participation by minimising isolation, building optimism, creatively utilising conflict and making people feel that their life is rewarding and productive. The social worker would act as public relations officer by establishing networks and by mobilising and strengthening the connections between clients and other systems. This will also mean that he/she would sometimes need to act as a manager to plan, organise, activate and control through decision making, co-ordination and communication, according to different policies. This, in turn, might require the social worker to act as an advocate for the rights of the



individual (in this case, PWD), groups and communities. Lastly, such as the case with this study, the social worker might act as a researcher to scientifically determine the extent of problems, needs and phenomena and to make recommendation, by analysing related factors (Engelbrecht, 1999).

#### ***4.3.6.2 Social work roles needed for service delivery to persons with disabilities and their families during COVID-19 pandemic***

The role of social workers around the world varies significantly. This is dependent on the specific country's balance of employment in governmental and nongovernmental organisations, whether social workers are recognised and regulated as professionals, the balance of casework, group work and community development work, as well as their cultural, religious, political and economic contexts (IFSW, 2018). Social work during Covid-19 reflects these differences. In the Global South, many social workers have undertaken community development work to support communities and offer education about hygiene and distribution of masks and sanitising products (IFSW, 2018). Nonetheless, Covid-19 and the measures introduced to control and prevent its spread have restricted the social work services and responsibilities, while simultaneously generating new needs and demands. This has created several practical and ethical challenges, as they had to make important decisions, often with no or minimal guidance, without being able to make face-to-face assessments (IFSW, 2018).

As mentioned earlier, one of the roles of social work is to act as advocate for their clients, including PWDs. This could be emphasised as more and more PWDs are being marginalised during the COVID-19 pandemic through inaccessible communication systems and sometimes even unethical DNR practices. In May 2020, the Minister of Social Development reported that additional social workers would be recruited to deliver psychosocial services within different communities in South Africa (Mahlati, 2020) to assist with mental well-being during the pandemic.

#### **4.4 CHALLENGES OBSERVED BY SOCIAL WORKERS IN DELIVERING SERVICES TO PERSONS WITH DISABILITIES AND THEIR FAMILIES**

In a study done by Strydom (2015) on the views of service providers (social workers) on services rendered to PWDs, some challenges were identified i.e. lack of financial resources, community facilities and struggles with family caregivers.

#### **4.4.1 Lack of financial resources**

In South Africa, NGOs have found it difficult to access international funding. After the first democratic elections in 1994, international funders directed financial support to the government, instead of the NGO sector (Swedish International Development Cooperation Agency (2003). In 2008, the global recession contributed to major cutbacks in funding, causing a remarkable strain on NGOs' service delivery to PWDs (ACPF, 2011). In 1993 in South Africa, the Disabled Children's Action Group was set up by parents of children with disabilities to provide low-cost, mutual support group to promote inclusion and equal opportunities in education. The organisation's services have been supported by financial support from international NGOs and national charities (Disabled children's action group, 2001).

NGOs have expressed concerns regarding access to government funding and the general lack of understanding regarding the nature of services required for children with disabilities. The DSD, on the other hand, is concerned about NGOs' lack of administrative capacity, skills for financial management and writing of business plans (DSD, DWCPD & UNICEF, 2012). Lack of financial resources could lead to ineffective service delivery and a shortage of personnel (professional and non-professional people) (Strydom, 2015). These findings – namely that insufficient funds hamper the initiation of programmes, and that the lack of personnel adversely affects service delivery – confirm the findings of other studies (Strydom, 2010; Weyers & Van den Berg, 2006; Brown & Neku, 2005) regarding challenges in delivering social work services in South Africa.

#### **4.4.2 Lack of community resources (including residential facilities)**

Lack of suitable public transport for PWDs have been identified as one aspect of lack of community resources (Strydom, 2015). This was discussed earlier as well under experiences of PWDs themselves (Chapter Two). Other community resources have also been identified as limited and/or over-utilised or too expensive for PWDs and their families (Strydom, 2015). Similarly, Muller-Kluits (2017) determined a lack of long-term care facilities for PWDs, raising the concern of continuous care opportunities for PWDs if the family is not capable to fulfil this role anymore.

#### **4.4.3 Struggles with families as caregivers**

Strydom (2015) identified certain struggles identified by social workers in terms of family caregivers of PWDs. These include inconsistent involvement, ignorance, and lastly, insufficient resources within the family of the PWD to fulfil caregiver role.

#### **4.5 CONCLUSION**

This Chapter provided the final component of the literature review. It concluded with the incorporation of the different chapters by discussing how the knowledge of disability (Chapter Two), disability models (Chapter Three), as well as the social work profession and social work practice models (Chapter Four) could be combined within disability service delivery. This application was discussed in terms of social work service delivery to persons with acquired physical disabilities.

## **CHAPTER FIVE**

### **RESEARCH METHODOLOGY**

#### **5.1 INTRODUCTION**

This Chapter will consider the research methodology used in this research study, from the planned research design and approach, sampling and ethical consideration, to the impact of the COVID-19 pandemic which required the study to be adjusted from its original nature. After 2020 started off with the news of a new coronavirus identified in Wuhan, China, South Africa introduced what became known as ‘lockdown regulations’ in March, Italy and USA followed with confirmed cases and preventative measures. The virus became known as COVID-19, and on 11 March 2020 it was announced as a worldwide pandemic. South Africa had its first confirmed case of the virus on 5 March 2020, and the number of cases quickly grew, with South Africa implementing its nationwide lockdown from 26 March 2020. These regulations were gradually relieved in stages from May 2020, but had already impacted all sectors, including the social work and higher education sectors. No face-to-face contact was allowed in public, and home visits were also prohibited. This impacted the research strategy of this study, as it had to be redesigned to comply with both lockdown regulations and research ethical considerations. The process of doing this will be thus be discussed and reflected upon in this Chapter.

#### **5.2 RESEARCH DESIGN AND APPROACH**

The research question for this study was identified after a reviewing of previous research done on similar topics. Once it was identified, the research study used a combination of descriptive and exploratory research to answer the question. The research study made use of a qualitative approach, which is seen as a valuable social work approach using both deductive and inductive reasoning. The COVID-19 pandemic also had an influence on the research design and approach, which will also be discussed in the relevant section.

##### **5.2.1 Research question**

This study came from the research question: What are the experiences of adults with acquired physical disabilities with regards to social work support (especially in assisting them after they

acquired the physical disability)? As mentioned Chapter One for the purposes of this study social work support also included aspects such as assisting PWDs with accessing resources, dealing with loss, identifying community resources, creating awareness regarding disability, etc.

This research question was identified after a consideration of previous research being done on similar topics. During this review, it was found that many previous studies have focused on the perspectives of the service provider (social worker) rather than the service user (PWD), while even fewer studies narrowed it down to physical disabilities and, more specifically, the experiences of adults with acquired physical disabilities on social work support in South Africa. Within the Nexus system (2018) no studies were found that had a specific focus on how adults with acquired physical disabilities experienced social work support, specifically in terms of assisting them with integrating and becoming full citizens in society.

### **5.2.2 Research design**

This research study used a combination of descriptive and exploratory research to answer the research question (Grove & Gray, 2019).

#### **5.2.2.1 *Descriptive design***

In the literature review chapters (Chapter Two to Four), descriptive research was used to provide a more comprehensive analysis and understanding for the research topic (Rubin & Babbie, 2005) aligned with the research objectives. The focus of the different chapter was established as follows:

Chapter Two aimed to provide an overview of the scope and nature of disability, as well as exploring relevant international and South African policies and legislations which focus on services to PWDs. Building on this, Chapter Three discussed different perspectives and models of disability. Finally, Chapter Four provided a theoretical discussion of the social work profession and how social work support to persons with acquired physical disabilities, especially adults, has been perceived from previous, similar studies.

#### **5.2.2.2 *Exploratory design***

Explorative research will provide insight into the topic (De Vos et al., 2011; Maree, 2016) during the empirical study. The research study was explorative due to the lack of current

research on the specific variables included in this topic. The different experiences shared among participants provided understanding for the experiences of adults with an acquired physical disability through unique narratives. Participants from both Cohorts provided their experiences on some of the challenges in service delivery to adults with an acquired physical disability and provided recommendations on the matter.

### **5.2.3 Research approach**

The research study made use of a qualitative approach with some quantitative elements in terms of the identifying particulars of participants. Qualitative research is seen as a valuable social work approach. One of its strengths, foregrounded in the empirical study (Chapter Six), is the extent to which it represents participants' perspectives on the research topic (Grove & Gray, 2019). In short, qualitative research allows the social work profession to learn from those they serve (Council on Social Work Education, 2012). Both the former aspect and the latter were true for this study, as the qualitative research was done with a vulnerable service user group (adults with an acquired physical disability) regarding their experiences of social work services. Within this research approach both deductive and inductive reasoning were used, as will be unpacked below.

#### **5.2.3.1 *Deductive reasoning***

Deductive reasoning was employed by using general findings from previous studies within the literature review and relating it to specific expectations of the study (Maree, 2016; De Vos et al., 2011). Due to the lack of comprehensive previous research on the experiences of adults with an acquired physical disability, research findings of similar research studies were used as a precedent for this study. One such example included studies on persons with physical disabilities (not specifically acquired). Another example was studies with family caregivers of persons with physical disabilities. These similar studies could be used as precedent for this study because in both family caregivers and persons with acquired disabilities, an adjustment had to be made to adapt to a lifestyle with a disability. This opens a potential discussion of shared experiences.

#### **5.2.3.2 *Inductive reasoning***

Where there were any empirical findings not mentioned within the literature review, inductive reasoning was used to relate specific findings to general reasoning (Maree, 2016; De Vos et

al., 2011). This was done when unanticipated findings were occurred during the empirical study, and reference was made to previous research studies on similar findings.

#### **5.2.4 Change in research strategy: Change from face-to-face interviews to using technology**

Initially, the researcher planned to conduct face-to-face interviews with participants identified by the organisation. Interviews were to be conducted in a communal venue that suited the participants to minimise the cost for them. For instance, they could opt to meet at their homes or the organisation's office. While these interviews were to be done face-to-face, they were also to be audio-recorded with a voice recorder. In this case, consent forms would have been given to participants as a hard copy, and they would be given the opportunity to read through and sign the forms. Although the research was not intended to focus on a pandemic outcome, circumstance rendered it an inherent part of this research study, as the planned research strategies had to be revisited once the COVID-19 pandemic lockdown regulations were implemented. The ethical clearance process is further discussed under 5.4.1.

##### **5.2.4.1 Reason for change in strategy – COVID-19 pandemic implications**

The outbreak of the COVID-19 pandemic came as an unprecedented shock to most of the world. Its spread was quick, and one by one countries started to implement preventative regulations to attempt to minimise the impact of the virus. However, in reality, countries were not prepared for the implications of the pandemic. Hospitals worldwide started to fill up, as increasingly more people became infected with this respiratory virus with no known cure. Vulnerable groups were identified as those with susceptible immune systems, such as elderly people, persons with chronic diseases and PWDs. Almost overnight, the world became unknown to most people, as global lockdown regulations started to restrict what was once known as 'everyday activities'.

##### **5.2.4.2 Global Lockdown restrictions**

To minimise the amount of newly confirmed cases of COVID-19, various countries started implementing lockdown regulations, restricting any public gatherings and closing most economic sectors, as well as schools. Most countries also required people to wear masks when going out in public and instructed them to maintain a distance of at least one metre distance from other people. Certain countries even restricted the operating hours of what was known as

‘essential services,’ such as grocery shops. Around the world, Wuhan remained under “lockdown regulations” for 76 days (Kaplan, 2020), whilst other countries that implemented the world’s largest and most restrictive mass quarantines included South Africa, India, (the rest of) China, France, Italy, New Zealand Poland, and the UK (Kaplan, 2020). The figure below indicates the regulations that South Africa followed for 35 days during Level 5 lockdown (South African Broadcasting Commission (SABC) News, 2020).



**Risk-adjusted strategy for economic activity**  
Alert system: Level 5

	Sectors permitted	Transport restrictions	Movement restrictions
<b>Level 5: High virus spread, and/or low health system readiness</b>	Only essential services	Bus services, taxi services, e-hailing and private motor vehicles may operate at restricted times, with limitations on vehicle capacity and stringent hygiene requirements	No inter-provincial movement of people, except for transportation of goods and exceptional circumstances (e.g. funerals)

*Figure 5.1: South Africa Lockdown regulations (Level 5 – strictest regulations) (Cape Town Travel, 2020)*

Under this regulation in Gazette No. 11062 (25 March 2020) section 11B, for the period of lockdown, no person was allowed to leave their place of residence, unless for the purpose of performing essential services, obtaining essential goods, collecting a social grant, seeking emergency, life-saving or chronic medical attention. All businesses and other entities had to cease operations during lockdown unless providing essential goods or services. Some essential services also faced further restrictions in terms of permits, operating hours and safety regulations. No social work home visits or meetings for higher education (including face-to-face research) were allowed under these regulations.

Despite some relief for during the lockdown regulations in South Africa, at the time of the study, these regulations had already lasted for more than 120 days. This had a tremendous impact on many sectors, leading to socio-economic crises also affecting PWDs, such as poverty from not being able to work.



### 5.2.4.3 *Persons with disabilities as a vulnerable group during the pandemic*

According to the WHO, people who are older than 60 years or who have health conditions like lung or heart disease, diabetes or conditions that affect their immune system are vulnerable groups for the COVID-19 virus (Koh & Hoenig, 2020). Although having a disability alone is unlikely to put someone at higher risk of contracting COVID-19, many PWDs do have specific underlying conditions that make the disease more dangerous for them (WHO, 2020). Due to this potential risk, as well as the lockdown regulations put in place under governmental guidelines, it was decided to rather restructure the research study to be done remotely through the use of technology such as cell phone calls, or VOIP such as WhatsApp and Zoom.

### 5.2.4.4 *Comparison between different research methods used*

There were advantages and disadvantages in employing cell phone calls, WhatsApp and Zoom for conducting interviews remotely. A disadvantage was that, for some participants, none of these three options were accessible. Accordingly, one participant from Cohort Two chose to only use e-mail, while another from this cohort chose to conduct interviews using both e-mail and Zoom. Since it was only one participant from Cohort Two (service provider) that used only e-mail, the analysis looked at the advantages and disadvantages of the three methods used by both Cohort One and Two. As mentioned earlier, participants had a choice between methods where cell phone calls were used for calls mostly and only one participant had a WhatsApp call. Other participants who chose WhatsApp preferred to use the voice note or “live chat” (i.e. responding to questions continuously over a period of a few hours) option as they found it difficult to communicate through calls. The table below indicates an analysis of each method.

**Table 5.1: Analysis of different interview methods used in this study**

METHOD	ADVANTAGES	DISADVANTAGES
WHATSAPP	<ul style="list-style-type: none"> <li>• Allows for a much clearer recording of the interview.</li> <li>• Allows for the participant to add to their answers and for the researcher to wait until they are done (can't interrupt by mistake).</li> <li>• Can happen when the client is available and in an environment where they feel comfortable.</li> <li>• Allows for both parties to have an immediate copy of the interview.</li> </ul>	<ul style="list-style-type: none"> <li>• No face-to-face contact.</li> <li>• Cannot assess non-verbal responses e.g. body language or facial expressions.</li> <li>• Takes longer (in that the researcher must wait for recording and after, listen to and respond to the recording).</li> <li>• Use of cell phone data and battery life of participant.</li> </ul>

METHOD	ADVANTAGES	DISADVANTAGES
	<ul style="list-style-type: none"> <li>• Allows for both parties to relisten to voice notes to ensure better understanding.</li> <li>• Minimal costs for both parties.</li> <li>• Allows participants who find it difficult to communicate verbally to type answers.</li> <li>• Allows for consent forms to be sent as well, and for participant to keep a copy.</li> </ul>	
CELL PHONE CALLS	<ul style="list-style-type: none"> <li>• Does not take as long as WhatsApp, as the discussion is in real-time.</li> <li>• Can happen when the client is available and in an environment, where they feel comfortable.</li> <li>• Has no cost to participant, only the research study.</li> </ul>	<ul style="list-style-type: none"> <li>• Can be costly for the research project.</li> <li>• Not all participants had sufficient cell phone signal.</li> <li>• Recordings of interviews were not always clear.</li> <li>• Cannot assess non-verbal responses e.g. body language or facial expressions.</li> <li>• Use of cell phone data and battery life of participant.</li> </ul>
ZOOM	<ul style="list-style-type: none"> <li>• Allows for face-to-face interaction through video chat.</li> <li>• Both video and audio can be recorded.</li> <li>• Does not take as long as WhatsApp, as the discussion is in real-time.</li> <li>• Can happen when the participant is available and in an environment where they feel comfortable.</li> </ul>	<ul style="list-style-type: none"> <li>• Requires sufficient internet connection, which is not always affordable and accessible.</li> <li>• Since it is online, it poses a risk for hacking of content, as is the case with all online mediums.</li> </ul>

Most participants preferred to make use of WhatsApp as a medium for the interview, which coincides with the analysis above, as WhatsApp seemed to have the most advantages compared to the disadvantages.

### 5.3 RESEARCH PROCESS

The research process will be described in terms of selecting a research topic, the literature review, as well as developing research instruments, sampling and data collection. The planned procedure will be mentioned, but changes due to the COVID-19 pandemic will also be discussed.

### 5.3.1 Selecting a researchable topic

The first step in the research process is the selection of a topic (Whittaker, 2009). A topic serves as a form of foundation which suggests the idea of the study, both to the researcher personally and others who may read the study (Cresswell, 2014). This topic may develop through observation of concerns in practice and the reviewing of literature which is of interest to the researcher (De Vos et al., 2011). It may also originate from reasons which may be personal, academic and social in nature (Blaikie, 2008). Related to this, the research problem can be described as the need for a topic to be studied (Fouché & De Vos, 2005). There are four key rules of importance in deciding on a topic, namely that the topic should be: relevant to the researcher's own career, intellectually stimulating, researchable, interesting and worthwhile (Mouton, 2011).

Taking these factors into account, this research topic originated from the researcher's previous study done on family caregivers of persons with physical disabilities, which recommended the need for similar studies that were both descriptive and explorative. She concluded that further studies should focus on different variables, such as different research areas, different age groups of PWDs, different disabilities as well as different socio-economic conditions of participants. Further, she argued that once there are enough studies considering the different variables, commonalities between these studies could be assessed (Muller-Kluits, 2017). In terms of Mouton's (2011) guidelines for selecting a research topic, this study met all three of the specified criteria:

- **Relevance to career:** As a registered social worker with both personal and professional experience in the field of disability, the researcher was interested in exploring how social work support is perceived by adults who acquire a physical disability later in life.
- **Intellectually stimulating:** This topic developed further as the social worker attended some workshops on related topics which had minimal social work perspectives at the time they were presented.
- **Researchable, interesting and worthwhile:** In the process of developing perspectives based on the previous two criteria, the topic became both a professional and personal interest worthwhile exploring.

### **5.3.2 Literature review**

A literature review serves to gain an understanding of the concerned issue, identifying similarities and differences between previous and current issues and identifying gaps or weaknesses in previous studies (Creswell, 2014; De Vos et al., 2011). The literature review in this research study took place over three chapters aligned with the first three objectives of the study. During the literature review, similar studies were explored and discussed. However, there were no studies available with the exact researchable variables explored in this study. The literature review thus served to establish relevant background in terms of related studies while also indicating how this study adds to research on disability.

### **5.3.3 Developing the research instrument**

Once the literature review was done, it guided the themes for the interview schedules. The decision was made to use semi-structured interviews, with a planned number of 25 participants over two Cohorts. Instead, the study had 24 participants, of which one from each cohort provided two means of their experiences used for the empirical study instead of one. One participant from Cohort One also shared a story he had written on acquiring a disability, which was offered to be used for the study. Another participant from Cohort Two did both a questionnaire interview (through e-mail) and an interview by means of Zoom. This essentially provided 26 sources with 24 participants.

A focus group was considered for the study, but due to the pandemic, which would have faced its own challenges because of lockdown regulations, the decision was made to include a broader range of participants. The interviews consisted of open-ended questions which provided participants the opportunity to elaborate on their answers. The interview schedules were available in both Afrikaans and English for the participant to decide in which language they prefer to conduct the interview. The table below shows the distribution of languages used to conduct interviews:

**Table 5.2: Languages in which interviews were conducted (n =19)**

	AFRIKAANS	ENGLISH	TOTAL
Cohort One	8	11	19
Cohort Two	1	4	5
	<b>9</b>	<b>15</b>	<b>24</b>

### 5.3.4 Population and sampling

The planned method of sampling was purposive sampling, but due to the COVID-19 implications, the gatekeeper organisation was not able to conduct home visits or work from their offices, where they had access to their client files to identify all potential participants. The researcher therefore had to make use of snowball sampling as well in order to access potential participants for the study. Most participants (fifteen of twenty-four participants) came from purposive sampling. Snowball sampling only occurred within Cohort One, where participants themselves referred more potential participants. This occurred simultaneously with the purposive sampling done with participants from the organisation. The organisation would first suggest a few potential participants at a time and then suggested the researcher also make use of snowball sampling. However, when there was no available participants anymore, the researcher would make contact with the organisation again, and the process will be repeated with purposive sampling and then snowball sampling where possible. Therefore, the researcher was in contact with the organisation throughout the process but the snowball sampling did allow for the research process to continue during lockdown restrictions where the organisation had limited access to their client systems. An information pamphlet was used to provide potential participants with more information regarding the research study (See Adeendum J to K). Research saturation occurred after four participants from Cohort Two and eighteen participants from Cohort One. The researcher did one additional interview for both cohorts to ensure a target as close as possible to the initial plan of twenty participants from Cohort One and five from Cohort Two was reached.

#### 5.2.4.1 Target population

The research project took place with two Cohorts. The first Cohort included nineteen adults with acquired physical disabilities and the second five social workers who had experience with working with PWDs. The researcher initially planned to contact participants through contact

details received from the participating organisation's different branches with prior consent from the participants. Later, also with the necessary consent from all parties involved, she added participants as suggested by the PWDs interviewed since the organisation did not have access to enough participants. In identifying the target population, as mentioned in Chapter One, it is important to understand the universe, population and sample. The universe includes all possible subjects that have the characteristics that the researcher is interested in for the study. The population, on the other hand, refers to the total set from which the individuals for the study are chosen, whilst the sample refers to the subjects chosen to participate fully in the study (De Vos et al., 2011). To aid confidentiality (see 5.4.2.4), coding was used to refer to participants during the empirical study in Chapter Six. To this end, a capital "C" indicated which Cohort group they were part of, whilst a capital "P" referred to the number of the participant within that cohort group, for instance C2P02 referring to Participant 2 from Cohort Two (social workers). The criteria for inclusion are as follows within the two Cohorts of the empirical study:

#### *A. Cohort One*

The universe for Cohort One included all adults with physical disabilities, whilst the population included all adults with acquired physical disabilities in South Africa. Finally, the sample included all adults with acquired physical disabilities that have received South African social work services. The motive for interviewing adults who have an acquired physical disability/s was to be able to gain a better understanding of the experiences service users had of social work support services received to assist in community integration as an adult with physical disability/s with/without the ability to live on their own. The specific focus also aimed to obtain a better understanding of how social work support services have assisted the relevant PWDs with adjusting to community life and their life with a disability compared to their life prior to acquiring a physical disability. The purpose of the study being open to a variety of physical disabilities and not a homogenous group of PWDs (i.e. all with the same disability) was to explore the shared experiences of PWDs from different backgrounds and impairment histories and strengthen the transferability of the study. This decision was informed by a study done by Muller-Kluits (2017), which found that family caregivers of persons with physical disabilities shared similar concerns and needs despite their family members having different types of physical disabilities and being of different age groups.

Taking these factors into account, the criteria for inclusion for Cohort One required the participant to:

- be an adult (over 18 years old) with an acquired physical disability which they acquired after the age of eleven years old;
- have had some exposure to social support services within the past five years in terms of their disability (e.g. rehabilitation or aftercare);
- be able to communicate in English or Afrikaans;
- decide to participate in the research study out of free will.

The criteria for exclusion was for persons who acquired a physical disability due to aging e.g. elderly people who have experienced gradual vision-, hearing- or other impairments. The reason for this is that acquiring a disability due to aging is often a more gradual process as is the impact of the adjustments that have to be made, whereas the purpose of this study was to examine more immediate impact.

#### *B. Cohort Two*

The universe for Cohort Two consisted of all social workers, whilst the population included all social workers that are registered and practicing in South Africa and the sample all registered social workers in South Africa who have delivered support services (e.g. rehabilitation or aftercare) to PWDs. This sample group was chosen due to social workers' unique psychosocial perspective, as well as their perspective on how they assist persons with acquired physical disabilities. This could be compared to data collected during Cohort One, after which this Cohort can also provide recommendations on how to improve social work support services and how to better align it to South African policies and legislation on support services to PWDs, such as the WPRPD.

In this light, the criteria for inclusion for Cohort Two were that the participant must:

- be registered with the South African Council for Social Service Professions (SACSSP).
- have experience providing social work support to PWD in a South African context within the last five years, including the relevant policies and legislation focused on service delivery to PWDs.

- be able to understand and communicate in English or Afrikaans.
- decide to participate in the research study out of free will.

#### **5.3.4.2 Sampling procedures**

The planned method of sampling was both purposive sampling, where a clear definition of the population and intended sample is very important (Creswell & Poth, 2018; Maree, 2016) and snowball sampling in cases where there was limited access to appropriate participants (Maree, 2016). As mentioned before, due to the regulations during the COVID-19 pandemic, the researcher had to also rely on snowball sampling. This was also accepted by REC (See Addendum A) in an adjusted proposal submitted after the implementation of lockdown regulations. There was a remarkable response to this request, as participants volunteered to find more participants after they were interviewed themselves. This could be a potential indication of the importance of ‘giving voice’ to service users.

#### **5.2.4.3 Research area**

The research was planned to take place within South Africa’s geographical boundaries, divided into nine different provinces including the Western Cape (primarily though not exclusively focused on in this study), each of which are run by unique governmental structures and sets of policies in line with national legislature. Afrikaans, English and isiXhosa are considered to be among the main languages in the Western Cape, although the researcher only included interviews conducted in the former two languages due to an inability to speak isiXhosa. Nonetheless, the overarching reason for this research area is to contribute to indigenous knowledge on disability, which considers the unique South African context and its correlating policies.

One evident advantage of remote interviews due to the COVID-19 pandemic was the ability to be able to interview any participant from any area with minimal costs involved. In the case of face-to-face interviews, interprovincial interviews would have been costly in terms of travelling. The remote interviews thus allowed for participants to range over different areas within the Western Cape, but also to include participants from Gauteng and KwaZulu-Natal, allowing the research study to be more transferable.



### 5.3.5 Data collection

The data collection and processing procedure for this study comprised of qualitative data collection and interpretation, and followed methodological congruence (Creswell & Poth, 2018). As a registered social worker with SACSSP, the researcher is trained in conducting interviews and has done so before. As specified and explained above, interviews were conducted in English or Afrikaans. Participants that had difficulty communicating verbally would have been given the opportunity to complete their interviews as a questionnaire. The researcher also has basic sign language skills that could have been utilised during the interview process should the need have occurred.

#### 5.3.5.1 *Planned method of data collection*

Qualitative interviews are generally minimally structured, audio-recorded and transcribed. The data collection for this qualitative study was planned to be done through means of a semi-structured interview schedule done with 25 participants in two Cohorts. Additionally, it was to be used to grant lengthy, valuable explanations from participants to gain knowledge of the research topic (Creswell & Poth, 2018; Maree, 2016; Wasserman et al., 2013). As mentioned earlier, semi-structured interviews were still used, but with 24 participants, some providing more than one contribution. This study's interview schedule was conducted in English and Afrikaans (see Addendum F to I), and consisted of open-ended questions (Maree, 2016) to allow adaptability to the research topic (Given & Munhall, 2008) and give participants the opportunity to answer honestly (Maree, 2016). The combination of the literature review and empirical study formed the basis of the data used for this study (Maree, 2016; Creswell, 2014; De Vos et al., 2011) according to its descriptive and explorative design.

Initially, the researcher planned to make use of a voice recorder in this study to audiotape the interviews after consent from participants was first obtained (Maree, 2016). However, owing to the nature of the redesign of the study to adhere to lockdown regulations, a variety of other methods were used. In the case of telephonic interviews, a voice recorder was still used to record the interviews, whilst with Zoom conversation was recorded with consent of participants, automatically providing a recording. In the case of interviews through WhatsApp, the researcher sent a WhatsApp voice note and participants responded by either also sending a voice note or typing their answers. Some participants indicated that they found it easier to type their answers than doing a voice note. However, both of these methods provided an immediate

recording of the interview for both the participant and the researcher. Once the medium of conducting the interview was selected and the process duly recorded, interviews were transcribed (Wasserman et al., 2013) through means of denaturalised transcriptions, which resulted in ‘clean’ data (see definition in Chapter One). This method of transcription is free of socio-cultural characteristics and information, and may even improve the study results (also explained in 5.3.5.4.G).

### **5.3.5.2 Data collection method due to COVID-19 pandemic**

The voice recorder was only used in the case of cell phone interviews, as both WhatsApp and Zoom have a method of recording the interview while it is being conducted. The process of data collection was affected slightly by a professional participant from Cohort Two, who preferred to fill in a questionnaire with the questions by means of e-mail, and another from the same Cohort who used both e-mail and Zoom as preferred methods for the interviews. Another participant from Cohort One shared a story he had written to explain more detail about his experience of acquiring a physical disability. Ultimately, this provided 26 sources for the empirical study with 24 participants. In the case of WhatsApp, it was possible for both the participant and the researcher to have a copy of the interview. All recordings were removed from the original devices and stored on a password-protected online system (also referred to as a cloud system). The table below indicates the number of participants that used each interview method:

**Table 5.3: Interview methods used (n = 24)**

	WHATSAPP	CELL PHONE CALL	ZOOM	E-MAIL/ WRITTEN	TOTAL (INTERVIEWS)
<b>COHORT ONE</b>	11	6	2	1 (combined with Zoom)	<b>20</b>
<b>COHORT TWO</b>	1	2	1	2 (one combined with Zoom)	<b>6</b>
<b>TOTAL (METHODS)</b>	<b>12</b>	<b>8</b>	<b>3</b>	<b>3</b>	<b>26</b>

### **5.3.5.3 Qualitative data analysis and interpretation**

Qualitative data analysis is a non-numerical analysis and interpretation of observations to discover underlying meanings and patterns of relationships (Babbie, 2007) to attribute to a social or human problem (Creswell, 2014). After conducting the interviews, the main

discussion points (themes), as well as the differences and similarities between the different participants' answers, were identified, discussed, and analysed further according to the research approach and design. This was done in Chapter Six, which discusses the empirical findings of the study.

#### **5.3.5.4 Data verification**

Maree (2016) and De Vos et al. (2011) agree that credibility and authenticity, transferability, dependability and conformability must be considered when establishing the candour of a qualitative research study. These elements, and some other elements of data verification will be discussed below.

##### *A. Reflexivity*

Reflexivity includes self-reflection that allows for an understanding of how personal background, culture, and experiences (Creswell, 2014) influence and construct the world, including research processes and outcomes (O'Leary, 2007). The research topic focused on the experiences of service users (PWDs) relating to social work support. As a social worker and a PWD, the researcher had to remain objective and not guide participants to answer in a certain manner. As a person born with a physical disability, the researcher decided to focus the research study on persons who acquired a physical disability later in their life. This distinguishing variable of Cohort One made it more feasible to stay objective during the research study, as participants had to make adjustments in their life whereas the researcher, as a person with a congenital disability, did not face the same challenge. A reflective report was done in Addendum Q.

##### *B. Credibility*

Member checking of at least one participant per Cohort (Maree, 2016) was used to ensure credibility and authenticity by confirming whether the themes have been accurately identified and described and whether the participants' views and the researcher's representation of their insights are accurate (De Vos et al., 2011).

##### *C. Transferability*

The study used two heterogeneous sample groups with different identifying particulars. This serves to provide different perspectives on the research topic, which in turn provides the

opportunity to correlate different groups with one another and/or literature review findings from previous studies to substantiate the transferability from one situation to another (Maree, 2016; De Vos et al., 2011). As mentioned before, the interviews had to be redesigned to be done remotely to adhere to global and national lockdown regulations during the COVID-19 pandemic. This provided a unique opportunity to expand the research across different provinces with no travel costs. The research study thus included different areas within the Western Cape as well as Gauteng.

#### *D. Dependability*

Dependability refers to the research process being logical, well-documented and audited (Maree, 2016; De Vos et al., 2011), which was explained to the participants in the Consent to Participate forms (See Addendum B to E). All participants were given a consent form prior to conducting interviews with them. As an extended measure, all interviews were started with the following narrative (also translated into Afrikaans where necessary):

“Thank you for agreeing to be part of this research study on the Experiences of adults with acquired physical disabilities on social work support in a South African context. Could I just confirm that you have received the consent form in a language you understand and that you agree to the conditions of this research?”

Before we start, just some general points of importance:

- Please try to refrain from using any names during the interview. Should a name be used by mistake, the researcher will delete it afterwards in the transcription.
- Since the research is voluntary, you may decide to not participate in the research at any point and time without consequences.
- You may also answer questions as much or little as you feel comfortable and may choose to skip questions that you do not feel comfortable with.
- All interviews are recorded and will be transcribed. No personal details will be used in the research document and information such as age, gender and disability type will purely be used to confirm that the inclusion criteria were met and to get an overview of the participants that took part in the study.

- All recorded data will immediately be saved on a password-secure online system so to protect the privacy of all participants.
- Should you require debriefing after the interview, a referral will be made to the relevant social worker who will then be in contact with you.
- Please note that I will only be in contact with you for research purposes and for any other needs, you will be referred to a relevant social worker.

“Do you have any questions before we start?”

After this clarification was sent to participants, the researcher granted time for responses and questions before conducting the interview.

#### *E. Conformability*

Conformability (De Vos et al., 2011; Maree, 2016) in this study, was ensured by an independent coder to confirm the themes identified for this research study as being objective (See Addendum M).

#### *F. Denaturalisation*

This study made use of denaturalistic approach to transcription (Oliver, Serovich & Mason, 2005), which removed unique elements of speech such as pauses and non-verbal factors whilst being cautious not to influence the understanding of what participants shared and the conclusions that are drawn from that.

## **5.4 RESEARCH ETHICS**

For this research study to be performed, some ethical considerations were considered i.e. ethical clearance and ethical issues.

### **5.4.1 Ethical clearance**

The ethical clearance for this study was guided by DESC and REC ethical procedures. However, the researcher had to resubmit the initial proposal once the lockdown regulations were implemented in South Africa on 26 March 2020 (See Addendum A).

#### **5.4.1.1 *Ethical clearance procedure***

Firstly, the research study had to be reviewed by the Departmental Ethics Screening Committee (DESC). This committee then requested an admission committee to whom the researcher had to motivate the relevance of the study for approval, after which, the researcher had to go to the Research Ethics Committee (REC) before commencing with the empirical study.

Qualitative researchers often need to access intimate details of participants' lives, which might leave them feeling exposed (Drisko, 2013). Taking this into account, the study was categorised as a medium-risk study under the REC submission, which meant that the researcher had to be aware of participants' possible feelings and approach the interviews with the notion of not doing them any harm. Interviews were also structured in such a way to begin and end the interviews with the least personal and emotionally sensitive questions in order to increase the comfort of the participant. Further, an empathetic and non-invasive approach was followed during the interviews. All the participants of this study were given the option to be referred for debriefing.

#### **5.4.1.2 *Resubmission of proposal due to change of research strategy***

As mentioned before, once the COVID-19 pandemic reached South Africa, with lockdown regulations being implemented just as the research study's empirical interviews were about to start, the data collection methods had to be redesigned. This also meant that the research proposal had to be resubmitted to the REC to allow approval for remote interviews using technology instead of the planned face-to-face interviews.

### **5.4.2 *Ethical considerations***

This research study had to make use of several ethical consideration in terms of technology as well as voluntary participation and informed consent, prevention of harm, confidentiality, compensation, debriefing of participants and publication of findings.

#### **5.4.2.1 *Ethical considerations for research through technology***

As mentioned earlier, this research study mainly made use of three interview methods i.e. cell phone calls, WhatsApp and Zoom. Participants could choose the method they considered most comfortable and convenient.

Traditionally, qualitative interviews have been conducted on a face-to-face basis (Qu & Dumay, 2011; Novick, 2008). This ‘natural encounter’ is often required for the interviewer to build and maintain rapport with participants (Gillham, 2005; Shuy, 2003; Hermanowicz, 2002). During face-to-face interviews, participants’ body language can also add to researchers’ understanding (Gillham, 2005; Bryman, 2001). It is argued that the qualitative telephonic interviews should not be used for all participant groups, and accordingly, researchers need to carefully consider their target research participants when selecting their interview mode (Farooq & De Villiers, 2017). While this research study initially planned to make use of face-to-face interviews, these had to be adjusted to alternative methods such as telephonic interviews due to lockdown restrictions. Most initial contact to discuss the interview process was done through WhatsApp, where the researcher had a profile picture as a photo of herself to compensate to some degree for the lack of personal contact of the interview. There were also three interviews done through video calling.

Video-calling (e.g. Skype/Zoom), or the use of text-based instant messaging (such as WhatsApp) to virtually replicate the face-to-face interview or focus group data generation, is considered some of the most common virtual interviewing methods. Apart from some disadvantages as mentioned before, such as participants not being able to use the technology or having a poor WIFI connection, video-calling is a close substitute to in-person interviewing and can allow for data to be collected over large geographical areas even when social distancing measures are not in place (Jowett, 2020). Both of these methods were thus used in this research study.

However, with a Skype (or similar technology such as Zoom) video interview, there are some additional ethical considerations to take into account, including that conversations are mediated through the use of technology owned by third parties. By using technology such as Skype, some social contact to establish a rapport might be lost. However, Skype-like interviews often allow for participants to be less worried about time, since they are already at home and in a comfortable environment, providing an opportunity for them to speak for longer (Iacono et al., 2016). This was the case with this research study, with most of the telephonic interviews being at least 50 minutes, and others even closer to 90 minutes. Conversely, the WhatsApp interviews in terms of sending voice notes and messages sometimes lasted up to three hours, while some spanned over several days (as the participant was able to respond to the questions).

When considering remote interviews due to lockdown regulations during a pandemic, the first relevant factor is the health and wellbeing of participants and researchers. Researchers should also consider whether asking people to participate in research at this time will put them under any additional unnecessary stress. Once all of these considerations are taken into account, any changes in data collection methods must be shared with the ethics committee (Jowett, 2020). This was done in terms of the resubmission to the REC prior to conducting interviews.

Ultimately, during this research, extra effort was made to ensure that the study adhered to the additional ethical considerations of conducting research remotely by means of technology. Participants were given choices in the different methods and all participants participated voluntarily.

#### **5.4.2.2 *Voluntary participation and informed consent***

Social workers must obtain participants' consent and should refrain from being too vague in aligning the research process (Creswell, 2014; Drisko, 2013). Possible participants can only decide to participate after being fully informed of what will be required of them, as well as the possible risks involved during the research process (Anastas, 2013; Boothroyd & Best, 2003). Once participants agreed to form part of the study, all of them were asked to sign informed consent forms, with the process being conducted in English or Afrikaans to accommodate their preferred language. Participants participated voluntarily, and no one was forced or persuaded to form part of the study (Creswell, 2014; Anastas, 2013; Drisko, 2013). The consent form explained voluntary participation. Due to the lockdown regulations, not all participants could sign the consent forms, as they did not have access to technology to assist with this. To compensate for this challenge, the researcher still sent them the consent form as a portable document format (PDF), or took a screenshot of the consent form sent. As an extra measure to ensure that full consent was given, the researcher used the narrative as discussed under Dependability (See 5.3.5.4.D), which would have been done similarly to face-to-face interviews where participants might have had difficulty signing a consent form. Consent forms were sent via WhatsApp or e-mail depending on the needs of the participant. An example of how consent forms were sent can be seen in Figure 4.2 below. Particularly in WhatsApp, it is possible to obtain a date and time stamp of when the consent form was delivered and read (opened).



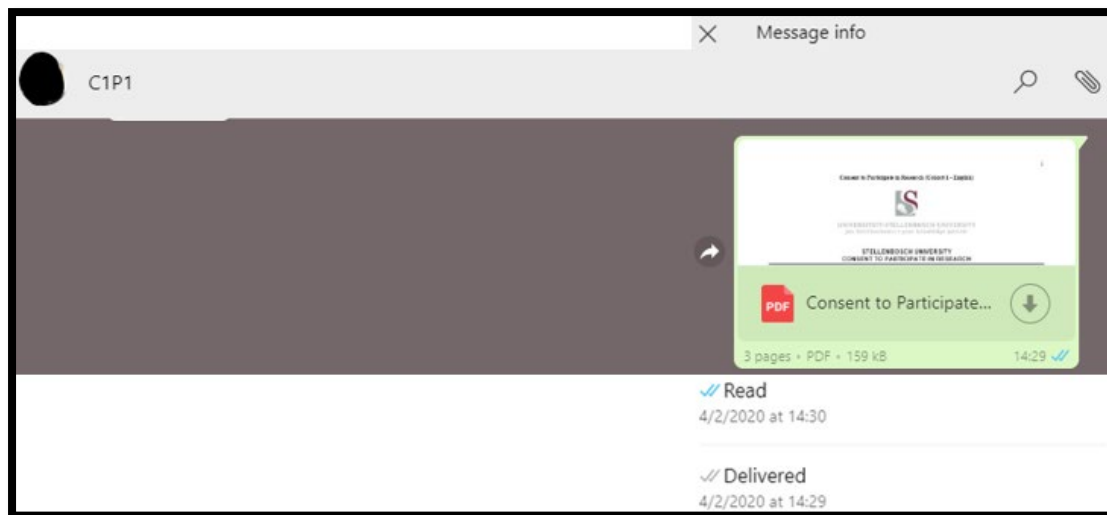


Figure 5.2: An example of a Consent form that was sent and received via WhatsApp

#### 5.4.2.3 Prevention of harm

During the research study all measures were put in place to prevent any harm at risk to participants. All recorded interviews were immediately removed from the original devices and the relevant participants given code names (as explained under 5.3.4) to minimise identifying particulars. Should any of the participants have felt the need for debriefing after the interview, a referral would have been made to a relevant, independent social worker to ensure the well-being of the participant. There were, however, no referrals needed for debriefing in this study. Only one participant that was identified by an organization requested the researcher to ask the organization to contact them regarding unrelated matters to the research study, which the researcher did. The lack of necessity for debriefing emphasised that the study did not intend to do any (emotional/psychological) harm to participants.

#### 5.4.2.4 Confidentiality

Confidentiality is one of the core values of social work (Drisko, 2013), where participants should be given the reassurance that their information will be kept confidential, not being disclosed in any way that could publicly identify them (Given & Munhall, 2008). Minimal identifying particulars were present in this study. Participants were informed that these identifying particulars, including signed consent forms and lists linking names to research codes (as explained under 5.3.4), would be stored separately from the research data itself, which in turn would be identified only by a code number or pseudonym (Maree, 2016). Data stored electronically would also be password-protected (Anastas, 2013). Names of participants

were, as far as possible, not mentioned during interviews. Likewise, with the transcription of the interviews, any names used were not given and only pseudonyms were used (Given & Munhall, 2008).

The following research-related records were kept in a safe and secure place i.e. on an online password protected system: the REC-approved research proposal and all amendments, informed consent documents, recruiting materials, continuing review reports, notes on adverse or unanticipated events, recordings and correspondence from the REC. No data were left on any devices to ensure confidentiality.

#### **5.4.2.5 Compensation**

To ensure the legitimacy and efficacy of the research study (De Vos et al., 2011), no participant was compensated for being part of the study. However, to ensure that participants did not have any transport costs, interviews were planned to be done in a communal area of their choice, such as their office or home (Grove & Gray, 2019). However, due to the COVID-19 pandemic, interviews were done remotely using technologies. This provided participants with the convenience of doing the interviews at a place (usually their home) they preferred with minimal cost. Participants were also given a choice in interview method to cater for their specific convenience and affordability.

#### **5.4.2.6 Debriefing of participants**

It is suggested in social work qualitative research done with vulnerable groups (Boothroyd and Best, 2003) to refer any participant who seems distressed to an independent source for professional assistance to avoid dual roles (Lunt & Fouché, 2010; Landau, 2008; Congress, 2001). All the participants of this study participated through their own choice, which minimised the potential need for debriefing. Should the need have arisen for debriefing, participants would have been referred to a relevant social worker in their area. Three potential independent social workers were identified to participants for debriefing (See Addendum L for an example of consent to debrief).

#### **5.4.2.7 Publication of findings**

The research study will only be published for academic or professional purposes in terms of the dissertation self, future publications or conferences. Participants' identities will not be

disclosed in these publications. The findings for the dissertation were published according to the REC guidelines.

### **5.4.3 Personal reflections**

During the research process there were many opportunities where the researcher could reflect on the study on both a personal and professional level. The biggest reflection was that of the impact of the COVID-19 pandemic, an unforeseen variable that became part of the research study.

#### **5.4.3.1 *Research during a pandemic (COVID-19: Historical impact)***

As mentioned earlier, the outbreak of the COVID-19 pandemic became an almost overnight news headline as it started showcasing its impact across the world. The pandemic was subject to many comparisons, such as the outbreak of the Spanish flu pandemic in 1918, and in some cases, even warfare. Around the world scenes were shared of virtually empty tourist attractions and, more somberly, of mass burials in countries such as Italy and USA, where the virus fatalities increased quite rapidly. Although the pandemic brought about uncertainties about the world's health systems and more specifically, each country's own health system, as well as the economic impact of lockdown regulations, it also resulted in unique opportunities for research. Despite all the different views and concerns about the pandemic, one aspect is certain, namely that this will be a historical event to look back on for generations to come. Being able to continue research during the pandemic brought a unique perspective on the research topic, but also provided different opportunities for the research process e.g. redesigning the interviews to be done remotely and including a wider geographical landscape. There are few research studies that would be afforded as unique a perspective as those that were able to continue during the pandemic.

#### **5.4.3.2 *Research as both a social worker and a PWD on experiences of persons with an acquired physical disability on social work***

As mentioned before, in terms of reflexivity (See Addendum Q) the researcher had to be aware of the potential challenge in remaining objective in this study as both a PWD and a social worker. Measures were, however, put into place to be able ensure this, such as using an independent organisation and focusing on persons with an acquired physical disability as opposed to persons with a congenital physical disability (as is the case of the researcher). There

were some instances where the researcher could relate to participants' shared experiences as both social worker and PWD, and the researcher had to remain objective during these interviews. This was not difficult to do, as the researcher was able to separate herself from the research at hand.

#### **5.4.4 Limitations of the study**

There were some limitations to this study, as discussed in the bullet points below:

- The scantiness of literature on the research topic inhibits the ability to relate to previous research and compare findings. However, it could hold potential for future similar studies (discussed in Chapter Seven).
- South Africa does not have a fixed measuring tool for disability, which means that statistics on disability prevalence cannot be compared with one another due to different criteria used.
- This study was done with only 24 participants, which means that the sample was a small representation of the research universe. As a result, assumptions about the findings of the study cannot be made.
- All the participants in this study seem to have a high resilience and acceptance for their life living with a disability. The findings of this study would therefore not necessarily correspond with a sample group that did not have the same level of resilience and acceptance.
- More in-depth studies, with bigger samples would have to be conducted to confirm that the outcome of this study is similar for other adults with an acquired physical disability in South Africa.
- The study provided an overview of many themes and participant groups, which holds potential for future studies, but also limits the extent to which this research study could focus on these aspects without overcomplicating the study.
- A pilot study was intended to take place, but due to the lack of participants, it could not be done.
- The COVID-19 pandemic did not allow for face-to-face interviews, and the research study had to be redesigned to be done remotely using technology. This

inhibited the ability to gather non-verbal information from the interviews such as body language.

- To not pose harm to any of the participants, identifying information was not asked for directly. Rather it was asked that participants introduce themselves to the researcher. Due to this open-ended question, no racial information was provided voluntarily by any of the participants. Therefore, despite having many other variables within the study, it cannot be confirmed whether experiences were shared across different cultures, as this information is not known in this study.
- Conducting interviews by using technology rather than doing them face-to-face posed different ethical considerations as discussed earlier.
- Some sources were dated, but the inclusion of other more recent sources compensated for dated sources.
- All consent forms could not be signed physically due to participants not having the resources themselves to print, scan and send them back to the researcher. Many participants thus opted to verbally acknowledge receipt and consent for the research study.

## **5.5 CONCLUSION**

This Chapter examined the research methodology used in this research study, from the planned research design and approach, sampling and ethical consideration to the impact of the COVID-19 pandemic, which required the study to be adjusted from its original nature. The pandemic impacted the research strategy of this study considerably, as it had to be redesigned to comply with both lockdown regulations and research ethical considerations. This provided a unique research experience and perspective, regardless of the limitations that were created.

## **CHAPTER SIX**

### **EMPIRICAL FINDINGS**

#### **6.1 INTRODUCTION**

This chapter builds on the previous chapters and relates to the fourth objective for this study. It presents the analysis of the experiences of adults with acquired physical disabilities on social work support in South Africa found during the empirical study. The empirical study was done through semi-structured interviews with two Cohorts. The first consisted of 19 adults who acquired a physical disability, whilst the second consisted five social workers who have experience in delivering social services to PWDs.

As mentioned frequently before, this study was influenced by the COVID-19 pandemic of 2020 and had to be redesigned to adhere to protocol during this phenomenon. This also had an influence on the results of the study, as considerations of the impact of the pandemic on both service users and service providers were included. The pandemic brought on new challenges, as discussed in Chapter Five, and a consideration for a ‘new normal’.

Taking these factors into account, this chapter consists of a brief discussion on the identifying particulars of the participants. In accentuating the explorative and descriptive nature of this study, different themes were identified in the literature review discussed in Chapters Two to Four, which guided this empirical study. These themes are thus discussed along with some new sub-themes and categories identified during the empirical study. It must be clarified that, although the researcher used the term person/people with disability/s throughout the study, within the narratives of the participants themselves, the term “disabled (person/people)” was used and kept that way to ensure the authenticity of this Chapter. Another example where narratives were kept as authentic as possible is within the discourse of participants i.e. sentence construction, leading to occasional grammatical errors.

This chapter includes information about other support outside of what generally falls under the category of social work to provide a background on the experiences of adults with an acquired physical disability. This is because social workers often connect their clients to resources in the community, and therefore, experiences with other support networks also influence the impact of social work services.

## 6.2 IDENTIFYING PARTICULARS

The research study made use of two Cohorts. The first Cohort consisted of 19 adults who have acquired a physical disability, whilst the second Cohort consisted of five social workers with experience in working with PWDs.

### 6.2.1 Cohort One – Persons with an acquired physical disability

In a study done by Graham et al. (2014) which used the inclusion criteria of disability as “a functional difficulty in at least one of the following areas: sight, hearing, mobility and self-care, where an individual reported some, a lot or severe difficulties in these functionings,” the disability prevalence rate in the South African population was 18%. This is similar to the inclusion criteria of this research study, with the further specification of adults who acquired a physical disability later in their life. It was estimated that, by 2023, there will be a 30% increase in the number of first-time stroke sufferers compared to results found at the beginning of the millennium (Wolfe, 2000).

#### 6.2.1.1 Gender of Participants

This study had participants that identified themselves as both female and male. Other gender types were not specifically excluded from the study, but rather were not identified by participants. The gender of participants is indicated in Figure 6.1.

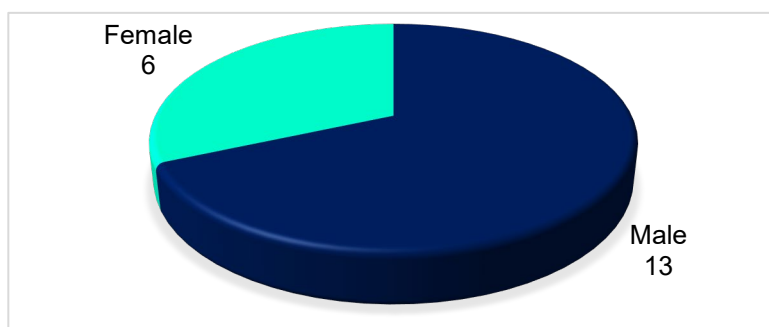


Figure 6.1: Gender of participants of Cohort One ( $n = 19$ )

Despite the gender of participants not being a critical criterion for the research study, it must be pointed out that the prevalence rate of disability seems to be higher in females (Graham et al., 2014). It was therefore important to include females in the research study to identify with this prevalence, although more males were ultimately interviewed.

### 6.2.1.2 Age of participants

The global average disability prevalence rate for the adult population of almost 16% (WHO & World Bank, 2011), with lower income countries demonstrating higher prevalence rates as mentioned earlier.

The significance of identifying the current different age groups of participants, as well when they acquired their disability, could be described by referring to the Erik Erikson's psychosocial development stages. Accordingly, Figure 6.2. depicts the breakdown of the different age groups of this study in terms of their current age, as well as the age that they acquired the physical disability.

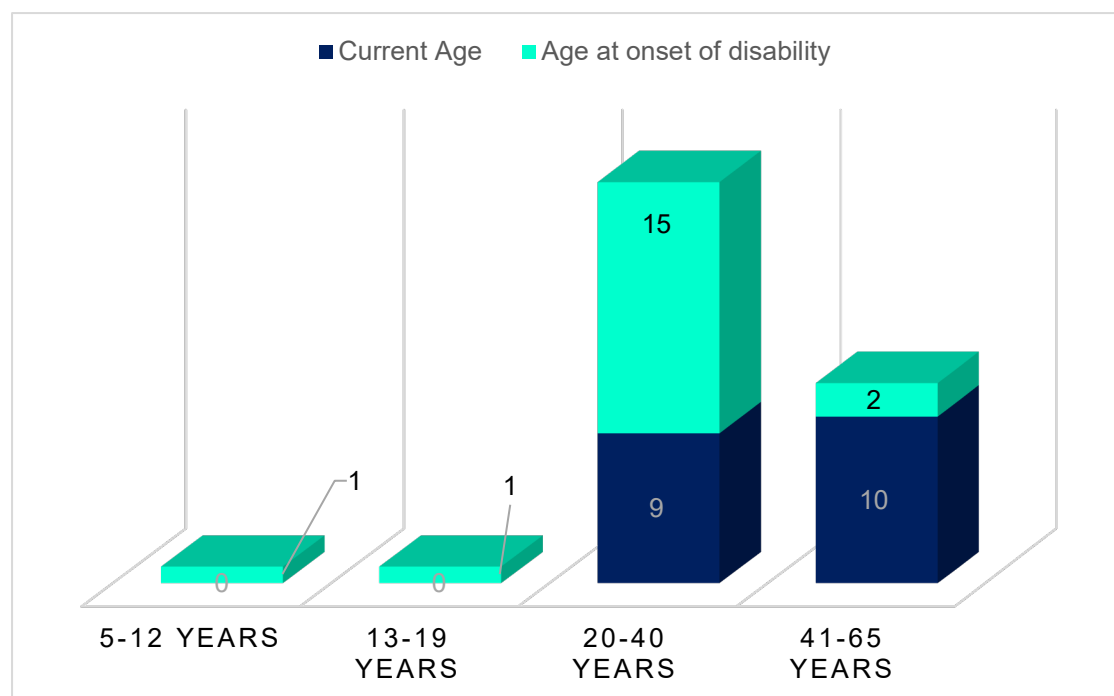


Figure 6.2: Age of participants ( $n = 19$ )

According to Erikson, an individual's personality develops by means of a predetermined order of eight stages of psychosocial development, ranging from infancy to adulthood. The individual experiences a psychosocial crisis during each of the stages, which could influence his/her personality in a constructive or adverse manner. Erikson (1982; 1968; 1964; 1963; 1959; 1958; 1950), describes these crises as being psychosocial in nature because they involve psychological needs of the individual (i.e., psycho) conflicting with the needs of society (i.e., social). The theory further suggests that the successful completion of each stage results in a healthy personality and the acquisition of basic virtues. However, having a significant



experience such as acquiring a disability during any of these different stages could affect the outcome of personality development. The applicable life stages as per Erikson's theory for this study are as shown in the table below:

**Table 6.1: Different life stages of participants according to Erikson's psychosocial theory**

STAGE	AGE	MAJOR QUESTION	VIRTUE	CONSTRUCTIVE OUTCOME	ADVERSE OUTCOME
<b>Industry vs Inferiority</b>	5 – 12 years	“How can I be good?”	Competence	Feelings of competence	Feelings of inferiority
<b>Identity vs Role Confusion</b>	12 – 19 years	“Who am I?”	Fidelity	Develop a strong sense of self	May not be sure of who they are
<b>Intimacy vs Isolation</b>	20 – 40 years	“Can I love and be loved?”	Love	Able to form lasting relationships	Can lead to feelings of loneliness and isolation
<b>Generativity vs Stagnation</b>	40 – 65 years	“What can I contribute to the world?”	Care	Feel a sense of accomplishment	Feelings of being uninvolved with the world

Adapted from: Explored Psychology (2018)

Despite Erikson's study not focusing on this aspect specifically, it could be noted that acquiring a disability during the different life stages could affect an individual's personality development in terms of feelings of competence, self-identity, love and accomplishment. Jordan and Tseris (2018) also noted that Erikson's theory has been commonly used by psychologists, social workers and other human service professionals. They further argued that it is necessary to include disability in theorisations of how people develop across their life course to challenge inherent beliefs about difference. The veritable correlation between Erikson's theory cannot be confirmed in this study, but is worth noting to gain a better understanding of participants' psychological experiences (discussed under Theme Two).

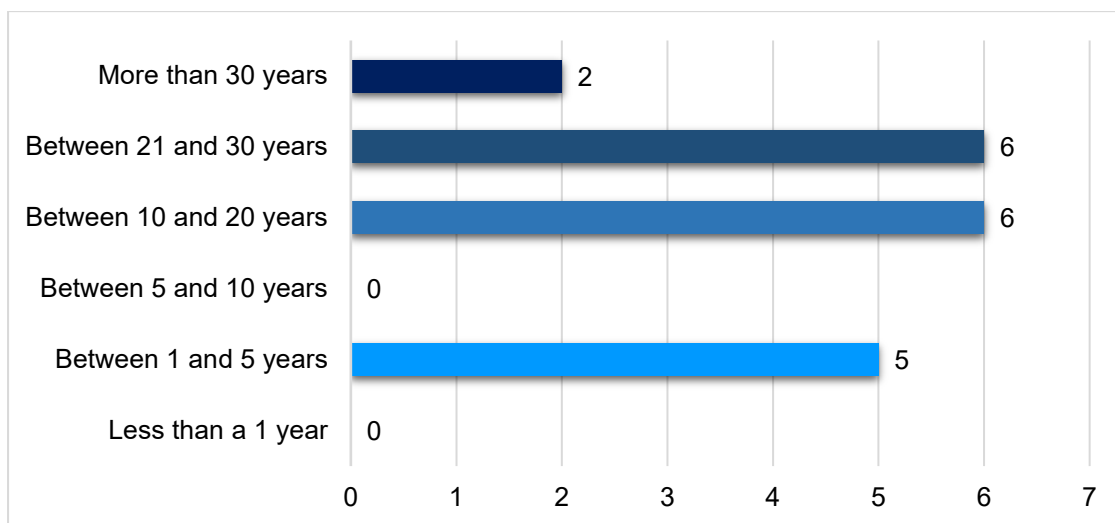
The WPRPD (discussed under Theme Six) further advocates for a “life cycle” approach, when providing socio-economic services to PWDs, which leads to a complementary element of being “person centred or people centred” (DSD, 2016).

### **6.2.1.3 Years since onset of disability**

Within research on disability, terms such as Years Lived with Disability (YLDs) and Disability Adjusted Life Years (DALYs) are often used to analyse the burden of disease. Within these

terms, YLDs refers to the number of years that an individual lives with some disease. This analysis is influenced by the severity of the disability that the disease causes to the affected individual. For instance, chronic disease disables an individual once disease is diagnosed, and the years that he or she lives until death are the number of years lived with disability. DALYs for a health condition, on the other hand, are calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for people living with the health condition or its consequences (WHO, 2020b).

The study acknowledges these analytical concepts, although this was not the purpose of identifying information for its research. Rather, the concepts serve to gain a better understanding of how the participants' (in this case the PWDs) experiences differed depending on the amount of years that they have lived with the disability. This relates to the Model of Grief (discussed in Theme Two), as learning to live with a disability is a process where individuals must go through different experiences (feelings) over time. The figure below displays the distribution of number of years participants have lived with the disability.



*Figure 6.3: Distribution of years since participants acquired physical disability (n = 19)*

The identifying particular of YLD was not the main purpose of the research study, but rather a variable for consideration in gaining a better understanding of the participants' experiences. In a study done in Taiwan (Lin, Knox & Barr, 2014) it was found that participants with a physical disability identified three aspects of their experience living with a disability, these being living with an impaired body, dealing with the mind and dealing with the need for support. These three aspects correlate with some of the findings in terms of psychological experiences (Theme Two) and support needs (Theme Four).

#### 6.2.1.4 Different acquired physical disability and their causes

According to Disabled World (2020), “[p]eople with disabilities are the [US’] largest minority, and the only one that any person can join at any time.” This statement is often echoed by disability advocacy organisations around the world. Almost everyone will experience a form of impairment or disability in their lives. Different types of impairment could occur at any given moment. This disability can persist for years or even permanently, requiring family members to act as informal caregivers (Muller-Kluits, 2017). Figure 6.4. below indicates the cause of the acquired physical disabilities of participants. The causes of the physical disability were discussed from a social perspective in this study, and for this reason, medical specifics about the cause of the disability were not discussed in detail but rather as participants described it themselves.

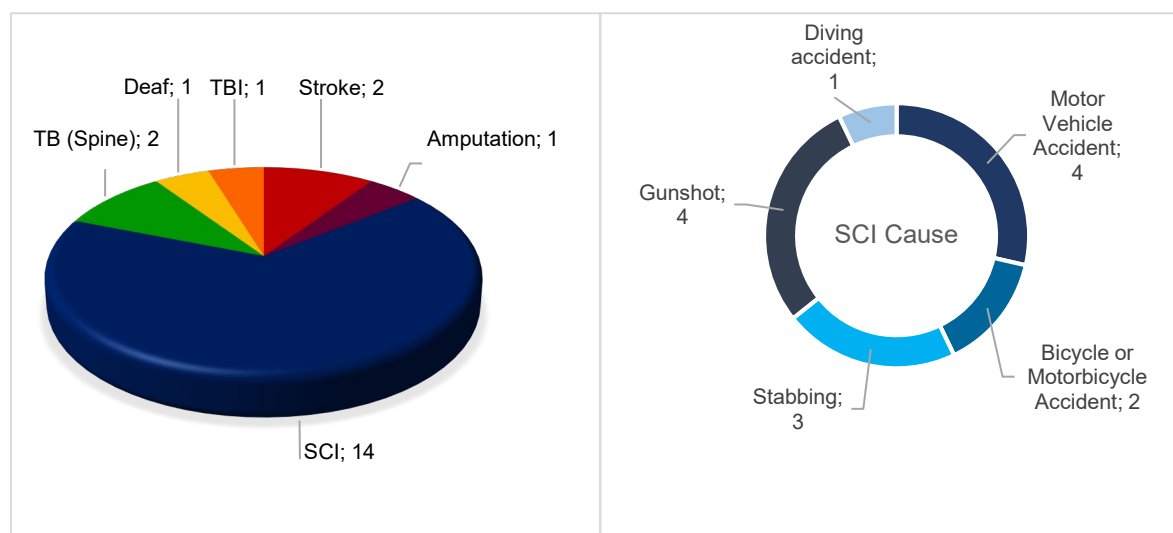


Figure 6.4: Cause for onset of physical disability (n = 19)

The prevalence of physical trauma as a cause of the various participant’s acquired disabilities, evident in the figure above, emphasises the statement earlier that disability can occur to anyone at any time.

An important cause of disability noted in this study was disability caused by spinal cord injury (SCI) due to road accidents, as well as violence such as stabbing and gunshot wounds. In South Africa, it was estimated that 1 170 people sustained injuries due to major crashes in 2018 (Department of Transport, 2018). This was also the case with some participants in this study, as can be seen from the narrative below:

*CIP15: (Ek) was in 'n motorvoertuig ongeluk ... Die ongeluk het in die nag gebeur ek het geslaap ... Die bestuurder was aangekla vir roekelose, nalatige bestuur en bestuur onder die invloed van drank en het drie jaar gevangenis straf gekry. [(I) was in a motor vehicle accident ... The accident happened at night while I was sleeping ... The driver was accused of reckless driving and driving under the influence of alcohol and received three years prison sentence.]*

Further, during the 2016/2017 financial year, it was reported that there were 140 956 cases of aggravated robbery recorded by the police, along with 16 717 hijackings and 170 616 counts of intent to do bodily harm, adding to the risk of injury and disablement through violence (Institute for Security Studies, 2017). In the Western Cape, it was found that the weapons most commonly used for murder were firearms in gang-related violence, whilst in other cases knives and other sharp objects were used. In Gauteng and KwaZulu-Natal, most murders were done by firearms followed by knives and other sharp objects (South African Police Service, 2017). The experiences of the participants below shed some light on the effects of such injuries:

*CIP8: I was a soccer player before and ... then on my way back home from a soccer match then I got robbed and I got stabbed in my neck and then I got paralysed.*

*CIP14: So, toe ek ... kar aanskakel, was ek deur die venster geskiet. [When I ... started the car, I was shot through the window].*

Apart from physical trauma such as road accidents and violent crime, Tuberculosis (TB) is also prevalent in South Africa, which could cause paralysis when it affects the spine. As can be seen in Figure 6.4 above, this was the case with two participants. Spinal TB is dangerous type of skeletal TB often associated with a neurologic deficit due to the compression of adjacent neural structures and significant spinal deformity (Rasouli, Mirkoohi, Vaccaro, Yarandi, & Rahimi-Movaghar, 2012). The WHO (2018) statistics gave an estimated incidence of 301 000 cases of active TB cases in South Africa in 2018 - a rate of 520 per 100 000 people. It is further estimated that about 80% of the population of South Africa is infected with TB bacteria, with the majority having latent TB rather than the active disease (RSA, 2016).

These statistics are important to note in understanding that disability could affect any one at any time. In South Africa where there is a high TB prevalence rate and high violent crime incidence, it brings forth the potential debate that acknowledging experiences of PWDs as a minority group could have a long-term influence on society, spreading far beyond the initial

minority sample. Although, as mentioned before, it is difficult to measure disability prevalence rate due to the different measures and inclusion criteria of research done, most studies estimate it to be one in six (range five to seven) people around the world (Graham et al., 2014; WHO & World Bank, 2011). It could further be investigated how the increase of risk factors such as chronic disease, road accidents and violence, affect the prevalence rate of disability.

#### **6.2.1.5 Marital status**

According to Blanes, Carmagnani and Ferreira (2007), nearly 90% of persons with chronic diseases are cared for by their relatives. In their study, more than a quarter (26.6%) of their participants relied on their spouses to act as caregivers. The marital status of participants is shown below:

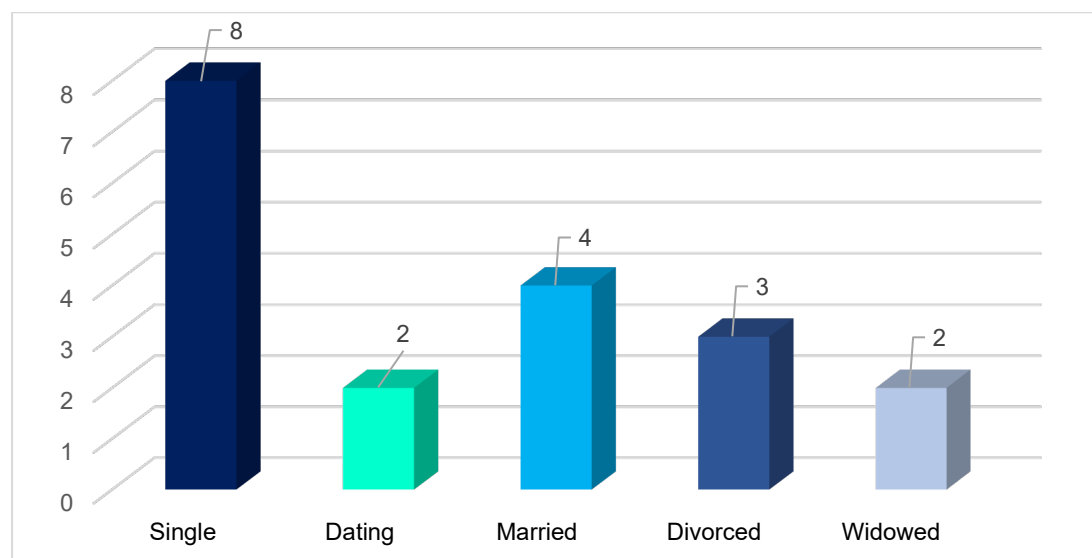


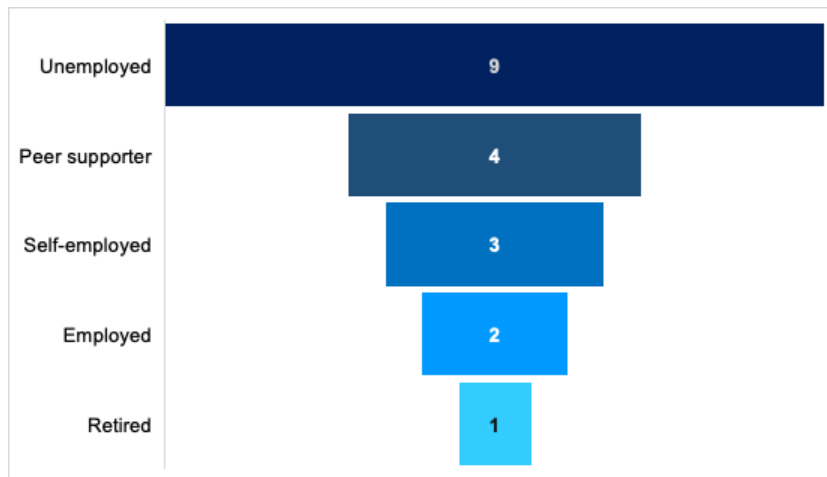
Figure 6.5: Marital status ( $n = 19$ )

The marital status of participants noted in Figure 6.5. helped to gain an understanding of social experiences according to Bronfenbrenner's ecological perspective as discussed in Themes 3 and 4.

#### **6.2.1.6 Employment status**

In 2015, the adoption of 17 SDGs by the UN served emphasise a holistic approach to achieving sustainable development for everyone through the principle of 'leaving no one behind.' These SDGs emphasise that vulnerable groups such as PWDs, of whom more than 80% live in poverty, should be empowered. The goals include, among others, to end poverty in all its forms

everywhere, as well as having an inclusive and sustainable economic growth, full and productive employment and decent work for everyone, and finally, promoting an inclusive and sustainable industrialisation (UN, 2015). Figure 6.6. illustrates the employment status of participants.

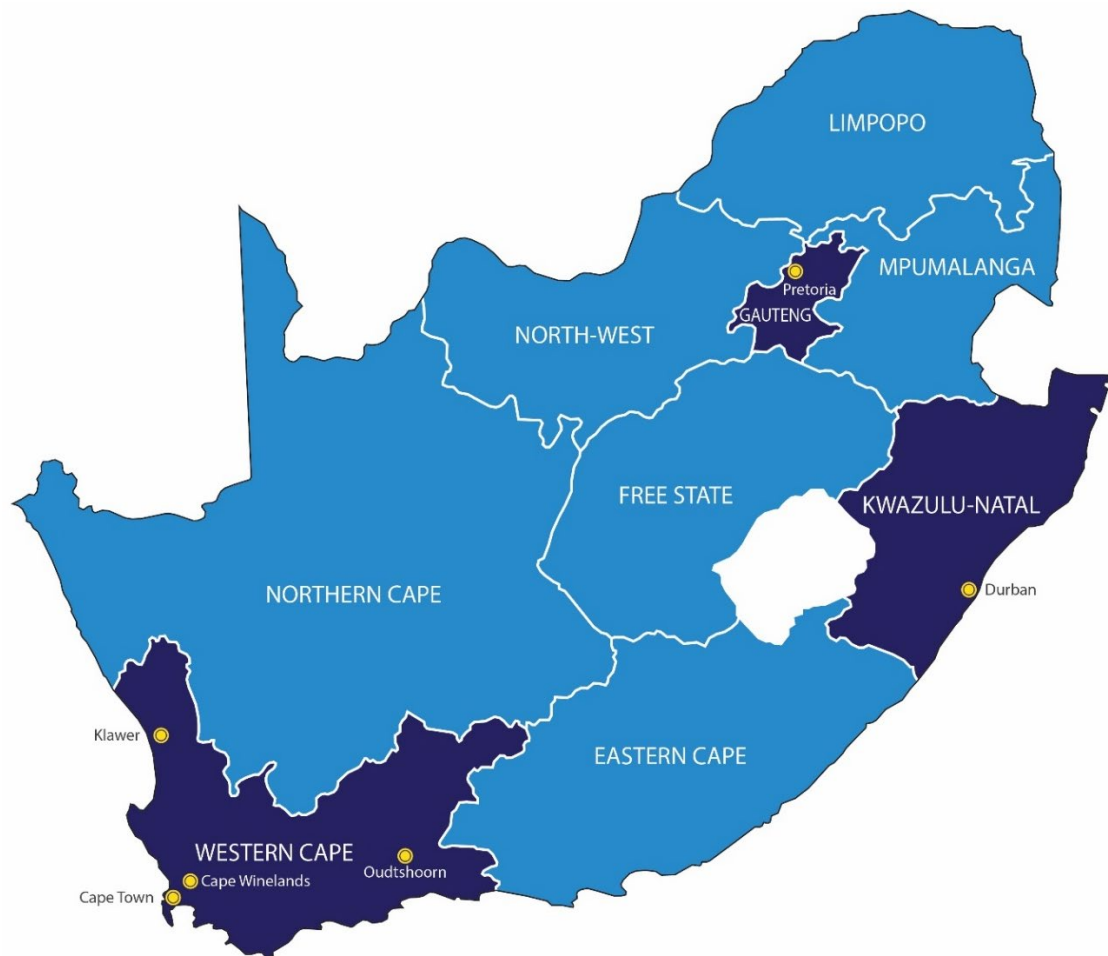


*Figure 6.6: Employment status (n = 19)*

In Chapter Two it was discussed that, despite the prevalence of policies such as UNCRPD, SDG and WPRPD aimed at eradicating poverty and increasing employment for PWDs, their rate of employment is still extremely low. Identifying the employment status of participants gave the research study a deeper understanding of the social experiences as discussed in Themes Three and Four.

#### **6.2.1.7 Living area**

The research study was based within the South Africa. The figure below illustrates in which provinces and regions within those provinces participants were from.



PROVINCE	CITY/TOWN	NUMBER OF PARTICIPANTS
Western Cape	Cape Town Area	11
	Cape Winelands Area	1
	West Coast area (Klawer)	1
	Klein Karoo/Garden Route area (Oudtshoorn)	2
Gauteng	Tshwane area (Pretoria)	3
Kwa-Zulu Natal	Durban area	1
<b>TOTAL</b>		<b>19</b>

Figure 6.7: Distribution of participants' living area ( $n = 19$ )

As mentioned previously, the research study took place over three of the nine provinces, these being Gauteng, the Western Cape and KwaZulu-Natal. According to the Census of 2011 (StatsSA, 2011), Gauteng and KwaZulu-Natal were the most populous provinces in South Africa, and by extension those with the highest prevalence number of PWDs.

## 6.2.2 Cohort Two – Social Workers

This Cohort consisted of five social workers with experience in delivering services to PWDs. The social workers in this Cohort all worked under one organisation, but within different branches in different areas within the Western Cape. The organisation is specifically focused on delivering social services to PWDs and their families.

### 6.2.2.1 Gender of participants

All five of the participants from this Cohort identified themselves as females. The combined total of both Cohort One and Two participants were almost divided equally, with eleven participants identifying themselves as female and thirteen identifying themselves as male.

### 6.2.2.2 Years' experience delivering services to PWDs

Social workers are trained generically (SACSSP, 2007; Patford, 1999), but once employed, often expected to provide a service within the specialised field of health, including services to PWDs. In such cases, they must rely on training within the workplace to assist with delivering services within a specialised field. Figure 6.8. shows the years of experience participants from Cohort Two had in delivering services to PWDs.

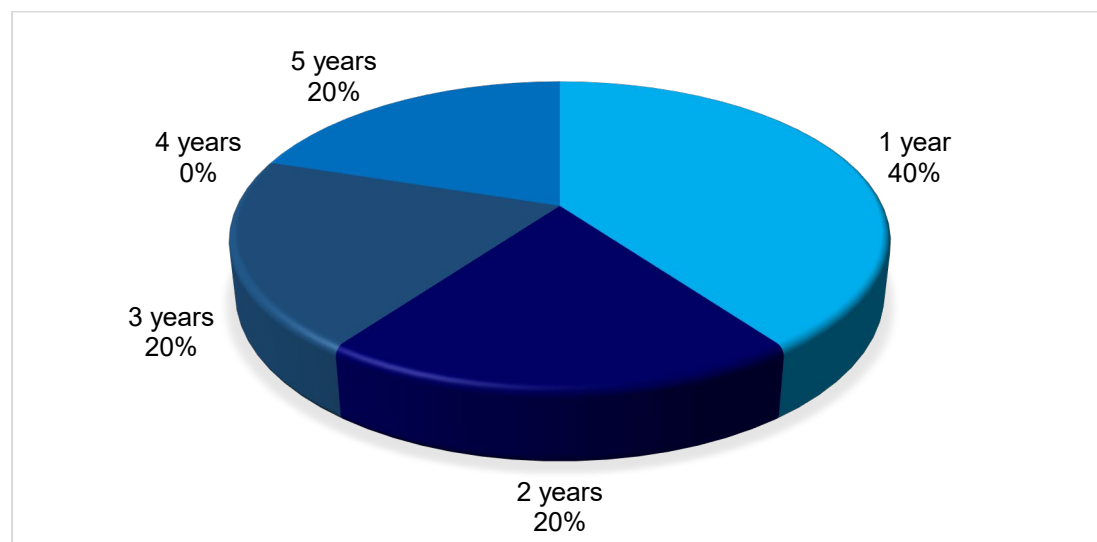


Figure 6.8: Years of experience delivering services to persons with disabilities ( $n = 5$ )

As can be seen from the figure above, participants in this study had five years or less experience working specifically within the field of disability. Their perceptions are therefore valuable for



understanding some of the obstacles faced by social workers that have joined the sector recently. This could also assist with understanding training needs for social workers in the field.

### 6.2.2.3 *Working area*

The participants within this Cohort were working in the same organisation, but within different branches from the Cape Town and Garden Route areas in the Western Cape. These regions are also where some of the participants of Cohort One were living.

## 6.3 DATA COLLECTED FROM PARTICIPANTS DURING EMPIRICAL STUDY

Ross and Deverell (2010) state that experience, personality, social background and coping style are important to consider in understanding how disability is experienced (Graham, 2014). From the literature review, five main discussion points were identified that guided interviews, which was then further developed into six themes based on the empirical data collected, as will be discussed in this chapter. These themes include: biological experiences of adults with an acquired physical disability according to biopsychosocial and ICF model, psychological experiences of adults with an acquired disability, support services used by adults with an acquired disability according to ecological theory (Bronfenbrenner), support needs of adults with an acquired disability according to ecological theory (Bronfenbrenner), cultural experiences of adults with an acquired disability within their community, as well as social work support services to persons with acquired physical disabilities aligned with policies in South Africa. The themes, sub-themes and categories are identified in Table 6.2. below:

**Table 6.2: Themes, sub-themes and categories identified during empirical study**

THEMES	SUB-THEMES	CATEGORIES
Theme 1 Biological experiences of adults with an acquired disability	1.1 Activity limitations (ADLs)	
	1.2 Participation restriction	1.2.1 Accessible housing
		1.2.2 Accessibility challenges in community
Theme 2 Psychological experiences of adults with an acquired disability	2.1 Model of Grief	2.1.1 Shock, numbness and disbelief
		2.1.2 Relief
		2.1.3 Denial
		2.1.4 Bargaining and guilt

THEMES	SUB-THEMES	CATEGORIES
		2.1.5 Depression
		2.1.6 Anger
		2.1.7 Anxiety
		2.1.8 Acceptance
	2.2 Loss of Independence	
	2.3 Resilience	
	2.3 Spiritual experiences	
Theme 3 Support services used by adults with an acquired disability according to ecological perspective	3.1 Microsystem	3.1.1 Spousal/partner subsystem
		3.1.2 Parental sub-system
		3.1.3 Sibling sub-system
		3.1.4 Child sub-system
	3.2 Mesosystem	3.2.1 Extended family
		3.2.2 Friends and peers
		3.2.3 Health professionals
	3.3 Exosystem	3.3.1 Social work/ Welfare Organisations
		3.3.2 Health facilities
		3.3.3 Other community facilities
	3.4 Macrosystem	3.4.1 The SA Health Care System
		3.4.2 Other support services
		3.4.3 Financial assistance
Theme 4 Support needs of adults with an acquired disability according to ecological perspective	4.1 Microsystem	
	4.2 Mesosystem	4.2.1 Extended family support
		4.2.2 Professional support and understanding
	4.3 Exosystem	4.3.1 Post-discharge rehabilitation facilities
		4.3.2 Community support services
		4.3.3 Transport systems
		4.3.4 Community safety
	4.4 Macrosystem	4.4.1 Disability-friendly employment

THEMES	SUB-THEMES	CATEGORIES
		4.4.2 Financial concerns
Theme 5 Cultural experiences of adults with an acquired disability within their community	5.1 Lack of understanding in community	5.1.1 Stigmatisation
		5.1.2 Need for sensitisation in communities
	5.2 Acceptance in community	5.2.1 Experience of acceptance
		5.2.2 Recommendations for improving acceptance as depicted by participants
Theme 6 Social work support services to persons with acquired physical disabilities aligned with policies in South Africa	6.1 Social work support services used	6.1.1 Social work services offered at an organisation
		6.1.2 Social work services used by adults with an acquired physical disability
	6.2 Experiences of social work services	6.2.1 Positive experiences of social work services received
		6.2.2 Negative experiences of social work services received
		6.2.3 Lack of knowledge about social work services
		6.2.4 Experiences from social workers
	6.3 Services aligned with policies	6.3.1 Services aligned with other international policies
		6.3.2 Services aligned with WPRPD (South Africa)
		6.3.3 Services aligned with other South African policies
	6.4 Impact of COVID-19 pandemic on social work services	6.4.1 Experiences of adults with acquired physical disabilities
		6.4.2 Experiences of social workers
	6.5 Role of social worker in rehabilitation of adults with acquired physical disabilities	6.5.1 Role of social worker as seen by Cohort One
		6.5.2 Role of social worker as seen by Cohort Two
	6.6 Recommendations for future social work services to adults with acquired physical disabilities	6.6.1 Recommendations from service users
		6.6.2 Recommendations from service providers
		6.6.3 Motivation for similar studies

These themes were aligned with the original objectives of the study as Theme One to Six addresses the overview of disability in terms of South African policies and legislations (Objective One). Theme One to Four looks at some of the models and perspectives of disability as it relates to the experiences of PWDs (Objective Two). And lastly, Theme Six focuses on the social work profession in terms of support to persons, especially adults, with acquired physical disabilities have been perceived (Objective Three). As stated before Objective Four relates to Chapter Six as a whole whilst Objective Five relates to Chapter Seven as a whole.

As discussed in Chapter Five, participants were coded to protect their privacy, with their narratives being represented with a capital “C” referring to “Cohort” and a capital “P”, referring to Participant. For instance, C2P02 will refer to Participant Two from Cohort Two.

### **6.3.1 Theme 1: Biological experiences of adults with an acquired physical disability according to biopsychosocial and ICF models**

The biopsychosocial model was introduced as an updated model to the medical model (Parsons, 1975), and integrates two opposing models i.e. medical model and social model (WHO & World Bank, 2011). It is based on the systems theory (Adler, 2009) focusing on three important components of the individual i.e. biological, psychological and social (Hatala, 2012). The biopsychosocial model is also used in the ICF, where disability is defined in terms of impairment, activity limitations and participation restrictions.

Impairment, the focus of this theme, is acknowledged as one of the dimensions of disability, as was indicated in Figure 6.4. The WHO defines impairment as “a problem in body function or structure” (WHO, 2017). Participants from Cohort One in this study had the following impairments: paralysis such as hemiplegia, paraplegia and quadriplegia due to spinal cord injury, stroke or spinal TB, as well as deafness and loss of a limb (amputation). As can be deducted from these causes of disability, most of the participants’ impairment is that they are not able to walk. Some other impairments included not being able to hear in the one ear and, in some cases, other mobility difficulties.

Activity limitation and participation restriction comprise the sub-themes of this theme, which will refer to findings from interviews with Cohort One. Although this model includes the psychological and social aspects as well, a more detailed discussion on these aspects will be discussed in Theme Two to Four.

### 6.3.1.1 Sub-theme 1.1: Activity limitations (ADLs)

Activity limitation refers to difficulties a person may have in executing tasks or actions of daily living, also referred to as ADLs (WHO, 2017). Participants from Cohort One identified a few activity limitations of everyday activities, as can be seen in the narratives below:

C1P01: *I can't get myself into a bath ... I need somebody to go to the shops for me I cannot walk fast, those little things that I cannot do.*

C1P02: *Koffie kan ek net maak as ek in die kombuis is ... Ek kan dit nie dra vir ander. Vir ander aanbied om vir hulle te maak ... Ander goed soos in die tuin in is baie moeilik, om die hond se strooi op te tel, want dit is moeilik vir my om vir lang termyne voor-oor te leun as gevolg van my blaas ... En klere, of spesifieke goed uit die kas uit te haal. Ek het dan baie van die tye nodig vir iemand om vir my die goed aan te gee.. [Coffee I can only make when I am in the kitchen ... I cannot carry it for others. To offer to make for others ... Other things like in the garden is difficult, to pick up after the dog because it is difficult for me to lean over for long periods due to my bladder ... and clothes ... or (taking) specific things out of the closet. I then often need someone, to pass things to me.]*

C1P06: *Dinge wat moeilik is om te doen soos om tussen klein spasies en ongelyke plekke deur te beweeg en dinge wat ek nie kan doen nie is die werk wat ek by die myn gedoen het soos swaar pype en plate op te tel. [Things that are difficult to do such as to move around between small spaces and uneven places and things I cannot do is the work that I used to do at the mine such as lifting heavy pipes and plates.]*

C1P12: *After the accident I struggle to clean the house like before.*

C1P13: *So ek het 'n gebruik van my arms ... So, halfpad af in die arms en aan die agterkant het ek nie gevoel nie. So dit is nogal 'n vreemde gevoel waaraan 'n mens moet gewoond raak ... Dan het ek 'n redelike neuropatiese pyn, permanent, wat 'n mens probeer bestuur ... Ek is baie afhanklik van my vrou. Wat gelukkig ... vir my 'n fisioterapeut is en heeltemal gemaklik is om my te oefen. Ek het ook 'n versorger wat meestal oggende my aan die gang kry en bad wanneer dit nodig is en maag funksie doen en so ... my versorger het my*

gewoonlik (voor inperking) opgekry en gevat tot by die werk en het my vrou my so vyfuur kom haal ... Ek kan nou nog nie bestuur nie ... Ek kan nie my eie vuur pak nie. Vir braai. [So, I have a use of my arms ... About halfway down into the arms and at the right I do not have any feeling. So, it is quite a weird feeling one has to get used to ... Then I have quite a neuropathic pain, permanent, which one tries to navigate ... I am very dependent on my wife. Who luckily ... for me ... is a physiotherapist and completely comfortable to exercise me. I also have a carer who usually gets me started in in the morning and baths me when necessary and does stomach functioning going and such ... My carer usually (before lockdown) got me up and took me up to work and then my wife came to fetch me at around 5pm ... Still now I cannot drive ... I cannot pack my own fire. For braai]

CIP14: Huis skoonmaak is vir my baie moeilik. Soos jy kan verstaan ‘n mens kan nie orals by kom en dit vat vir my baie langer om die huis uit te vee. [Housecleaning is very difficult for me. Like you can understand, one cannot reach everywhere and it takes me much longer to sweep the house]

CIP16: I struggle sometimes in the kitchen to reach for the cupboard and that makes me mad.

CIP17: For me the most significant part was ... more the finer movements. It was being able to write ... at the functional level. I use writing splints. One of my hobbies are painting flowers. Turning switches on and off, navigating the mobile phone to smart phone.

CIP18: ... dit begin nou wat jy ouer raak ... begin jy sukkel om te verplaas ... want jou skouers is ook nou maar opgebruik so oor die jare. [... it starts now that one gets older ... one begins to struggle to transfer ... because your shoulders are also now exhausted from use over the years.]

CIP19: Ek dink die grootste uitdagings of frustrasies vir my is as ek klein goedjies moet doen wat ek altyd selfgedoen het en ek kan dit nie doen ... Gister wou ek die “aircon” se filter uithaal en skoon maak, maar ek kan nie daar by kom nie ... Ek kan nie af buk en onder die bed te kyk wat daar is nie. Soos as ‘n muur prop agter ‘n kas is kan ek hom nie inprop nie. Daai frustrasies bly maar daar ... Om badkamer toe te gaan bly die enkele grootste probleem vir elke ou in ‘n

*rolstoel wat ek ken. Die feit dat jy nie kan loop nie is nie 'n probleem nie. Die feit dat jy nie normaal kan badkamer toe gaan nie bly altyd die probleem. En vir my nou, is dit die enigste struikelblok as ek rondreis op enige plek [I think the greatest challenges or frustrations to me is when I must do the small things that needs to be done which I always did myself and I cannot do it ... Yesterday I wanted to take out the aircon filter to clean but I cannot reach it ... I cannot bend down and look what there is under the bed. Like if there is a plug behind a cupboard I cannot plug it in. Those frustrations stay there ... To go to the bathroom keeps being a single big problem. To go to the bathroom remains the single largest problem for any guy in a wheelchair I know. The fact that you can't walk isn't a problem. The fact that you can't go to the bathroom as normal always remains the problem. And for me now, it is the only obstacle when I travel to any place.*

As can be deduced from these narratives, some of the activity limitations participants in this study experienced included not being able to walk fast, lean over, use arms, have stable stomach functioning, move around in small spaces, reach certain things and conduct certain finer movements. One participant also experienced neuropathic pain which influenced activity. In terms of everyday activities, participants experienced limitations in terms of being able to bath themselves, transferring themselves, taking things out of the closet, picking up after the dog, lifting and carrying things, driving, arranging the fire for a braai, cleaning the house, turning switches on and off and navigating smart phones. Despite the significance of these activity limitations, a social anthropological study of disability found that the severity of impairment had to be considerably greater for women than for men before it was considered socially acceptable for them to be relieved from their general household tasks (Harriss-White & Erb, 2002).

Most participants were not able to walk due to the impairment caused by their acquired disability. However, many indicated that not being able to walk was not the aspect that they missed most. Some participants did not indicate this directly, but it can be seen from the narratives above that walking is rarely mentioned. On the other hand, some participants explained the fact that other factors were missed more specifically, as can be seen from the following narratives:

- C1P14: *As mense vir jou vra wat jy eerste wil terug hê is seker loop. Maar dit is eintlik, die meeste ouens sal vir jou sê, jou blaas is die eerste ding wat jy wil terug hê van alles wat jy verloor het. [If people ask you what the first thing you want back is probably to walk. But it is actually, most guys will tell you, your bladder is the first thing you would want back of everything that you lost.]*
- C1P17: *If you had three wishes, walking again wouldn't be in the top three ... walking would come maybe 10<sup>th</sup> ... Life is not about being upright mobile I'm sitting down and I'm mobile.*
- C1P18: *As jy gestremd raak het jy mos maar 'n probleem met die seksuele sy van die saak ... dit tas jou maar aan. [When you become disabled, you have a problem with the sexual side of things ... it does affect you.]*

The narratives above are aligned with a study done of 5 262 SCI patients (Simpson, Eng, Hsieh & Wolfe; and the Spinal Cord Injury Rehabilitation Evidence Research Team, 2012), which identified functional recovery priorities such as motor, bowel, bladder, and sexual function. In addition, health, as well as relationships, surfaced as important life domains within this study. Despite some limitations, many participants still that mentioned they were able to do most activities themselves, as can be seen in the accounts below:

- C1P01: *I can dress myself can do my own hair because I'm right hand dominant.*
- C1P03: *It doesn't affect me at all because I can do everything on my own although ... I take my own time but at the end I can do everything on my own.*
- C1P06: *I can wash, cook for myself.*
- C1P18: *(Ek was) baie aktief omdat ek gimnastiek gedoen het so ... ek kon al op my hande loop in die hospitaal al in die gange af so ek kan maklik aangepas het ... ek het baie maklik in die bad geklim of in die kar geklim ... dit begin nou wat jy ouer raak ... begin jy sukkel om te verplaas ... want jou skouers is ook nou maar opgebruik so oor die jare ... ek maak elke aand kos so as my vrou van die werk af kom is die kos klaar gemaak ... ek het altyd tot bo-op die trekker geklim en self geploeg. [(I was) very active because I did gymnastics ... I could already walk on my hands in the hospital down the corridors so I could adapt easily ... I could get in the bath and car easily ... it starts now that one gets older ... one starts to struggle to transfer ... because one's shoulders are*



*also now used up over the years ... I make dinner every evening so when my wife gets home the food is already made ... I always climbed to on top of the tractor and ploughed by myself.]*

*C1P19: Daar (is) bitter min dinge wat ek nie meer doen nie ... sekere aktiwiteite, sekere sporte, om sekere leefwyses uit te leef is daar nog geweldig baie wat ek nog steeds doen. Ek het marathonne gedoen in die rolstoel. Ek speel nog steeds gholf. Ons ski ... So ek het nog baie wat ek steeds kon bly doen het. [There (are) very little things that can't do anymore ... certain activities, certain sports, to live out certain lifestyles there is a lot I still do. I have done marathons in the wheelchair. I still play golf, we ski ... So I do still have a lot I still could keep doing.*

This is aligned with the capabilities approach, where functionings are described as activities (e.g. being able to play sport) (Mitra, 2006) as discussed in Chapter Three. One participant indicated the significant difference that an operation played in her ability to do everyday activities:

*C1P15: Die eerste vyf jaar was moeilik. Ek kon nie myself was, aantrek, hare kam nie, moes vir vyf jaar sonder grimering ... Die sesde jaar het ek n operasie ontvang aan my linkerhand, dokter het 'n pen ingesit dit was baie pyn ... toe kon ek my hand gebruik en tot vandag, sestien jaar gelede, kan ek my was, hare kam, grimeer, aantrek met minder hulp ... en ja, ek maak huis skoon, kook kos, kry net iemand om vir my groente te skil [The first five years were difficult. I could not wash myself, dress, comb my hair, had to go five years without make-up ... The sixth year, I received an operation on my left hand, doctor put in a pen and it was a lot of pain ... then I was able to use my hand and until today, sixteen years ago, I can wash, comb my hair, (put on) make-up, dress with less help ... and yes, I clean the house, cook food, just get someone to peel the vegetables for me.]*

In a study in the Eastern Cape province of South Africa (Dingana, 2012), it was found that people with physical disabilities often made use of caregivers to assist them in in everyday activities such as to fetching water from the well or from a communal tap, doing their washing and to helping them with other activities. Aligned with the existing research and the findings

of this study, this indicates that there are some significant activity limitations experienced by PWDs.

### **6.3.1.2 Sub-theme 1.2: Participation restriction**

Both impairment and activity limitation can influence the PWD's participation restrictions, which refer to the person not being able to experience full involvement in life situations (compared to a person without a disability). Examples of participation restriction of participants from this research study are included in the narratives below:

*CIP01: I need somebody to go to the shops for me.*

*CIP02: Ek wag nog steeds vir [naam van versekering] om te “conversion” van my voertuig goed te keur sodat ek kan beweeg soos wat ek kon beweeg, sodat ek nie so gereeld vir mense hoef te vra om my te vat waarheen ek wil gaan [I am still waiting [name of insurance] to conversion of my car to be approved so I can move around like I used to, so that I do not have to ask people so often to take me where I want to go.]*

*CIP19: As ek rond toer, toer ek alleen. Ek is net afhanklik van die omgewing [When I travel, I travel alone. I am just dependent on the environment.]*

How the PWD experiences these limitations can be affected by contextual factors such as social attitudes, legal and social structures and internal personal factors (DWCPD and UNICEF, 2012). This will be discussed under Theme Two (psychological experiences), Theme Three and Four (societal experiences), as well as Theme Five (cultural experiences). Society could inhibit a PWD's performance by creating barriers (e.g. inaccessible buildings) or not providing facilitators (e.g. unavailability of assistive devices). Participants in this study identified the need for accessibility as a major contributor to their participation restriction. This will be discussed in terms of accessible housing and the accessible community in general. The Housing Policy and Strategy for South Africa (1994) indicated that a housing programme should not only include housing itself, but also address the needs of individuals to promote and give meaning through creating practical communities.

○ **Category 1.2.1: Accessible housing**

Despite some participants being able to make their own homes more accessible (see Theme Three), several of them indicated that even their own home was not accessible for them. This inhibits their ability to participate as they have to rely on others for assistance, as can be deducted from the following narratives:

*C1P03: Even in the flats we are staying in it there is no ramp for wheelchair people meaning you can't stay there if you are using wheelchair.*

*C1P06: Hier is nog nie "ramps" nie daarom is dit buite nie so maklik om te beweeg nie. [There are no ramps here yet so it is not so easy to move around outside.]*

*C1P07: Die huis is nie toeganklik nie, want ons het trappe by al twee deure. [The house is not accessible, because we have stairs at both doors.]*

*C1P08: (The house) is not (wheelchair friendly) ... even the toilet is not wheelchair friendly ... the problem is when I want to go out ... the gate ... my cousin takes me out to the toilet.*

*C1P15: Voor ek my huis verkoop het was dit nie maklik nie, want buite was dit nie toeganklik nie. Moes sukkel met munisipaliteit vir toeganklikheid. Daar het hulle gesê hulle het nie geld nie ek het aanhoudend gegaan. Op die ou end toe sê hulle elkeen is huis eienaars ek moet self my erf toeganklik maak, so het ek dit gedoen kan nou vrylik met my rolstoel beweeg. [Before I sold my house, it wasn't easy because outside it wasn't accessible. Had to struggle with the municipality for accessibility. There they told me they do not have money and I kept going repeatedly. At the end they said everyone is their own homeowners I must make my yard accessible myself, so I did and can move around freely with my wheelchair.]*

One participant explained the 'gap' of houses being built without wheelchair accessibility by stating:

*C1P09: When you build a house, you have to build it as if someone is going to be in a wheelchair because you don't know what could happen tomorrow.*

This coincides with the view of Disabled World that any person can become disabled at any time (2020). Inaccessibility, even in the home, where most would feel safe and comfortable, contributes to participation restriction of PWDs. This was also found in a similar study done in South Africa (Dingana, 2012), where the inaccessibility of houses was attributed to steps at entrances, houses with small passages, minimal wheelchair movement, or toilets too small for the wheelchairs to enter.

As can be seen from these narratives, there seems to be a lack of assistance in ensuring that PWDs' homes are accessible from the community. One of the social workers from Cohort Two explained the importance of accessible housing in contributing to a PWD's ability to participate by stating:

*C2P02: When someone acquires a disability later on in life, their own house can automatically become inaccessible to them and changes may need to be done and this can be a costly exercise ... It is better to consider universal access when building houses but even now when I observe community building projects. There is no universal access. Disability is a human condition that can happen to anyone, but it seems that it is not a priority that should be prepared for when building houses for people. Residential homes for those who are not able to take care of themselves should be increased because some clients are living in shacks ... where there is no accessible sanitation.*

Despite the lack of input from communities, some of the principles upon which the negotiation process and the substantive content of the UN Convention were premised included respect for inherent dignity, individual autonomy and independence; full and effective participation and inclusion in society, which would include accessibility. Accessibility is thus a means to an end, rather than an end in itself (Lang, 2009).

#### ○ ***Category 1.2.2: Accessibility challenges in community***

As became apparent in the previous category, many participants indicated that they experienced accessibility challenges within their communities, contributing to participation restriction. For instance, some of the participants stated:

- C1P01: *The challenges are outside in the community on the streets. Our cities weren't designed with disabilities in mind challenges with the steps on the streets and pavements major challenges, staff at the social development.*
- C1P02: *Om in die paaie te beweeg is ... met die rolstoel ... is verskriklik ... onder die omstandighede ... veral by ongelyke “surfaces”. [To move around in the roads ... with the wheelchair ... is terrible ... under the circumstances ... especially with uneven surfaces.]*
- C1P03: *Like in the community shop there is no ramp for disabled person.*
- C1P15: *Elke dag het sy uitdagings. Baie van die besighede is nie toeganklik nie ... Ek is by Munisipaliteit op wykskomitee ... maar al jou klagtes van op dowe ore, dan raak jy mismoedig. [Everyday has its struggles. Many of the businesses are not accessible ... I am on the municipality ward committee ... but all one's complaints fall on deaf ears, then one becomes despondent. ]*
- C1P16: *Sometimes when I go out maybe going to another areas experience some struggling in terms of accessibility.*
- C1P19: *Daar is mense wat sê hulle verander nie hulle verblyf nie want niemand kom bly daar wat in 'n rolstoel is nie. Maar dit is ook hoekom niemand daar kom bly nie. Party keer is die kleinste verskilletjie nodig. En natuurlik is dit vir elke ou in 'n rolstoel, die verskil baie, baie groot. Die verskil tussen 'n kwadrupleeg en 'n parapleeg is baie, baie groot. Die verskil tussen die (bejaarde persoon) in 'n rolstoel en teenoor my is baie groot. Dat mense sê: “Nee, ons het al baie mense in rolstoele hier gehad.” Maar hulle weet nie dit is 'n (bejaarde persoon) wat kan op staan en loop nie ... klim uit die kar dan stoot hul hom tot by die trappie, dan klim (bejaarde persoon) die trappie ... ek kan nie ... trappies klim nie. [There are people that say they do not change their accommodation because no one in a wheelchair comes to stay there. But that is also why no one comes to stay there. Sometimes the smallest change is necessary. And of course for every guy in a wheelchair, the difference is very, very big. The difference between quadriplegic and paraplegic is very, very big. The difference between the (elderly person) in a wheelchair and me is very big. That people say: “No, we have had many people in wheelchairs here already.” But they don't know it is an (elderly person) that can stand up and walk ...*

*climb out of the car then they push him to the stairs, then the person climbs the stairs ... I cannot ... climb stairs.*

As can be seen by the distinctions made in the final participant's narrative, the ICF model's definition of disability is invaluable. In this definition, disability is characterised as the result of a complex relationship between an individual's health condition, and personal factors and external factors, representing the circumstances in which the individual lives. An environment with barriers, or without facilitators, will restrict the individual's ability to participate within that specific society (WHO, 2001).

### **6.3.2 Theme 2: Psychological experiences of adults with an acquired disability**

As mentioned before, acquiring a disability could lead to different psychological experiences due to the life stage individuals were in when they acquired the disability, as well as how long they have been living with the disability. This theme referred to experiences from Cohort One. The connection between physical disability and the occurrence of emotional and psychological problems is noticeable in terms of aspects such as socialising difficulties, stigmatisation, disruption in marital and family life and suicide risk (Pelletier, Rogers & Thurer, 1985). Participants discussed how they had to adapt and come to terms with their life with a disability which, for many, required a lot of reflection, as can be seen from narratives below:

*C1P02: Ek probeer sin maak met die verskillende tipe aspekte wat kom met die kondisie. 'n Mens is nooit elke dag dieselfde nie, jy leer ken nou weer jou liggaam. Dit is soms bietjie moeilik om weer aan te pas [I try to make sense with the different aspects that come with the condition. One is never the same every day; you start to learn your body again. It is sometimes a little difficult to adjust again.]*

*C1P10: It takes time to realise that your leg is no longer with you because sometimes you will feel the pain or itch in the toes or the leg or something but you won't realise the leg has been cut. You only realise ... when you look but when you are sleeping ... you still have that feeling ... that you still have your leg.*

*C1P13: 'n Groot klomp kop dinge wat 'n mens nou nog moet regskuif. En 'n deel van jouself ... moet jy weer van voor afskep. Dat jy nie meer die persoon was voor die ongeluk is maar jy is ook nog dieselfde ou. En ander mense sien jou nog as 'n geheel ... Dit is meer in 'n ou se kop wat 'n mens nie maklik kan*

*verduidelik nie. [A whole lot of head things that one must now still get right. And a part of yourself ... you have to create from the beginning. That you are not the person like before the accident but you are also still the same guy. . And other people still see you as a whole ... It is more in one's head which one cannot explain easily.]*

*C1P19: Toe ek begin by kom het moes ek geleidelik begin sin maak dat ek my ribbes alles gebreek het ... Ek het my kop baie hard gestamp ... Die gestremdheid was op daardie stadium op die agtergrond gekuif. So ek moes eers deur die onmiddellike probleme kom. So, die heelyd het die gestremdheid in my agterkop gebly. Natuurlik weet jy hier is 'n probleem. Ek is eers daarmee gekonfronteer twee of drie maande later toe ek begin "rehab" het.[When I started to come to, I had to gradually make sense of the fact that I broke my ribs ... I hit my head very hard ... The disability was at that stage moved to the background. I had to first go through the initial problems. So, the whole time the disability stayed at the back of my mind. Of course, you know there is a problem. I was first confronted with it two or three months later when I started rehab.]*

Previous studies found that the psychosocial consequences of living with a SCI result changes in body image after acquiring the injury (Brown, Bell, Maynard, Richardson & Wagner, 1999; North, 1999 as cited in Mothabeng, 2011). Adapting to these changes can be a significant psychological challenge for some individuals, leading to depression and anxiety, fear of rejection by partners or peers, poor coping skills and a struggle with self-identity (Levins, Redenbach & Dyck, 2004; Craig et al., 1999; Carpenter, 1994). Some participants also explained how they had to come to terms with the realisation that the life they planned was not going to be possible for them anymore, as can be seen in the following narratives:

*C1P08: I was going to be a soccer player ... then that was my career ... then that disappoint me very much ... It made me feel down, and not (want to) see people play soccer. It made me jealous because I think they took it from me ... and I can't do anything.*

*C1P18: So rukkies voor dit (gimnastiek proewe) het ek toe die ongeluk gehad terwyl ek besig was om vir Springbok proewe te oefen ... en dan natuurlik jou beroep wat jy wou gedoen het ... (kon nie) by (besigheid se naam) gaan werk nie, want*



*hulle laat nie gestremdes daar toe nie. [A little before it (gymnastic try outs) I then had the accident while I was practicing for the Springbok tryouts ... and then of course your career you wanted to do ... (could not work) at (company name) because they do not allow people with disabilities.]*

Acquiring a physical disability, as in the case of the above two narratives where participants had to give up on major goals after their injuries, could influence a person's self-concept. Self-concept includes self-esteem, group identity, and self-efficacy (Judge, Erez, Bono & Thorensen, 2002; Crocker & Major, 1989; Bandura, 1977; Rosenberg, 1965). To gain a better understanding of the psychological experiences of adults with an acquired physical disability, the sub-themes of the model of grief, loss of independence, resilience and spiritual experiences were identified.

### **6.3.2.1 Sub-theme 2.1: Model of Grief**

Almost five decades ago, a study at a New York Hospital identified a four-stage process by which newly diagnosed paraplegics come to terms with their disability. These stages included shock, denial, anger and depression (Weller & Miller, 1977). These stages are similar to the stages of grief identified by Kübler-Ross (1972) i.e. denial, anger, bargaining, depression and acceptance. Participants in this study identified that accepting their disability is definitely a process made up of different stages.

Building on the five stages of grief identified by Kübler-Ross (1972) Ross and Deverell (2010) adapted the grieving process to nine phases i.e. shock/disbelief, relief, denial, bargaining, guilt, depression, anger, anxiety and acceptance. They define grief as process whereby an individuals separate themselves from someone or something meaningful that has been lost. It should not be considered as only a negative experience, as it can stimulate a re-evaluation of the individual's existential values. Although they focused specifically on the scenario of congenital disability, their study could also be relevant in considering how adults experience acquiring a disability, as in both cases an adjustment of the 'planned life' and 'life with a disability' had to be made. It is important to note that not all participants openly explained how they experienced all the stages but overall, the participants did identify that they experienced most of the stages of grief.



○ **Category 2.1.1: Shock, numbness and disbelief**

One of the first reactions an individual has with the unexpected diagnosis of a disability, is a feeling of shock, numbness and disbelief (Ross & Deverell, 2010). Accordingly, some of the participants stated:

C1P04: *It was terrible. Couldn't believe, (I) thought he's bluffing.*

C1P06: *Skokkend, traumaties en hartseer ... Dit het verbeter, maar van die gevoelens is nog daar. [Shocking, traumatic and sad ... It improved, but some of the feelings are still there.]*

C1P17: *I had no understanding of disability and I couldn't pronounce the word quadriplegic.*

In considering the narratives above, it is clear that participants felt shocked and sometimes even confused (linked with the feeling of disbelief) at the initial diagnosis.

○ **Category 2.1.2: Relief**

A feeling of relief may occur in cases where a diagnosis is received after suspicion that something is amiss, or with finding out that the disability is not as severe as expected (Ross & Deverell, 2010). Accordingly, two participants expressed that they had suspected that something was not completely right, while one of them specifically mentioned feeling relief after diagnosis:

C1P02 *Ek was voorbereid vir ... enige iets toe ek daar in die hospitaal gelê het. [I was prepared for ... anything while I was lying there in hospital.]*

C1P14: *Ek het 'n redelike vermoede gehad ... Ek dink ek het my redelik voorberei daarvoor, sielkundig in my onderbewussyn. En die slegste verwag klaar. Dit was eintlik net vir my OK ... Ek het net by myself gesê: "OK, het so gedink OK, ten minste het jy nou vir my gesê." [I had a pretty strong suspicion ... I think I prepared myself quite well, psychologically in my subconscious. And expected the worst already. It was actually just OK for me ... I just told myself: "OK, I thought so. OK at least you've told me now."]*

Ultimately, the diagnosis granted these participants the opportunity to gain clarity on what they suspected, and as a result, they could work through all the different emotions originating from this diagnosis.

○ **Category 2.1.3: Denial**

Another of the initial responses after a disability diagnosis is denial. The individual may have disputes with the health professional, or even completely ignore the diagnosis and prescribed treatment (Ross & Deverell, 2010). Similar to the feelings of shock and disbelief, a few participants stated that they experienced a sense of denial with the initial diagnosis, as can be seen from the narratives below:

*C1P04: (It) was difficult to admit that I'm really paralysed*

*C1P15: Maar die woord “gestrem” wou ek nie hoor nie, want ek is nie gestrem gebore nie ... Eerstens, dit was moeilik om te aanvaar. Ek was ‘n baie lewenslustige persoon en lief vir die natuur, alles moet perfek wees as ek kan begin met my voorkoms en was ‘n baie private persoon en nou is ek afhanklik van ander mense en sit in ‘n rolstoel. [But the word “disabled” I did not want to hear because I am not born disabled ... Firstly, it was difficult to accept. I was a very energetic person and loved nature, everything has to be perfect if I can start with my appearance and I was a very private person and now I am dependent on other people and am sitting in a wheelchair. ]*

Discussed later in this chapter under the subtheme need for professional support, one participant mentioned being misunderstood for being in denial when believing it would be possible to walk again despite eventually coming to the self-realisation that this was not probable.

○ **Category 2.1.4: Bargaining and Guilt**

The bargaining phase is characterised by fictional thinking of bargaining with oneself, God or health professionals. During this phase, individuals may make idealistic promises for a complete or significant recovery. It may occur because of the individual feeling guilty about the cause of the disability. Such guilt can be displayed in three ways, namely through stories of what they believe caused the disability, a belief that the disability is a punishment and through the ‘just world’ hypothesis. where the belief is that bad things happen to bad people

(Ross & Deverell, 2010). Participants in this study did not indicate that they had experiences of bargaining or guilt as, in most cases, they were victims of crime, accidents or even illness. This might have been different if their disability was caused by different means. These phases are, therefore, acknowledged but not be discussed in detail.

○ **Category 2.1.5: Depression**

Many individuals may experience reactive depression, which often occurs during the grieving process and is a normal and necessary part of it as long as it does not continue for too long (Ross & Deverell, 2010). Most participants admitted to feeling a sense of depression at some point after acquiring the physical disability, as can be seen from these examples:

*C1P01: I had depression for almost seven months. I cried for seven months, because I realised that I couldn't be so active as I ... was.*

*C1P04: It took me about six months to cope. It was hectic. When you go to sleep, (the) morning (you) think you would be able walk again it was terrible ... I was crying everyday eventually I adapt that it's real.*

*C1P07: Daardie oomblik het dit nie regtig by my in gegaan dat ek gestrem is nie ... Ek was teleurgesteld, en dit het gevoel my hele lewe bestaan nie meer nie, so moedeloos gevoel.[That moment it did not really sink in that I am disabled ... I was disappointed, and it felt that my whole life did not exist anymore, felt so helpless.]*

*C1P14: Maar die eerste paar maande was verskriklik baie moeilik. 'n Ou het baie gehuil ... Maar dit is die uitkom uit die hospitaal uit en jy besef dit is net jy in 'n rolstoel. Jy gaan na 'n "mall" toe en dit is net jy in 'n rolstoel. Dan besef jy, jy kom by trappe en jy kan nie op of af by trappe nie. Dit is toe wat dit my baie erg gevang het dat jy uit die hospitaal gekom het en jy sien nie ander ouens in rolstoel buite die hospitaal. En nou besef jy, jy is in die groot wêreld nou. Jy is verlam en in jou omgewing is jy die enigste een in 'n rolstoel. So daai aanpassing was baie moeilik van die hospitaal na die samelewing toe ... Ek was hartseer gewees en geweet dit wat ek altyd gedoen het gaan ek nie meer kan doen nie. Ek dink dit was vir my die heel ergste en ook daardie emosies dat ek later begin huil het.[But the first few months was very difficult. One cried a lot ... But it is leaving the hospital and realising that you are in a*

*wheelchair. You go to a mall and it is only you in a wheelchair. Then you realise, you get to stairs and you cannot go up and down the stairs. It is then when it hit me hard that you came out of the hospital and you do not see others in a wheelchair outside the hospital. And now you realise, you are in the big world now. You are paralysed and in your environment you are the only one in a wheelchair. So that adjustment was very difficult from the hospital to society ... I was sad and knew that what I always did, I would not be able to do anymore. I think this was the worst for me and also those emotions that I later started crying.]*

*C1P16: It was so terrible you know I cried every day after I found out ... It took me a whole a year.*

Depression is described as “anger turned inward” towards oneself (Moses, 1985: 93). Although this definition might not be able to describe depression within all settings, it could be a guide towards understanding depression within the context of this study, as individuals had to come to terms with their disability diagnosis.

#### ○ **Category 2.1.6: Anger**

Anger can reveal itself in different ways during the grieving process, where individuals often question the disability diagnosis (Ross & Deverell, 2010). Only one participant explicitly described that they had a feeling of anger in stating:

*C1P15: Ek was bitter, haat en kwaad want ek sit in ‘n rolstoel. Ek het net gedink (persoon wat ongeluk veroorsaak) het geen skraap opgedoen met ongeluk ek sit in n rolstoel.[I was bitter, hated and angry because I am sitting in a wheelchair. I just thought (the person who caused the accident) did not have a scratch with the accident and I am sitting in a wheelchair.]*

#### ○ **Category 2.1.7: Anxiety**

Ross and Deverell (2010) explain that anxiety is usually displayed by caregivers of PWDs, caused by concern regarding how to balance the extra responsibility of caretaking versus having an independent life of one’s own (Ross & Deverell, 2010). However, in this study, a few of the participants from Cohort One also explained how they experienced some form of anxiety after their diagnosis. The one participant had anxiety in the form of Post-Traumatic

Stress Disorder, more so because of the manner in which the disability was acquired (hijacking), than due to the diagnosis itself:

*C1P14: En ook waaroor ek paranoïes was om in die aand uit te gaan. Om nie voor son onder by die huis te wees nie. So met daai was ek paranoïes veral. Angstig geraak as dit donker geraak het en ek is nog nie by die huis nie. So vir die eerste paar maande was dit vir my baie, baie erg gewees. [And also, what I was paranoid about was to go out at night. To not be home before dark. So, with that I was paranoid especially. Got anxious when it got dark and I was not home yet. So, for the first few months it was very, very hard for me.]*

Conversely, another participant indicated that they felt anxious about how their life would be affected after acquiring the physical disability:

*C1P18: Toe jy uit die hospitaal kom toe kry jy so 'n beklemming van hoe gaan jy regkom op jou eie, want jy weet by die hospitaal is daar darem altyd iemand wat jou help ... dan begin dit jou vang ... dan sit jy maar die dae om en jy kan niks doen nie. [When you got out of the hospital you got an anxious feeling of how are you going to get by on your own, because you know at the hospital there is at least always someone to help you ... then it begins to get to you ... then you sit through the days and you cannot do anything.]*

In the case of the PWDs themselves, anxiety could be displayed when they are uncertain of how the disability diagnosis will affect their life. A study done with persons with Multiple Sclerosis indicated that there was a definite increase in anxiety with the onset of a physical disability (Jones, Jones, Middleton et al., 2014).

#### ○ **Category 2.1.8: Acceptance**

The final phase of grief is acceptance, which coincides with Kübler-Ross' (1972) final stage of grief. This phase can occur when the disability is seen as a positive aspect, and the individual is able to live their life with the disability (Ross & Deverell, 2010). A number of participants admitted that they have grown to accept their disability, as can be seen in the narratives below:

CIP14: *Ek sal sê so vir oor ses maande het ek redelik oor alles gekom en redelik aangegaan met my lewe. [I would say about within six months I mostly got over everything and I could generally go on with my life.]*

CIP17: *I decided almost immediately that I will tell quadriplegia what my dreams and goals are, what I need to do and achieve in life, quadriplegia was not going to define me.*

Despite participants experiencing most stages of grief while coming to terms with their disability, it could be deduced from an analysis of the content that most participants, at the time of the interview, had grown to accept their life with a disability. Social workers play an important role in assisting PWDs and their families in working through the feelings during the different stages of grief. Albrecht (in Mackelprang, 2013) argued that individuals must work through all these stages to be fully socialised, which is aligned with the goals of policies such as the WPRPD (2016) and the UNCRPD (2006), to name a few. This will be further discussed in Theme Six.

### 6.3.2.2 *Sub-theme 2.2: Loss of independence*

The ultimate goals of rehabilitation include minimising disability by ensuring equalisation of opportunities, full participation, independent living and economic self-sufficiency (Dingana, 2012; WHO, 1994). This is an important factor to remember in understanding how the loss of independence could have a psychological impact on the individual. On the other hand, gaining independence again through rehabilitation could have a positive psychological impact on persons with an acquired physical disability. Several participants indicated that they had difficulty adjusting to a life where they were dependent on other people, as is apparent from the narratives below:

CIP01: *I had to constantly rely on people to do things for me really, became a burden for people ... So, and that just what depressed me more.*

CIP07: *Dit was baie moeilik gewees, want ek moes van ander mense afhanklik wees. Ek was jonk en moes weer leer om self vir my dinge te doen soos leer was (en) om my bed op te maak. [It was very difficult, because I had to be dependent on other people. I was young and had to learn again how to do things for myself like learn to wash (and) make my bed.]*

CIP08: *I can't go to some places ... I have to take a taxi ... or I have to ask people ... because I cannot walk.*

CIP13: *So, ek het (vroeeër) nie vier en twintig uur 'n dag iemand saam of iemand in jou onmiddellike omgewing ... So dit is in sy eie 'n groot aanpassing gewees. Maar ons kom daar. [So, I did not (before) have someone with me twenty-four hours a day or someone in my immediate environment ... So, it was in itself a big adjustment. But we are getting there.]*

Some participants even expressed how they experienced people that would want to assist them at times, but that it was not always helpful. Accordingly, they came to realise the importance of gaining back their own independence, as can be seen in the following accounts:

CIP14: *Daar is miskien een ding waar 'n ma baie "protective" was oor my. Maar dit is maar hoe 'n ma is. En ek dink ook wat 'n baie goeie ding was dat 'n mens baie maklik in daardie groef kan val waar 'n ma alles wil doen ... as dit algemeen raak en normaal raak. En met daai ding het ek van die begin af gevoel uitkom, ek wil onafhanklik wees en ek wil nie in so 'n situasie wees waar mense vir altyd vir my iets doen nie. En ek weet dit is uit die goedheid van my ma se hart en dit is hoe 'n ouer is. Maar ek het besef dit kan 'n probleem raak as ek eers in daardie groef beland. 'n Ou raak luier en luier en later moet almal vir jou goed aandra en goed vir jou doen en jy kry jouself jammer as goed nie gedoen word vir jou nie. Ek dink net in daardie opsig was dit vir my moeilik waar ek gevoel het ek moet uit en ek moet aangaan met my eie lewe. [There is maybe one thing where a mum was very protective over me. But that is how a mum is. And I think what was also a good thing that one could easily fall into a habit where a mum wants to do everything ... when it becomes common and normal. And with that thing I felt coming out from the beginning, I wanted to be independent and I don't want to be in such a situation where people always have to do something for me. And I know it was out of the goodness of my mum's heart and that is how a parent is. But I realised it could become a problem when you first fall into that rut. A person becomes lazier and lazier and later everyone needs to carry things for you and do things for you and you feel sorry for yourself when things are not done for you. I think*



*just in that instance it was difficult for me where I felt I just have to get out and I have to go on with my own life.]*

*C1P19: Iemand wat jou sommer begin stoot terwyl ek marathonne doen. Ek is vinniger as ek marathonne doen. En as hulle jou stoot, stoot hy jou uit die stoel uit. Die stoel haak vas ... Vir my is dit die belangrikste dat ek so onafhanklik as moontlik kan wees ... As ek stop en ek klim uit die kar uit dan moet iemand nie kom en my stoel kom vat nie. Want hulle vertraag net die proses. As ek oor klippies met 'n rolstoel ry, doen ek dit met 'n rede stadig want as iemand begin te stoot en die stoel haak vas dan val ons almal. [Someone that simply starts pushing you while I do marathons. I am faster when I do marathons. And if they push you, they push you out of the chair. The chair gets stuck ... To me it is most important that I am as independent as possibly can be ... If I stop and climb out of the car then someone should not come and take my chair. Because they just delay the process. If I ride over rocks with a chair, I do it slowly for a reason because if someone begins to push and the chair gets stuck then we all fall.]*

As discussed in Theme 1, despite the difficulties, many participants were still able to fulfil some of their daily activities. Dingana (2012) found that people with physical disabilities tried to be as independent as possible, such as by continuing to do housework, which is similar to the findings in this study. This emphasises how the loss of independence could have a psychological impact on the adult who acquires a physical disability later in life.

### **6.3.2.3 Sub-theme 2.3: Resilience**

Resilience refers to a universal capacity to prevent, minimise or overcome adversities. It could be a powerful personal factor, which plays a pivotal role in the individual's quality of life (Aranguren, 2017). The concept of resilience has been engaged in diverse disciplines – such as psychology, ecology, and engineering – which in turn influenced its analytical relevance (Evans, 2011; Pickett et al., 2004). Modern use of the term resilience includes exploring both the ability to absorb shocks as well as the ability to reorganise and transform (Ahern, 2011; Folke, 2006; Pickett et al., 2004). There were a number of participants in this study that displayed tremendous levels of resilience and an overall ability to be able to cope with acquiring a physical disability. Some of their thoughts included:



- C1P02: *Maar dan sê ek net vir myself: “Deurdruk is die belangrikste”, want ek het ‘n gesin om voor te leef. [ But then I just tell myself: “Pushing through is the most important”, because I have a family to live for. ]*
- C1P09: *I told myself I have to be strong for my aunt’s sake and for me in order for me to survive in this world ... If I do not accept it, who’s going to accept this kind ... because it is for me, not for other persons. I’m the one who is the victim, I’m the one who is going to use the wheelchair ... so I have to understand it. I cannot put the blame on someone else ... I don’t take my problems to give to other people ... I have to make sure everything is going according to my plan ... I have to face my own problem to be able to survive in this kind of situation ... by the time I was normal, when I see someone in a wheelchair I ... see a shame ... because (they) cannot do anything by himself ... without knowing if I can put myself in (their) shoes, it can be survived.*
- C1P14: *Maar ek dink andersins was ek altyd baie maklik aanpasbaar gewees ... En ek dink daar het ek net vir myself gesê: “OK, ek is verlam. Ek moet die beste van die saak maak”. En onmiddellik het ek my ingesteldheid verander en besef wat is fout met my. Ek was nog altyd so. Ek is ‘n rekenmeester. So hy balanseer of hy balanseer nie. Ek het nog my hele lewe daai ding ... Van daardie dag het ek besluit dit maak nie saak aan my situasie nie ... Ek het net gesê (dat) ek gaan uitgaan, want ek het geweet hoe ongemaklik was dit vir my gewees in so situasie om met iemand te kon praat met iemand wat in ‘n rolstoel is ... so ek gaan dit net omdraai en ek sal net uitgaan en met hulle begin praat. Om net sê moet nie bang wees nie. Moet nie “worry” nie. Ek is net verlam. Daar is niks fout met my brein, kop of enige iets nie. Ek dink ook in daai sin het dit my baie gehelp. Ek het onmiddellik begin uitgaan. [But I think otherwise I have always been very adaptable ... And I think there I just said to myself: “OK, I am paralysed. I have to make the best of the situation.” And immediately my attitude changed and realised the fault is with me. I have always been like that. I am an accountant. So, it balances or does not balance. I have had that my whole life ... From that day I decided it does not make a difference to my situation ... I told myself (that) I am going out because I knew how uncomfortable it was for me in the situation to be able to speak to someone who is in a wheelchair ... so I am just going to turn it around and I will just go*

*out and talk to them. Just to say don't be scared. Don't worry. I am only paralysed. There is nothing wrong with my brain, head or anything. I also think in that sense it helped me a lot. I immediately started to go out.]*

*CIP17: In order to take in the consequences of a spinal cord injury, apply myself in rehabilitation and then have to face the world again while using a wheelchair, I needed some of the business acumen I learnt at UCT, the strategic planning, bullet dodging and the mind of the Fox learnt in the army as well as the resilience needed to complete a Comrades Marathon. In hindsight, I became grateful for all of those experiences ... Quadriplegia needed to fit in with my goals, not the opposite way around. I also will decide where I go, not my wheelchair. Using a wheelchair would not confine me, it will allow me to participate and be mobile in society ... I have achieved most of my goals, I have travelled most of my bucket list, I have worked for myself, as an entrepreneur, for a company as an employee and for an NPO as the CEO. I have travelled more than I have dreamt of. Moreover, I know there's still more to come and be done.*

*CIP19: Maar dit het met die tyd gevat. Aanvanklik het jy gedink jou lewe is ingeperk. So met die tyd het ek meer en meer goed begin doen. Maar ek gelukkig in die posisie wat ek wel baie dinge kon gaan probeer het en gaan doen het ... ek het onmiddellik bedink op goed wat moontlik is eerder as goed wat ek nie meer kan doen nie ... "OK, ek is nou in 'n rolstoel, maar wat kan ek doen met hierdie rolstoel? Hoe kan ek hom gebruik om meer goed te kan doen?" ... Ek was nog altyd 'n pragmatiese ou gewees. So, my onmiddellike reaksie was: "OK, dit is nou dit. Dit help nie nou ek "worry" daaroor nie" ... Ek was nog altyd so met klomp goeters en so. Ek fokus nie op die donker dele van die lewe nie. [But it took with the time. Initially you thought your life is limited. So with time I started to do more and more things. But I am luckily in the position where I could go try and do many things ... I immediately started thinking about things that are possible rather than things I cannot do anymore ... "Ok, I am in a wheelchair now, but what can I do with this wheelchair? How can I use it to do more things?" ... I have always been a pragmatic guy. So, my immediate reaction was: "Ok, this is it. It does not help to worry about it now." ... I have*

*always been like that with a lot of things and such, I don't focus on the dark parts of my life.*

Viemero and Krause (1998) explain quality of life experiences, stating that this is not merely determined directly by disability, but rather how individuals negotiate their disability within certain contexts. As can be seen from the narratives above, most participants at the time of the interview were able to navigate this negotiation quite well.

#### **6.3.2.4 Sub-theme 2.4.: Spiritual experiences**

The term “religion” is not present in the World Report on Disability (WHO and World Bank, 2010). The relationship between religion and disability is complex, and there is evidence indicating that PWDs in the Global South rely heavily on religion. For this reason, authors such as Patricia Bruce (2010) argue that, in Africa, there is a strong belief in God as a healer (Watermeyer et al., 2019). Some participants did indicate that they had a spiritual experience in terms of their diagnosis, as can be seen in the following narratives:

*C1P02 Al gebeur wat, ek gaan weer kan loop ... wie is die dokter om te sê dat ek in “denial” is om te glo dat ek weer eendag sal kan loop? [Come what may, I will walk again ... who is the doctor to tell me that I am in denial for believing that I will be able to walk again?]*

*C1P10: I go to church.*

*C1P15: In my koma het ek ‘n ontmoeting met die Here gehad ... toe ek wakker skrik het ek vir die Here gesê: “Kom werk in my lewe al is dit seer.” En na die ongeluk het ek beseft dit wat jy vra by die Here dit gee Hy vir jou. Ek sê altyd dit was die manier van die Here om my in ‘n hospitaal bed verlam neer te lê, want ek moes luister wat Hy vir my wil sê om terug te kom na die koma. [In my coma I had an encounter with the Lord ... when I woke up I told the Lord: “Come work in my life even though it hurts.” And after the accident, I realised that what you ask of the Lord, that He gives to you. I always say it was the way of the Lord to put me in the hospital paralysed, because I had to listen to what He wants to say to me to come back after the coma.]*

These experiences from participants in this study, correlated with studies in Africa, Uganda, Ghana and South Africa, which found that PWDs describe their impairments as caused by

misfortune, karma, ancestral punishment, witchcraft, or bad luck and associated disability with being sick, worthlessness, or in need of charity, and pity (Visagie, 2018). More specifically, it was also found that, in South Africa, most PWDs (91%) emphasised the importance of religious activities (Graham, 2014).

### **6.3.3 Theme 3: Support services used by adults with an acquired disability according to ecological perspective**

The environment in which an individual finds themselves has a considerable effect on the prevalence and extent of disability. By examining PWDs' social-ecological world, their barriers or whether or not they are integrated into their social environments can be determined. This could also indicate their perceptions of their interpersonal support availability (WHO, 2011). Beyond the family and household, PWDs may find support networks within their communities, either through informal arrangements such as neighbourhood friendships, or through more structured arrangements like organisations (Graham et al., 2014).

The decision was made to make use of Bronfenbrenner's ecological model as a theoretical framework for this study, as it considers the influence that the environment has on the individual depicted as a series of systems which fit into one another. As social workers working on individual, familial and community levels, this model provides a good guide for understanding the PWD in relation to their (social) environment. This theme refers to the experiences of participants from Cohort One.

#### **6.3.3.1 Sub-theme 3.1: Microsystem**

Within Bronfenbrenner's ecological perspective, the microsystem consists of the immediate social environment (e.g. family), or more specifically the most intimate and closest system to an individual (Parker, 2011) where interactions refer to the face-to-face, long-term relationships (Donald, Lazarus & Lolwana, 1997). Participants made use of the spousal/partner, parental, sibling and child sub-system as support networks.

##### **○ Category 3.1.1: Spousal/Partner sub-system**

In a study done by Setareh, Mahmoodi, Jojora et al. (2013), it was found that there were significant associations between marital status and functional and structural support. In their study, married participants appeared to have stronger support. Similarly, number of participants

in this study referred to their spouse or partner as their main source of support, as is apparent in the narratives below:

C1P03: *My boyfriend ... he is always there for me and he understand sometimes that I'm disabled so I need support although he knows I can do everything on my own.*

C1P04: *My girlfriend gave me strength to see that there still life after all this nightmare.*

C1P06: *Ek sal sê die persoon wat my die meeste ondersteun is my meisie. [I would say the person who supports me the most is my girlfriend.]*

C1P13: *Ek is baie afhanklik van my vrou. [I am very dependent on my wife.]*

C1P15: *Ek (was) afhanklik van my man. Hy (het) doen alles vir my. [I (was) dependent on my husband. He (did) everything for me.]*

The finding in Setareh et al.'s (2013) study suggested that a relationship with spouse could be an important factor which influences social support, well-being and quality of life. This finding is consistent with similar studies (Mehrotra, 2004; Fyrand, Moum, Finset, Wichstrøm & Glennås, 2001; Allen, Ciambrone & Welsch, 2000; Reisine, 1993), as well as this study, where participants indicated that their spouse/partner was their biggest source of support.

### ○ **Category 3.1.2: Parental sub-system**

Parents play an important role in providing social and emotional support for children and adolescents, especially for children with a physical disability. This is due to the shift of rehabilitation services from being institutionalised to being provided at home. A few of the participants in this study indicated that the support of their parents was significant by stating:

C1P05: *Especialy my mum she is my hero ... she is always there for me anytime I need her. That's why (I) am saying she supports me because she sees the way I dedicate myself on doing positive things.*

C1P08: *My mother always supports(s) me ... no matter what.*

It must be noted that participants in this study were adults and that most did not live with their parents anymore. One participant specifically noted that they had to move back in with parents and felt a sense of over protection in terms of the support received:

*CIP14: En ek moes weer in trek by my ouers ... Daar is miskien een ding waar 'n ma baie “protective” was oor my. [I had to move in again with my parents ... There is maybe one thing where a mum is very protective over me.]*

The role of parental support is complex and has produced contrasting results within previous research, with some studies suggesting that PWDs experience a sense of overprotection by their parents (as discussed under Theme Two's loss of independence), whilst others identifying the relationship with parents as being supportive and contributing to their success (Antle et al., 2008).

### ○ **Category 3.1.3: Sibling sub-system**

This subsystem teaches siblings to show mutual support to the person with a physical disability (Seligman & Darling, 2007). A few of the participants in this study indicated that they considered their siblings to be a strong support system by stating:

*CIP03: It's nice because when I experience some problems while I'm staying with my boyfriend, I can share that with my sisters especially the young one she even gives me money.*

*CIP14: (Praat oor broer). Ek het nog altyd met hom 'n baie “close” verhouding gehad ... Soos ek sê hy het my altyd verskriklik ondersteun ... Hy het regtig verskriklik baie moeite gedoen om my te ondersteun en te help waar hy kan om dinge te doen wat hy weet ek geniet. [(Talking about a brother.) I have always had a very close relationship with him ... Like I say he has always supported me a lot ... He really put in a lot of effort to support me and to help me where he can to do things that he knows I enjoy.]*

Meyer (1993) discusses the cognitive coping strategies of family members with physical disabilities, who are often overlooked, specifically fathers, siblings and grandparents. He points out that these family members of children with disabilities frequently learn to cope alone, without talking to a peer who has shared a similar experience.

### ○ **Category 3.1.4: Child sub-system**

The social model of disability would associate the need for family members to act as caregivers for PWDs with the failure of both the state to provide services effectively and society to enable

adults with a disability to have independence and freedom from discrimination (Aldridge & Becker, 1999). In such cases, parents may be required to care for children with impairments, or in the case of a parent acquiring an illness or disability, lead to children undertaking care responsibilities. In many families, another adult may also provide care from inside or outside the family unit, along with the family receiving support and services from health professionals, social services, or the voluntary and private sectors (Aldridge & Becker, 1999), as discussed later in this theme. In this study, children were seen only as giving support in addition to other support systems. However, participants indicated that the support received from their children was invaluable, as can be seen from the following narratives:

*CIP10: My children – most of the time they do help me a lot with some house things ... with the shopping, the groceries ... and also when I do the washing, they can also help me.*

*CIP13: Hulle (kinders) is ‘n groot rede om aan te hou. Hulle is regtig ondersteunend ... [They (children) are a big reason to keep going. They are really supportive.*

Aldridge and Becker (1999) argue that it must be recognised that caring for and caring about other people is something that most children are encouraged to do to benefit themselves and society. Parents and teachers often encourage children to have a caring personality and put value to caring and being ‘helpful.’ For this reason, most children will help parents (disabled or non-disabled) in the home with household tasks, childcare, etc.

It was clear within this study that participants placed great value to the support they received from their family members. As a concluding remark on the importance of the different family subsystems under support within the microsystem as discussed, one participant said the following:

*CIP17: Functional family is very significant if you want to be functional.*

This statement is supported by various other studies on PWDs and persons with other chronic diseases that indicate a reliance on family members for caregiving and other support. Similarly, it was found that 90% of persons with chronic diseases are cared for by their relatives (Blanes et al., 2007).



### 6.3.3.2 Sub-theme 3.2: Mesosystem

Within the ecological perspective (Bronfenbrenner, 1979), the mesosystem refers to interconnections between two or more interactions outside the immediate environment (Wait et al., 2005). For the purpose of this study, extended family, friends and professionals were identified as components within the mesosystem of adults with an acquired physical disability. In a survey of 1 505 PWDs in United States of America, it was found that 70% of participants relied on family and friends for assistance with daily activities (Hanson et al., 2003).

#### ○ Category 3.2.1: Extended family

Academic focus specifically identifies extended family members as support systems for persons with physical disabilities as scarce. Most studies refer to extended families as support systems for the family caregivers of PWDs instead of the PWDs themselves. Edmonds (2003) points out that family caregivers do not only make use of their closest family members for support, but also gain a form of support from extended family members, friends, professionals and other community members. In this study, however, two of the participants from Cohort One identified that they received support from their extended family. These extended family members were considered to be their main source of support in both cases, as can be deduced from their statements:

*C1P09: Even my aunt was there for me ... all the time. Supported all the time.*

*C1P15: My “support” van familie was baie goed. Ek sê altyd as dit in plek is sal aanvaarding gouer intree ... My man se suster en haar man ... Die rolle het nou verander, ek kyk nou aan hulle. [My support from family has been very good. I always say if that is in place acceptance will happen sooner ... My husband’s sister and her husband ... The roles have now changed ... I look after them now.]*

Reichman, Corman and Noonan (2008) mention that living with a PWD could have substantial effects, both positive and negative, on the entire family, including the extended family members. Similarly, in the case of this study, it was found that, from the perspective of the PWD, the extended family support was positive at times (as can be seen with the above narratives) and negative at other times (as discussed in Theme Four).



○ **Category 3.2.2: Friends and Peers**

In a study done on the perceived barriers to and facilitators of physical activity in young adults with childhood-onset physical disabilities, it was found that friends or peers were considered to be a facilitator (Buffart, Westendorp, van den Berg-Emons, Stam & Roebroek, 2009). Under the ICF model, facilitators are considered as environmental factors in a person's environment that improve functioning and reduce disability. Facilitators can prevent an impairment or activity limitation from becoming a participation restriction (WHO, 2002). Participants in this study contributed a lot of their ability to accept their disability and be part of society, to their friends or peers, stating:

C1P12: *(My neighbour) brings me water every day.*

C1P13: *Dan kry jy natuurlik jou vriende wat moeite maak met jou en kuier. Wat saam met jou dinge gaan doen ... Ek het 'n baie goeie vriend saam met wie ek fiets gery het, wat vreeslik moeite gedoen het om tydens rehabilitasie, elke dag kom kuier. Hy het eintlik die huis saam met my vrou, die leisels gevat en kontak gemaak met ouens in rolstoele om te hoor hoe die aanpassing moet maak. Gereël dat daar bouers kom ... Toe ek by die huis kom was daar 'n kamer oor gedoen en daar was 'n badkamer langs die kamer opgerig wat daar nooit was nie. Met 'n inry stort en alle geriewe soos dit moet wees. [Then of course you get your friends that make an effort and visit. Who does things with you ... I have a very good friend with whom I used to ride the bicycle, who invested a lot of effort to visit every day during rehabilitation. He actually did the house with my wife, took the lead and made contact with guys in wheelchairs to find out how to do the adoptions. Organised for builders to come ... When I got home, there was a room redone and there was a bathroom next to the room which there never was before. With a drive-in shower and all the equipment like it had to be.]*

C1P17: *The visits and support from friends was actually overwhelming. I decided to talk to many of my friends and ask them to give me the space, time and rest to participate in rehabilitation.*

C1P18: *Ek het toe vinnig vriende gehad wat my ondersteun het. [I quickly had friends that supported me.]*

*CIP19: Dit is een van die grootste dinge wat ek agter gekom het in 'n rolstoel is “peer support”. Jy het nodig om iemand in jou omstandighede te sien om agter te kom dit is OK ... Die ouens wat my bewus gemaak het van my omstandighede en die probleme was rolstoel ouens. Hulle kon my vertel wat was die probleme. Daar is baie persoonlike dinge wat niemand van weet nie ... net iets wat jy kan leer by iemand anderste. En om dan te sien hoe daai ou normaal aangaan met sy lewe. En om dan te hoor hy is al tien jaar in 'n rolstoel of twintig jaar in 'n rolstoel en hy gaan aan. Hy bly op sy eie. Hy maak sy eie kos en ry met sy eie kar rond en dit gee vir jou hoop. So dit bly vir my een van die belangrikste dinge is “peer support”. Sodat ouens kan sien jy hoef nie jouself in 'n rolstoel weg te steek nie ... En dit bly vir my seker die enkele grootste belangrikste ding is om nie groepies te maak ... waar jy mekaar jammer kry nie. Inteendeel. Dit gaan om mekaar uit te daag en te sê : “Wat is daar om te doen?” En dan so gou as moontlik op daardie vlakke te kom ... Ons het 'n klomp pêle wat saam kuier en dinge uitdink om te doen. [It is one of the biggest things I have realised in a wheelchair is peer support. You need to see someone in your circumstances to realise that it's OK ... The guys that made me aware of my circumstances and problems were wheelchair guys. They could tell me what the problems were. There are very personal things that no one knows about ... things you can just learn from someone else. And to see how that guy goes on with life as normal. And then to hear he has been in the wheelchair for ten or twenty years and he goes on. He stays by himself. He makes his own food and he drives around with his own car around and this gives you hope. So this remains one of the most important things for me is peer support. So that guys can see you do not have to hide yourself in a wheelchair ... And for me this is still the single most important thing to not make groups ... where you feel sorry for each other ... On the contrary. It is about challenging one another and to say: “What is there to do?” And then to get to those levels as soon as possible. We have lots of friends who hang out together and think of things to do.]*

From the narratives above, it is clear that friends and peers provided support to adults with an acquired disability in terms of social integration. Further, they supported participants in terms of being able to live a life with a disability. Similar findings emerged from a study done with people living with spinal cord injury in the Tshwane Metropolitan Area (one of the areas also

covered in this study), namely that peer support is crucial in acceptance of the condition and as a source of motivation and encouragement (Mothabeng, 2011).

○ **Category 3.2.3: Health professionals**

Palisano, Almars, Chiarnello et al., (2010) reported that physiotherapists, occupational therapists, speech therapists, developmental paediatricians, neurologists and orthopaedic surgeons are among the health professionals who provide services to children/youth with Cerebral Palsy and other physical disabilities. This finding could also be considered for this study in that participants mentioned that, over the course of their rehabilitation, they made use of psychologists, doctors, pain specialists, physiotherapists and occupational therapists. Since the study was focused on the experiences of social work support, participants also made use of social workers during this process, but this will be discussed more in detail under Theme Six. In short, the participants made specific mention of the health professionals that assisted them in the process of coming to terms with their acquired disabilities, stating:

*C1P02: ... Dat ek van tyd tot tyd 'n plaaslike sielkundige sien ... dit help my soms om met 'n persoon wat my nie persoonlik ken te kan gesels. [ ... That I see a local psychologist from time to time ... it helps me sometimes to be able to chat to a person I do not know personally.]*

*C1P13: Dokters en pynspesialiste, fisios ... Die arbeidsterapeute laat jou probeer eet al mors jy jou hele "T-shirt" vol ontbyt, maar jy moet aangaan. 'n Mens verstaan dit. Daai is nodig. [Doctors and pain specialists, physios ... The occupational therapists let you try to eat even if you mess your whole T-shirt full of breakfast, but you must continue. One understands it. This is necessary.]*

*C1P14: Ek het in die hospitaal net die fisio en arbeidsterapeut gehad wat "obviously" elke dag met 'n mens gewerk het. Ek het ook 'n sielkundige in die hospitaal gehad. [I only had the physio and occupational therapist in the hospital who obviously worked with me everyday. I also had a psychologist in the hospital.]*

*C1P15: Arbeids- en fisioterapie het my baie gehelp.. [Occupational- and physiotherapist helped me a lot.]*

Similarly, one of the social workers also indicated the use of physiotherapists in service delivery to PWDs.

*C2P04: Dan het ek ook nou saamgewerk met die fisioterapeute [Then I also worked closely with the physiotherapists.]*

Ross and Deverell (2010) indicate that the ability to work with professionals is one of the indicators of the final stage of grief i.e. acceptance. In a study done with family caregivers of persons with physical disabilities (Muller-Kluits, 2017), it was found that professionals provided support (emotional support and services) to both the family caregiver as well as the PWD. This finding was also confirmed in this study, as participants indicated support from professionals to be in terms of either emotional support or service delivery.

### **6.3.3.3 Sub-theme 3.3: Exosystem**

The exosystem, under the ecological perspective, is referred to as the community context that may not be directly experienced by the individual, but which may influence the elements of the microsystem. It could include medical, educational and recreational resources, and even the media that could have an impact on the individual (Wait, Meyer & Loxton, 2005). In this study the components identified within this system by participants included social work/welfare organisations, health facilities and other community facilities.

#### **○ Category 3.3.1: Social work/welfare organisations**

After the disability inclusion movement, organisations such as local non-governmental organisations (NGOs) became important resources for PWDs and their families, providing additional training, peer groups of support and advice to households (Graham, 2014). Participants made use of these organisations in terms of social work support services, as can be seen in the following narratives:

*C1P07: Ek maak tans gebruik van ‘n gestremde organisasie ... [I am currently making use of a disability organisation ...]*

*C1P13: Ek moet dam ook sê, die (gestremdeheids-) vereniging het ook baie moeite gemaak in die eerste paar maande. [I must also say, the (disability) association also made a lot of effort in the first few months.]*

*C1P16: We have an organisation ... for disabled people ... I got motivated there.*

Disabled Persons Organisations (DPOs) can support PWDs to become aware of their rights, live independently, and develop their skills (WHO & World Bank, 2011). It is thus important

to include social work/welfare services as a service used by participants. However, as mentioned before, more detailed discussions of this service delivery will be explored under Theme Six.

○ **Category 3.3.2: Health facilities**

In 2001, South Africa adopted a comprehensive primary healthcare package, covering the continuum of primary health care services (ACPF, 2011) aiming to have at least one community health centre (CHC) in each of the health districts. CHCs serves, in most cases, as the first medical point of contact for stroke survivors (Rhoda et al., 2009). In terms of health facilities, participants in this study made use of hospitals (at the onset of the disability) and rehabilitation centres, stating:

*C1P01: When I came out of the coma, I went into rehab.*

*C1P03: She saw that I'm having a stroke ... they take me to (name of hospital) hospital.*

*C1P04: I was taken to (name of hospital) hospital where they are dealing with spinal injuries where I stay for five months.*

*C1P07: Gelukkig het ek geleer by die rehab sentrum. [Luckily I learned at the rehab centre.]*

These narratives correlated with one of the social worker's description of her working within an interdisciplinary professional team along with physiotherapists and occupational therapists in providing services to PWDs.

*C2P04: Dan het ek ook nou saamgewerk met die fisioterapeute in die provinsiale hospitale ... om opvolgbesoeke by die hospitale te doen., met die dokters, fisioterapie of arbeidsterapie [Then I also worked closely with the physiotherapists in the provincial hospitals ... to do the follow-up visits at the hospitals ... with the doctors, physiotherapists or occupational therapists.]*

None of the participants exclusively mentioned CHC's or clinics as a support system. Most of them would return to the hospital or a private practitioner when health services were needed. Anderson et al. (2000) suggested that there is a heavy reliance on hospitals for services such as physiotherapy with limited access to community-based rehabilitation facilities, and that this could be due to patients viewing the physiotherapy services offered at CHCs as inferior. This

can also be seen from the reference made by the participant from Cohort Two to liaising with the provincial hospitals.

○ **Category 3.3.3: Other community facilities**

Although most participants made use of family and friends for support, there were a few that indicated that, besides social work and disability organisation, they also received support from other community facilities. These facilities included religious institutions, their work as well as community sport groups, as specified in the following narratives:

*CIP04: My pastor gave me job at his shop where I was doing stock taking.*

*CIP13: Daar was 'n predikant van ons bure wat na die hospitaal my kom besoek het en by die huis. Vir twee keer 'n maand kom hallo sê. [There was a pastor of our neighbours that came to visit me at home after the hospital. Two times per month come to say hello.*

*CIP14: Behalwe my familie is die werksondersteuning definitief die beste ... [Besides my family the work support is definitely the best ... ]*

*CIP19: Dan is ek ook betrokke by rolstoel sport. Dit is waar die gholף, die ski en padwedlope in kom. [Then I am also involved with wheelchair sport. That is where the golf, the ski and road races come in.]*

The minimal indication of participation for the use of other community facilities could be due to various reasons, including the lack of resources. Fisher (1997) is of the opinion that NGOs have often stepped in where government services have failed to provide for communities' unique needs. In a study done in Uganda, Kenya and Zambia, most participants made use of the assistance of an organisation for support.

In a study done in Butterworth in the Eastern Cape province of South Africa, service providers felt there were not enough resources for people with disabilities (Dingana, 2012). This coincides with some of the challenges experienced by social workers (Cohort Two) discussed further in Theme Six.

#### **6.3.4 Sub-theme 3.4.: Macrosystem**

The macrosystem is the wider social, cultural, and legal context that encompasses all the other systems (Xu & Filler, 2008), including those in which the individual does not necessarily have

direct contact. For the purpose of this study, the macrosystem components for services used by participants included the South African Health Care System, as well as other support services.

○ ***Category 3.4.1: The South African Health Care System***

The South African health-care system is divided into public (government) health services, which are funded through taxes and private health-care services as well as through medical schemes or out-of-pocket payments from patients themselves. Both public and private of health care services have their advantages and disadvantages, as discussed in Chapter Two (Ngubo & Muller, 2015). Participants in this study made use of both the private and public health care system, and some even a combination of both. Most participants, however, made use of the public health care system, relying on governmental support.

○ ***Category 3.4.2: Other support services and utilities***

Assistive devices like wheelchairs, walking frames, crutches, orthotics and prosthetics, are important tools that are used by people with physical disabilities to overcome barriers, (DPSA 2001).

- ***Assistive devices***

An assistive technology device can be defined as any item or piece of equipment that is used to increase, maintain, or improve the functional capabilities of PWDs (ATA, 2004). Common examples of assistive devices include (but are not limited to) mobility devices; hearing devices; visual devices; speech devices; and cognitive devices e.g., day calendars with symbols (Assistive Technology Act, 2004). Participants in this study mostly made use of mobility devices and devices that assist with finer motor skills, accessibility and continence.

*A Mobility devices*

Mobility devices could include crutches, prostheses, orthoses, wheelchairs, and tricycles (ATA, 2004). Most of the participants acquired a spinal cord injury, and accordingly made use of wheelchairs as mobility devices. There were, however, also participants that made use of other mobility devices such as crutches, a quadrupod or a walking cane. The specific types of mobility devices used by participants is expressed in the following narratives:

C1P01: *Yes, only when I was going out shopping or go somewhere long distances then I use my wheelchair. I use a ... smaller quadrapod if I move around.*

C1P07: *Ek maak gebruik van krukke. [I make use of crutches.]*

C1P15: *Die eerste vyf jaar was ek in rolstoel. Met baie oefeninge kon ek weer leer loop. Ek kan alleen in huis rond beweeg, maar as ek buite loop gebruik ek 'n loopstok of haak by iemand in. Om my daaglikse werk te kan doen gebruik ek 'n elektriese rolstoel. [The first five year I was in the wheelchair. With a lot of exercises, I could learn to walk again later. I can move around alone in the house, but when I walk outside, I use a walking cane or link arms with someone. To be able to do my daily work, I use an electrical wheelchair. ]*

One participant noted that people tend to think that all wheelchairs are similar, and stressed that, essentially, they are extremely specific to the person:

C1P15: *Jy moet net 'n rolstoel kry maar 'n rolstoel is vreeslik spesifiek (van) jou lengte, jou gewig, jou heupe en arm lengte. [You must get a wheelchair but a wheelchair is very specific (of) your length, your weight, your hips and arm length. ]*

This was also stated in an article in Rolling Inspiration, a South African publication for people with mobility impairments (Rolling Inspiration, 2016). In this article, it was noted that good seating was individual-specific, and that incorrect seating could often lead to secondary disabilities such as pressure sores, collapse of the spinal column and lung and kidney complications. Some participants in this study agreed to share photos of the wheelchairs they use as can be seen from Figure 6.9. Here, the difference in seating, height and footrests can be seen. A few participants also made use of an electrical wheelchair.



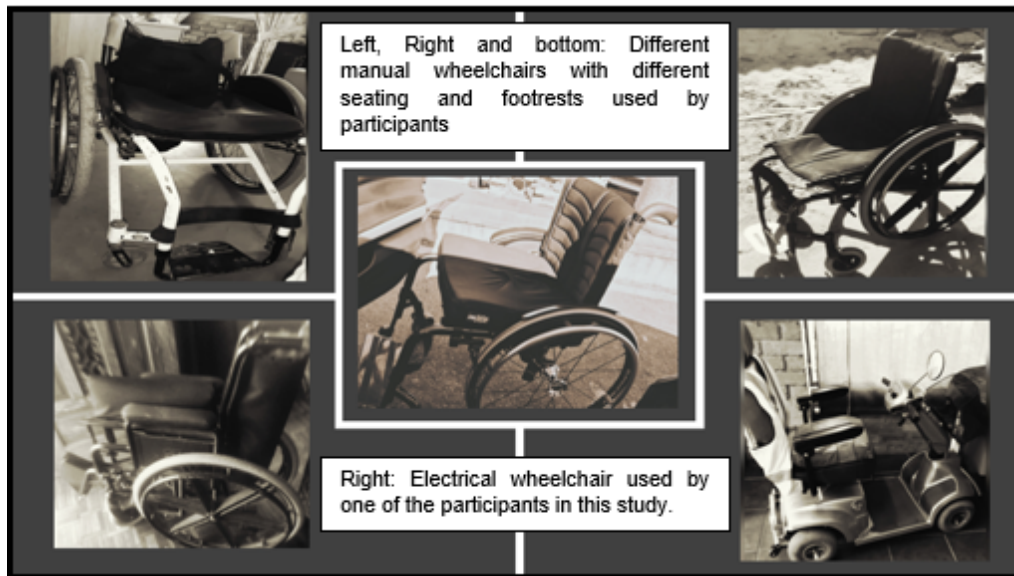


Figure 6.9: Wheelchairs used by some of the participants of this study.

One participant indicated that, as part of their sport group, they buy different sport equipment that are adapted and share this equipment to save on the cost, but that these also allow people to be able to participate in different sports:

*CIP19: Dan is ek ook betrokke by rolstoel sport ... gholf, die ski en padwedlope ... Wat jou terug hou van rolstoel sport is dit is baie duur ... My ski stoel (wat ek) gebruik is 'n baie duur stoel. Ons het ... geld ingesamel en toe koop ons 'n stoel. En daai stoel is beskikbaar vir ander rolstoel ouens om te kan gebruik ... Ons het 'n water ski ... stoel daarvoor ook. [Then I am also involved in wheelchair sport ... golf, the ski and road races ... What inhibits you in wheelchair sport is that it is very expensive ... My ski chair (that I) use is a very expensive chair. We have ... raised funds and then we bought a chair. And that chair is available for other guys to use as well ... We have a water ski ... chair for that as well.]*

Only a few participants were able to adapt their cars to still be able to drive it after acquiring their disability. One participant consented in providing a picture of how the car was adapted, as can be seen in Figure 6.10.



Figure 6.10: An example of a car that was adapted for one participant.

Being able to drive a car contributes to independent mobility (Ranney & Hunt, 1997). Two participants described how their vehicles were adapted, stating:

*CIP14: Net my kar is aangepas. [Only my car is adapted.]*

*CIP18: Ek het 'n bakkie wat ek meer ry elke dag ... en dan het ook 'n kar wat aangepas is ... so hulle is al twee aangepas. [I have a “bakkie” that I drive with every day ... and then I have a car which is adapted ... so they are both adapted.]*

Driving a car can prevent involuntary isolation and facilitate participation in work, education, and social life for PWDs (Hendriksson & Peters, 2004).

### *B Fine motor devices*

One participant, specifically made use of several assistive devices that assisted with fine motor skills in terms of typing, writing and even painting. The individual identified one of the devices in particular, stating:

*CIP17: I use writing splints.*

An example of the devices used can be seen in Figure 6.11 (left and middle) with another device that assist with fine motor skills such as typing on the computer (right).



*Figure 6.11 An example of some of the assistive devices used by one participant to assist with fine motor skills.*

Several studies (Bolton et al., 2006; Metz & Whishaw, 2000) found that even a slight improvement in hand function can have a vast effect on the PWD's quality of life after acquiring a spinal cord injury.

### *C Accessibility*

Accessibility is an important aspect in terms of inclusion and independence for many persons with physical disabilities. The impact of lack of accessibility will be further discussed in Theme Four. Many participants adjusted their own home to make it more accessible by means of ramps, as can be seen from one participant's photos in Figure 6.12.



*Figure 6.12: Example of ramps built by one participant*

Despite South Africa's increase in housing construction and delivery since 1994, the growing number of households living in informal dwellings contributes to the fact that the goal of ensuring universal access to adequate housing is not being met (Selebalo & Webster, 2017).

Adapting homes such as the one above is expensive, and would not always be possible for PWDs from low socio-economic circumstances.

#### *D Continence devices*

There were a few participants who indicated the use of continence devices, especially those who experienced some form of spinal cord injury, as the injury affected this aspect of their life. This can be seen in the narratives below:

*C1P02: Dit is op die oomblik die “kemout” wat ek gekry het om te gebruik ... dan is dit die ramp wat hulle gegee het. [It is at the moment the commode that I got to use ... then it is the ramp that they gave.]*

*C1P14: Ek het ‘n kateter wat ek nie altyd gebruik nie ... Ek gebruik dit net as ek weg gaan waar ek nie weet, hoe die geriewe by die plek lyk nie. [I have a catheter that I do not always use ... I only use it when I go away where I do not know, how the facilities at the place looks.]*

As stated in Theme One, many participants indicated that the use of their bladder would have been one of the main things that they would want to have back. In the example of a SCI (affecting most participants from Cohort One), a temporary or permanent deficit in sensory motor, bladder and bowel function can occur as a result of a pathology or a traumatic lesion of neural elements in the spinal canal (Nielsen, 2003; Dorsett, 2001), requiring the use of continence devices.

#### ○ ***Category 3.4.3: Financial assistance***

It has been suggested before that the occurrence of disability in a family can often place extreme financial demands on the family, as there are increased medical and transport expenses. Therefore, disability can create and aggravate poverty by increasing economic strain. This bi-directional link was explained in Chapter Three under the Capabilities Approach, and will be further discussed in Theme Four. To overcome this financial concern, some participants made use of financial assistance in terms of social grants and insurance.

#### *- Social Grants*

Graham et al. (2014) indicated that 51% of people with disabilities in South Africa make use of social grants as a source of income. The South African province of KwaZulu-Natal had the

highest access to disability grants (25.5%), followed by the Eastern Cape (16.5%) and the Western Cape (14%). KwaZulu-Natal also had the highest access to Grants-in-Aid (54.7%), followed by Limpopo (19.1%) and the Eastern Cape (14.4%) (DSD, 2016). Graham et al. (2014) noted that, even with the assistance of the disability grant, 69% of PWDs in 2014 lived below the poverty line (less than R502 (US\$52.84) per month). In Figure 6.6. it was indicated that nine of the nineteen participants were unemployed, and therefore likely would rely on the disability grant for financial support. A few participants specifically made mention of the disability grant as a support mechanism:

*CIP01: I have to rely on my disability grant.*

*CIP05: I do get grant ... I do get money from SASSA.*

During the 2020 South African Budget it was indicated that the DSD, through its agency the South African Social Security (SASSA), provides social grants to over 18 million eligible beneficiaries (31% of an estimated 58.5 million population). Of this number, close to 12.5 million receive Child Support Grants, followed by the Old Age Grants at 3.5 million, Disability Grants at just over 1 million, and the balance covering Care Dependency, Foster Care, Grant in Aid and the War Veterans Grant (RSA, 2020b).

#### - Insurance

A few participants indicated that insurance played a large role in supporting them. One participant noted an insurance policy of a deceased spouse as a support system. Another mentioned that social insurance played a role in supporting them with both monetary and physical resources, stating:

*CIP02: By die (naam van versekering) het ek aanspraak gemaak sodat hulle vir my ‘n tydelike ramp kan gee, ek het dit ontvang ... ek het ‘n “kemout” gekry. [I made a request with the (name of social insurance) so that they could provide me with a temporary ramp, and I received it ... I received a commode.]*

A study with SCI patients in Tshwane Metropolitan Area found that, for 40% of participants, their main source of income was a disability grant, while 25.6% were employed and 21.3% had other sources of income including a disability pension and compensation for occupational injuries. A further 15% had no income at all and were financially supported by other family members (Mothabeng, 2011). These sources are consistent with this study, where one

participant indicated that they received monetary support from their life insurance policy in terms of the incapacity policy that they took out prior to acquiring the disability:

*CIP13: Die lewensversekering is die laaste twee jaar die grootste verskil maak en ek was gelukkig genoeg om 'n ongeskiktheid polis te hê wat ook insluit die kinders se skool en universiteits gelde. So hulle is ongelooflik ondersteunend en hulle altyd onmiddellik beskikbaar as daar probleme is. [The life insurance has made the biggest difference the past two years and I was lucky enough to have an incapacity policy which also includes the children's school and university fees. So they are incredibly supportive and immediately available when there are problems.]*

According to the World Report on Disability (WHO & World Bank, 2011), assistance and support are prerequisites for participating in society for many PWDs, who are identified as a priority in both international and South African policies such as the UNCRPD and WPRPD. In terms of the ICF model, aspects such as an accessible physical environment, the availability of relevant assistive technology, positive attitudes of people towards disability, as well as services, systems and policies that aim to increase the involvement of PWDs, could all act as facilitators (WHO, 2001).

#### **6.3.5 Theme 4: Support needs of adults with an acquired disability according to ecological perspective**

Dingana (2012) did a study specifically focusing on the needs of persons with physical disabilities in Butterworth in the Eastern Cape province of South Africa. This study found some of the needs of persons with physical disabilities to include accessibility of buildings, accessibility of transport, assistive devices, rehabilitation, employment, skills training and income generation, independence, social integration, caregivers, and other social services.

Some other needs of people with physical disabilities, identified by other studies and discussed in Dingana (2012) include social inclusion (Kennedy, Sherlock, McClelland, Short Royle & Wilson, 2010), economic independence (Vila, Pallisera & Fullana, 2007), need for primary health care (Burns, Batavia, Smith & DeJong, 1990; Schopp et al., 2002; Jelsma, Maart, Eide, Ka & Loeb, 2007), need for love and intimacy (Chance, 2002), and finally, a need for access to knowledge about policies and rights for people with disabilities. Accordingly, this theme will refer predominantly to the experiences of participants from Cohort One, with participants



from Cohort Two providing some input. The needs will also be unpacked within the different nested systems of the ecological perspective.

### **6.3.5.1 Sub-theme 4.1: Microsystem**

Although many of the participants received adequate support at the microsystem level, there were some that still identified a need within this system. The need identified in this study within the microsystem of adults with an acquired physical disability was the need for intimate relationships.

Figure 6.5 indicated that the majority of participants were either single, divorced or widowed. Although the need for intimate relationships were not identified exclusively, the discourse of interviews suggested that there was a general feeling of missing deceased spouses and a form of regret for marriages not working out. This sense of loss and regret is expressed by two participants, who state:

*C1P15 My man sterf aan hartaanval 2003 nou weet ek nie watter kant toe nie ... hy doen alles vir my. [My husband died of a heart attack (in) 2003 now I do not know which way to go ... he (did) do everything for me.]*

*C1P17: If you had three wishes ... one maybe being successful marriage.*

This finding is aligned with a study done by Nganwa, Batesaki, Balaba, Serunkuma & Yousafzai (2002), who found that PWDs have a need for marriage and to have their own children who, in turn will look after them in old age.

### **6.3.5.2 Sub-theme 4.2: Mesosystem**

The mesosystem consists of the interrelationships between two or more settings in which a person actively participates (Edmonds, 2003). The support needs within this system identified in this study include the need for extended family support, professional support and understanding.

#### **○ Category 4.2.1: Extended family support**

Despite some participants in this study finding support from extended family members, there were also a few participants who indicated that they had the opposite experience. They

indicated that extended family support was lacking and could even be described as fading, as can be seen in the following narratives:

*C1P01: Extended families can also be your worst enemy (you) will constantly have to ask them then they will make you wait they will not fetch you on time.*

*C1P02: Die “support” van familie is nie meer dieselfde nie, soos aan die begin hoe dit was nie. En dit is net soos die maatskaplike werker vir my daar by die rehab gesê het dat mense geneig is om aan die begin ‘n helpende hand te wil wees of te ondersteun en dan ... later ... dit “fade”. En dit is wraggies die waarheid ... vir sekeres kan ek nog op staat maak om vir my goed te doen, waar ander gesmeek en gesoebat moet word. [The support of family is not the same anymore, as the beginning how it was. And that is just like the social worker at the rehab told me that people are inclined to want to be a helping hand at the beginning or to support and then ... later ... it fades. And that is really the truth ... for some I can still rely on to do things for me, where others have to be begged.]*

These experiences are similar to the findings of Quittner et al. (1990), who discovered that social support often deteriorates over time for many family caregivers of persons with chronic health conditions.

#### ○ **Category 4.2.2: Professional support and understanding**

In Theme Three it was identified that participants made use of professionals. However, not all the participants had positive experiences with these service providers. Several participants indicated that they did not feel they received adequate support and understanding from these professionals. Therefore, sufficient professional support and understanding for their circumstances was identified as a need by some participants, as is apparent in the following narratives:

*C1P02: Al ding wat my net baie afgesit het was die dokter nadat ek met die maatskaplike werker by die hospitaal gepraat het, het die dokter gevoel dat ek in “denial” is omdat ek gesê het al gebeur wat, ek gaan weer kan loop. Dit is die optimisme in my persoonlikheid wat vir my gedra het deur die tyd ... volgens my het dit vir my gehelp, want ek het agterna self vrede gemaak met*



*as dit so gebeur dat ek nie weer kan loop nie, dan sal ek nie weer kan loop nie. Maar wie is die dokter om te sê dat ek in “denial” is om te glo dat ek weer eendag sal kan loop. Dit het vir my afgesit . [The only thing that really just put me off was the doctor after I spoke to the social worker at the hospital, the doctor felt I was in denial because I said no matter what, I would walk again. This is the optimism within my personality that carried me through this time ... according to me it helped me, because afterwards I made my own peace with if it so happens that I won’t be able to walk again, then I won’t walk again. But who is the doctor to say that I am in denial because I believed I would be able to walk again. That put me off.]*

*C1P14: Ek het ook ‘n sielkundige in die hospitaal gehad op daardie stadium wat ‘n fiasco was. Ek dink, dit was ‘n jongerige ou gewees en ek dink nie hy was genoeg opgelei op daardie stadium nie ... So ek voel net dat hy nie ‘n “clue” gehad waarvan hy praat nie. [I also had a psychologist at the hospital at that point that was a fiasco. I think, it was a youngish guy and I don’t think he was trained enough at that point ... So I felt he did not have a clue what he talked about. ]*

*C1P17: The orthopaedic surgeon who performed my neck fusion came to me and said: “you are a quadriplegic. You won’t be able to do this, you won’t be able to do that ... “. I could not spell the word let alone understand what it meant in terms of recovery and future agility and lifestyle and choices. I wanted to walk again. Let us be honest all of us suffering SCI want to.*

*C2P04: Dat die hospitaal self ... die gesinslid ... nooi vir ... ‘n paar sessies rondom die emosionele ondersteuning en die fisiese ondersteuning wat gebied moet word om hierdie persoon te versorg, dan sal dit ook baie help ... [ That the hospital itself ... invite ... the family member ... for a few sessions around the emotional support and physical support that must be given to care for this person, then that will also help a lot.]*

The need for professional support and understanding seems like a paradox, as both extended family and professionals were identified as support services used by participants in Theme Three. It is, however, important to note the explanations given by participants in the narratives above concerning why these were still important needs for some participants. Particularly

striking is the participant who identified that support provided to family caregivers in explaining the physical and emotional needs of the PWD could in turn benefit the person who acquired the physical disability.

### 6.3.5.3 *Sub-theme 4.3: Exosystem*

The exosystem is the community context that may not be directly experienced by the individual (Xu & Filler, 2008; Visser, 2007; Chetkow-Yanoov, 1997). Under this subsystem, participants identified social work/welfare organisations (which will be discussed under Theme Six), post-discharge rehabilitation, community support services, community safety as well as transport systems as needs. As mentioned in Theme Three, participants did make use of social work/welfare organisations, but this was also not always experienced in a positive manner and will be discussed more thoroughly under Theme Six.

#### ○ *Category 4.3.1: Post-discharge rehabilitation facilities*

In terms of health facilities, Rhoda et al. (2009) examined the rehabilitation of stroke survivors at community health centres in the Western Cape, and identified the limited rehabilitation services as a challenge. One participant, specifically, identified the gap between the hospital and community health centres by stating:

*C1P01: There was a gap between hospital and the community health centres ... There was really nothing no support in between the mainstream hospitals in the local hospital there was no referrals from social workers ... I think the public health system must use an integrated strategy we are concerned from where it happens to the hospital from the hospital to the community health centres in home there is no intermediate. we have to do that ourselves ... . People don't know where to go.*

When considering stroke survivors as an example, it is important to realise that most of these survivors still have impairments when discharged, but are often sent home with no post-discharge rehabilitation services (Edwards, Hahn, Baum & Dromerick, 2006). The value of post-discharge rehabilitation must be noted for community reintegration. Unfortunately, in South Africa there is a shortage of post-discharge rehabilitation services for patients who use government facilities (Kusambiza-Kiingi et al., 2017). In 2009, it was established that, of the

39 community health centres situated in various districts within the Western Cape, only 20 offered rehabilitation services (Rhoda et al., 2009).

A few of the participants in this study also indicated a lack of community support, but did not identify a need for post-discharge rehabilitation specifically, merely a lack of community support in general.

○ **Category 4.3.2: Community support services**

Building on the lack of post-discharge rehabilitation facilities, a few participants in this study also felt that there were not sufficient community support services available, as can be seen in the narratives below:

*C1P01: It was very difficult to find a place because there was money involved and there was no support, the only support I had was from my husband and that wasn't enough, there was no outside support.*

*C1P06: Ja, hier by ons is nogal 'n gebrek aan dienste. Hier is nie ondersteuningsgroepe nie. [Yes, there by us is quite a shortage of services. There aren't support groups.]*

*C1P07: Ek het al drie keer my "learners" geslaag en verval want hier is nie 'n aangepaste kar om uit ge"pass" nie. [I already passed my learners three times and it expired because there is no adapted car to do the test.]*

*C1P09: We don't have a place where we can train ... to avoid to go to the physio ... you have to do things on your own without waiting for the physiotherapy to help you.*

*C1P13: En daardie maande na jy uit rehabilitasie kom waar jy een of twee stoele kan probeer voor jy self "commit" om 'n stoel te koop ... Dit sal 'n reuse verskil maak as dit beskikbaar is. [And those months after you get out of rehabilitation where you can try one or two chairs before you commit yourself to buying a chair ... That would make a huge difference if it is available.]*

The statement from one of the participants (C1P07) above coincided with a finding from Dingana's study (2012), which also had one participant who pointed out that need for a driving school that catered to people with physical disabilities. This participant also indicated the

concern for the expiration of their learner's license. The lack of community services (or resources) is also mentioned later in Theme Six, as some of the challenges experienced by social workers are discussed.

○ **Category 4.3.3: Transport systems**

Dingana (2012) found that normal public transport was not suitable to be used by people with physical disabilities. It was found that climbing into the vehicles was not possible for some people with physical disabilities, which meant that they had to be lifted into the taxis. Participants in this study had similar struggles, stating:

*C1P01: I cannot get in a taxi because of taxis don't pick up people with wheelchairs.*

*C1P04: Transport travelling with taxi (is) difficult, but you have to ignore rude taxi drivers. They talk nonsense to you asking you why can't you get private transport. (Name of business) disability transportation got poor service.*

*C1P07: Publieke Vervoer ... Soms is dit moeilik, want die persone weet nie hoe om ons gestremdes te help by die taxi nie en dan word daar gesê ons kan net in sekere taxi's in klim. [Public transport ... Sometimes it is difficult, because the people don't know how to help us (PWDs) into the taxi and then we are told that we can only get into certain taxis.]*

*C1P09: The transport is a nightmare for us ... the taxi ... sometimes you have to put your chair on top of you ... and then you going to pay for that chair ... The (company name) that is supposed to help us ... you have to book them seven days earlier ... so some people they don't want to travel because of this kind of situation they are facing.*

*C1P11: Yes, it's the transport ... because you want to do something ... you need transport ... you need to put money to hire taxis and the taxis treat us in other way. They don't treat us like a human being. They treat us (in) other way.*

Despite these challenges, many participants did not have their own, private transport, and relied on public transport. Transport was identified by adults with an acquired physical disability in this study as one of their biggest needs. It was also interesting that even social workers from Cohort Two identified this as a struggle for their clients with disabilities, as can be seen from the narrative of one participant below:

*C2P03: The taxis don't want to assist you. You are taking up space, taking up time ... and you will have to pay for your wheelchair ... (company name) is supposed to assist persons with disabilities but their vehicles are breaking down ... they are also experiencing financial difficulties*

Mothabeng's study on SCIs (2011) found that one of the main barriers to community participation for PWDs, as also emerged from this study, was transportation. Accessible transport is essential in the lives of people living with spinal cord injury because of their limited mobility

#### ○ **Category 4.3.4: Community safety**

As indicated in Figure 6.4., many participants acquired their disability through means of violence i.e. gunshot or stabbing, indicating a potential lack of safety in their community. For this reason, a few participants mentioned their concern for community safety, stating:

*C1P04: My community is rough there are thugs ... I was shot gunshot wound by thugs, but it was a cross-fire.*

*C1P10: The other day ... this guys was driving my trolley ... sometimes at the end of the month there's lots of people ... so he., ran away with my trolley ... I tried to find him but it was difficult because ... I cannot run. Imagine someone take your ... monthly grocery ... and then there is nothing you could do about that.*

It is again critical to take cognisance of the difference of experiences between participants. Despite some utilising services such as welfare organisations and other community services (as discussed in Theme Three), some specifically identified these services as needs, the implication being that they would not survive without them. The reasons provided by participants for these needs could assist in understanding how to improve on these services.

#### **6.3.5.4 Sub-theme 4.4: Macrosystem**

In South Africa, PWDs face multiple forms of discrimination in various capacities, including in respect of access to health care services, employment and education (SAHRC, 2015). The needs identified within this system by adults who acquired a physical disability, coincided with this research, as disability-friendly employment and financial concerns were identified in this study.

○ **Category 4.4.1: Disability-friendly employment**

The 2030 National Development Plan states the employment equity and work opportunity targets for PWDs should increase to a minimum of 7% by the year 2030 (SAHRC, 2015). According to the Employment Equity Act No 55 of 1998 (Department of Labour, 1998), PWDs have a right to be employed. This act further states that measures must be taken to identify and eliminate employment barriers, including unfair discrimination. Nine participants in this study were unemployed, and many identified employment for PWDs as a critical need. Some participants also identified that they were employed prior to acquiring their disability, but struggled finding employment since. These factors can be seen in the following narratives:

*C1P03: I was working at (name of business) Head Office as Data Capture, that's where I got a stroke ... It did affect me because I can't find a job because I'm disabled, only learnership ... I think the people who viewed my CV's, when they see on disability I wrote physical disabled they reject it because they've got that little knowledge of that when you are disabled you can't work properly.*

*C1P10: To get a permanent job is very difficult as a disabled person ... because the company, most of the time, I don't know if they feel like we are not going to be able to do the job well because we are disabled.*

Despite many policies such as the Employment Equity Act, National Development Plan and WPRPD being in favour of people with disabilities being employed, there are still few PWDs who are employed. Mothabeng (2011) found that, in addition to transport, employment was one of the main barriers to community participation by people living with spinal cord injury.

○ **Category 4.4.2: Financial concerns**

Understandably, the lack of employment opportunities for participants in this study lead to financial concerns. Although some participants had some financial support, as indicated under Category 3.4.3, a significant number experienced financial challenges. These concerns, however, were not only expressed by participants who were unemployed. Many expressed a concern for the finances and the cost of different services, equipment and other support. Struggles faced by different participants of Cohort One are expressed in the narratives below:

- C1P01: *I didn't have the finances to have a full-time nurse so yes, it was really very complicated to adjust to the conditions at home.*
- C1P03: *Not yet, but since I stayed with my boyfriend from 2016 until now I only start this year to be not working, so that give me a problem because I'm not used to asked everything from my boyfriend ... I have to ask him money for pads, I didn't used to do that.*
- C1P08: *The grant money is too little.*
- C1P10: *When I go and do the shopping ... it is because I have to go buy from this shop to another shop ... which for me is difficult to carry those items ... so I need to maybe pay a R10 trolley extra to go to another shop instead of carrying those few things to the shop. Then from that shop I must pay another R10 and then when I go home ... then I have to take the public transport, the taxi again ... and then when I arrive home I have to pay someone again to carry the stuff for me. Maybe another R10 ... to help my son to help carry from the taxi to home, the plastic bags ... It is quite expensive.*
- C1P13: *Die hulpmiddels is duur en baie spesifiek. [The assistive devices are expensive and very specific.]*
- C1P15: *Nou is ek weer bitter, haat, en kwaad, want ek het nie geld om vir my behoeftes te voorsien nie. [Now I am bitter again, hate, and anger, because I don't have money to cater for my needs.]*
- C1P19: *En dinge in 'n rolstoel is duur. As jy iets breek in 'n rolstoel is dit altyd duur. So dit bly 'n groot frustrasie as daar iets fout gaan. [And things in a wheelchair are expensive. If you break something in a wheelchair, it is always expensive. So it remains a frustration if something goes wrong.]*

Some participants from Cohort Two also stressed the financial concerns experienced by PWDs. As mentioned earlier, disability places extra financial strain on a family, as it often requires extra expenses (See Category 3.1.4.). Related to the discussion on lack of disability employment, Mothabeng (2011) emphasised the significance of employment in providing people with better social reputation, good sense of self-worth, purpose in life and financial stability. Particularly the latter is important for PWDs, who often have to cover more costs than their able-bodied counterparts, as can be seen in the following narratives:



*C2P03: It is only the people that have money that can go in this residential care and the cheapest will cost you R10 000 upwards.*

*C2P02: Taxi drivers demand that a wheelchair user should pay for two people.*

The link between poverty and disability experienced by some of the participants in this study is also depicted in studies that utilised the capabilities approach, as discussed in Chapter Three. In these studies (Dubois & Trani, 2009; Mitra, 2006; Sharma, 2005), the bidirectional link between disability and poverty was explained (Braithwaite & Mont, 2009) i.e. that the one could increase the risk of the other (WHO & World Bank, 2011), resulting in a potential recurring cycle (Yeo, 2005). Participants in this study came from different socio-economic backgrounds, which could add to the explanation of the sometimes seemingly contradicting answers between the services used and support needs.

### **6.3.6 Theme 5: Cultural experiences of adult with an acquired disability within their community**

Within, the Global South, studies in Zimbabwe and Uganda have found that disability is often seen as a “deficit” and the PWD as a “lesser person” (Visagie & Swartz, 2018). This theme includes the experiences of participants from Cohort One and discusses their experience with both lack of understanding in the community and acceptance within the community.

#### **6.3.6.1 Sub-theme 5.1: Lack of understanding of community**

In rural Mpumalanga, South Africa, a study with 30 PWDs found a prevalence of attitudinal barriers that lead to discrimination and deprivation, as well as psychological, physical and sexual abuse (Neille & Penn, 2015). Likewise, participants in this study identified that they experienced stigmatisation and a need for sensitisation in the community.

##### **○ Category 5.1.1: Stigmatisation**

In identifying some of stigmatisation experienced within their communities, some of the participants stated:

*C1P07: Soms van die mense dink as jy fisies gestremd is, is jy ook intellektueel. Hulle wil vir jou dink soos as jy byvoorbeeld dorp toe wil gaan dan word daar gevra waarom stuur jy nie iemand om dit vir jou te doen nie. Hulle besef nie dat ons ook self sekere dinge wil doen nie. [Some of the people think if you are*



*physically disabled, you are also intellectual. They want to think for you like for example if you want to go to town then it is asked why you didn't send someone to do it for you. They don't realise that we also want to do some things for ourselves.*

CIP13: *Daar is baie mense wat dink gestremdheid is onnatuurlik en ons moet genees word. [There are many people who think disability is unnatural and we must be healed.]*

CIP15: *Daar is nog mense wat neersien op gestremdes. [There are still people who look down on the disabled.]*

These experiences by participants correlate with Chance (2002), who stated that PWDs face many misconceptions in that the community assumes that disability spreads out into all aspects of a person's life. This manifests in the belief that, if the person is disabled in one way, they are disabled in all ways e.g. a person with a physical disability assumed to also have an intellectual disability.

#### ○ **Category 5.1.2: Need for sensitisation in communities**

In a study done in Johannesburg, South Africa, it was recommended that guidelines be developed in consultation with DPOs to encourage the news media to give an accurate, sensitive and fair portrayal when representing and reporting on disabilities and PWDs in radio, television, film, photography and print (Whitehead, 2004). Disability awareness is one of the factors needed to enhance participation of people living with SCI (Mothabeng, 2011). The experience of stigmatisation (combined with some of the needs discussed in Theme Four) thus brings about a need for sensitisation within communities as discussed by participants below:

CIP14: *Ek dink net die enigste probleem is wat ek nog baie ervaar is mense wat op rolstoel parkeer plekke stop en mense wat rolstoel badkamers gebruik. Selfs by die werk ook ... Soos mense sal daar stop en ek sal sê: "Jy is nie verlam nie" waar hul sal sê: "Dit OK ek gaan net gou vinnig inkopies doen." ... Sulke aanmerkings. Ek voel dit is die enigste twee goed waar ek voel wat mense regtig nie respek voor het vir gestremde mense nie. [I think the only problem is what I still experience a lot is people who park in wheelchair parking and people who use wheelchair bathrooms. Even at work too ... Like people will park there and I will say: "You are not paralysed" where they would say: "It*

*is OK I am just quickly going to do shopping.’] ... That kind of comments. I feel this is the only two things where I feel people do not really have respect for people with disabilities.]*

*C1P15: Die gemeenskap moet meer inligting ontvang oor gestremdheid. Baie is onkundig, veral die kinders. Ouers moet met hul kinders by die huis praat oor gestremdheid dan sal hulle nie die maatjie terg of spot nie. [The community must receive more information about disability. Many are uninformed, especially children. Parents must speak to their children at home about disability then they will not tease or their friend.]*

*C1P18: Baie van die gemeenskappe weet regtig nie hoe om mense te benader nie wat ‘n gestremdheid het nie. Hulle weet nie of hulle moet help, moet wegbly of ... ek dink hulle is nie ingelig nie. [Many of the societies do not really know how to approach a person with a disability. They do not know whether they should help, should stay away or ... I think they are not informed.]*

*C1P19: My grootste uitdaging is inligting. Dat mense weet wat aangaan is my grootste uitdaging ... Ek dink vir my die grootste probleme is mense se begrip van ons situasie. Mense sal sê: ... “Jy sal maklik in die huis bly. Daar is net vier trappies.” Wat hulle nie kan verstaan nie is dat ek kan nie vier trappies klim nie ... Jy kom bly plekke dan is daar ‘n handvatsel langs die toilet want hulle dink ek het ‘n handvatsel nodig, maar die handvatsel in die pad van my rolstoel. Ek kan nie inkom nie, want die handvatsel is in die pad ... sit ‘n badreëlingtjie op, maar hulle sit hom so hoog op dat niemand daarby kan uitkom nie. Ek dink dit is my grootste frustrasie. Net mense se begrip vir ons omstandighede. [My greatest challenge is information. That people know what is going on is my biggest challenge ... I think for me the biggest problems are people’s understanding of our situation. People will say: ... “You will be able to live in the house easily. There are only four steps.” What they do not understand is that I cannot climb four steps ... You arrive at places and then there is a handle next to the toilet because they think I need a handle but the handle is in the way of my wheelchair. I cannot come in, because the handle is in the way ... put up a bath rail, but they put it so high that no one can reach it. I think that is my biggest frustration. Just people’s understanding of our situation.]*

As discussed earlier, there are many misconceptions in terms of disability. These negative experiences could have a psychological impact on the PWD. From the narratives above, it is evident that a lot of the stigma experienced was due to the community not having enough information about disability, which inhibited PWDs' acceptance within their communities.

### **6.3.6.2 Sub-theme 5.2: Acceptance in community**

The social model acknowledges that disability is a social construct, and assesses the socio-economic environment and the impact that barriers have on the full participation, inclusion and acceptance of PWDs as part of mainstream society. Not all participants had negative experiences within their community, and some felt accepted.

#### **○ Category 5.2.1: Experience of acceptance**

There were a few participants in this study that felt supported and accepted within their communities, as can be seen from the following narratives:

*C1P04: Everyone in community look after us. Maybe it's our culture.*

*C1P08: They (the community) are supportive.*

*C1P19: So deur die bank sal ek altyd iemand kry wat eerder sal wil help ... [So across the board I'll always find someone that would rather help ... ]*

Morris (2005) identified self-determination, participation and contribution as important factors in understanding citizenship for PWDs. Acceptance within the community could be considered a contributing component to these factors.

#### **○ Category 5.2.2: Recommendations for improving acceptance as depicted by participants**

Some of the participants in this study shared their perspective on how to improve acceptance of PWDs:

*C1P01: So that's why I decided to educate my extended family especially with meals sitting together I take the opportunity to discuss certain issues in how do you have to deal with people disabled people ... I've been an activist all my life.*

*C1P09: The community treat you according ... they notice how you treat yourself ... If you say you can't do things ... they are going to react like that.*

*CIP19: Maar daaroor dink ek jy kan nie verwag dat die gemeenskap moet opgevoed word deur 'n buite instansie oor "disability" nie. My uitgangspunt is, ek is verantwoordelik vir daardie inligting. Ek moet vir die mense wys ek is OK. Of ek kan dit doen of ek kan daai nie doen nie. En as elke ou daar buite sy "disability" nie wegsteek nie en eerder wys wat moontlik is dan maak jy deure oop vir ander ouens ook. Dat ouens nie dink dit is nou dit en klaar en jy kan niks doen nie. [But because of that I think you cannot expect that the community must be educated by an outside disability organisation. My conclusion is, I'm responsible for that information. I have to show people I'm OK. Whether I can do this or cannot do that. And if every person out there does not hide his disability and rather show what is possible then you open doors for others too. So that people don't think this is it now and you can't do anything.]*

As stated before, how the community is experienced by the PWDs (i.e. stigmatisation or acceptance), could influence their ability to be able to fully participate in society. This could then be identified as a barrier, under the ICF model, that can hinder the priorities of policies like the UNCDRP and WPRPD for disability inclusion. According to the WPRPD (DSD, 2016), Pillar 3 titled Supporting Sustainable Integrated Community Life for Independent Living can only happen once awareness raising takes place (Article 8 of UNCRPD).

### **6.3.7 Theme 6: Social work support services to persons with acquired physical disabilities aligned with policies in South Africa**

Many participants made use of social work support services through means of DPOs and other welfare/social work organisations. Some of the functions of these organisation include advocating for the rights of PWDs, contributing to the evaluation and monitoring of services, collaborating with researchers to contribute to service development, promoting public awareness and understanding by professionals about the rights of PWDs, as well as conducting audits of environments, transport, and other systems and services to promote the removal of barriers (WHO, 2011). This theme will explore social work services to adults with acquired physical disabilities by combining the experiences of both the service user (Cohort One) and the service provider (Cohort Two).

### 6.3.7.1 *Sub-theme 6.1: Social work support services used*

This section will provide an overview of both the social work services used by adults with an acquired physical disability (indicated by Cohort One) and the services that were offered (as indicated by Cohort Two).

#### ○ *Category 6.1.1: Social work services offered at an organisation*

A research study of 27 health facilities in New York identified the role of social work as being that of “a jack-of-all-trades” (Mizharhi & Rizzo, 2008: 113). As discussed in Chapter Four, social workers can deliver a variety of services to PWDs and their families in terms of welfare, rehabilitation and family preservation services. This can be seen in the perspectives of the following participants from Cohort Two:

*C2P01: Therapeutic services; supportive, empowerment and option counselling; loss and grief counselling; referrals to day hospitals, physiotherapists as well as occupational therapists; referrals for work assessment with a view to job opportunities available to persons with disabilities as well as support to workgroups (participation in forums and activities which provides an opportunity for social interaction).*

*C2P02: I've provided therapeutic counselling by listening to the experiences of clients ... and I've done rehabilitation counselling and if that did not work out, refer clients to other relevant service providers ... I have supported families who seem not to understand at times, and help them to understand that their family member is still the same person as some may start thinking that they are no longer who they used to be. I have intervened on family conflicts where family members sometimes take advantage and abuse a client. I have also advocated for some clients because suddenly because of a disability, a client may find that his or her own house is no longer accessible. I had to make contact with the Housing Department in order to find an alternative accommodation for a client because she could not go up the stairs ... For my clients who are still economically active, I have supported them by helping with CV writing and looking for learnerships around the city and helping them to apply and provide the necessary documents. I have also invited other organisations to my support group so that they can give tips to my clients on how to start a small business.*

*I also monitor my clients' health by asking whether they are attending scheduled hospital visits and doing exercises. For my older clients, I connect them to other organisations within the community who provide activities for older persons like beadworks so that they do not sit at home doing nothing.*

*C2P03: Finding placement for them (PWD) in residential care, trying to ... reunite families ... we try to get learnerships for them ... we will try to link you (PWD) up with the necessary resources in the area ... I have a work group where we try to create employment opportunities for our clients ... that work group is also a form of support ... where clients speak about their experiences and try and support each other ... I liaise with the day hospital ... where they have a stroke club where we take the clients and they assist you with physiotherapy ... and rehabilitate you to get you back on track again ... We do have counselling*

*C2P04: Ek het gefokus op die volgende dienste soos uiteengesit in ons diensplan – ondersteuningsdienste ... “psychosocial support services”. Dan het ek ondersteuningsgroepe gehad aan hierdie persone met gestremdhede en dan hulle versorgers. Dan het ek bewusmaking gedoen in die gemeenskap oor verskillende gestremdhede, aansoeke vir hulpmiddels by die provinsiale hospitale (en mobiliteit spesialis besigheid). Ek het baie nou saam gewerk met (rehabilitasie sentrum se naam) ... en dan die “follow-up visits” as die persoon nou terugkom soos van die rehab sentrums ... om hom weer te “reintegrate” in die gemeenskap en ook die gesinne om die versorger op te lei en gereed te kry voor die persoon uit die “rehab” sentrum uit kom. Dan het ek ook nou saamgewerk met die fisioterapeute in die provinsiale hospitale ... om opvolgbesoeke by die hospitale te doen., met die dokters, fisioterapie of arbeidsterapie ... Ons het ook “protective workshops” ... hulle is meestal intellektueel gestremdes en dan persone wat “strokes” gehad het. Ons het daar “work skills” wat ons daar aanbied vir hulle, net om hulle besig te hou en dan een of twee persone terug te plaas in die arbeidsmark, maar wat weinig gebeur ... ons gee vir hulle ‘n maaltyd of twee ... hulle is net besig met “arts and crafts” ... “life skills” ... sport. [I focused on the following services as they appear in our service plan – support services ... psychosocial support services. Then I also had support services for these PWDs and then their caregivers.*

*Then I raised awareness in the community about different disabilities, applications for assistive devices at provincial hospitals (and mobility specialist company). I worked together very closely with (rehabilitation centre name) ... and then the follow-up visits when the person now comes back such as from the rehab centres ... to reintegrate him into the community again and also the families to train the caregiver to prepare them before the person returns from the rehab centre. Then I also worked closely with the physiotherapists at the provincial hospitals ... to do the follow-up visits at the hospitals ... with the doctors, physiotherapy or occupational therapy ... We also have protective workshops ... they are mostly the intellectually disabled and then the people who suffered strokes. There we did work skills which we present there for them, just to keep them busy and then to place one or two people back into the labour market but which happens seldom ... we give them a meal or two ... they are just busy with arts and crafts life skills ... sport.]*

*C2P05: I have been counselling ... maybe in the group with people with disabilities and also community work ... I also do workshops ... it is to empower them ... we also do the learnerships (PWDs).*

○ **Category 6.1.2: Social work services used by adults with an acquired physical disability**

Participants in this study also identified a variety of social work services, including employment opportunities. This is aligned with previous discussions of the role of NGOs in promoting the development of a disability-friendly environment (ACPF, 2011). Participants described the social work services they made use of as follows:

*C1P01: We have a local group community group once a week.*

*C1P02: Hulle het gereeld 'n persoon tot by my gestuur. Ook 'n persoon wat 'n gestremdheid het wat altyd kom kyk het na my ... Hulle het altyd twee keer 'n week na my toe gekom en my gevra hoe dit gaan, wat stel ek belang om te doen in my kondisie ... Dit het vir my nogal regtig opgebeur in die tyd wat ek nou by die huis was. [They regularly sent a person to me. Also a person who had a disability who always came to take care of me ... They always came twice a week and asked me how it is going, what I am interested in doing in my*



*condition ... That really cheered me up quite a bit during the time I was at home.]*

*C1P03: They helped me because they gave me a 6-month contract on being a peer facilitator ... It's nice working with a disabled person although you have a disability yourself that help me to see that I'm really not disabled it's just that I can't use my right-hand side properly.*

*C1P09: Even sometimes (social worker) bring us a little food parcel ... to bring something home.*

*C1P12: The social worker gives us information about job.*

*C1P13: Die rehabilitasie eenheid was deel van die program. So, daar was 'n voltydse maatskaplike werker ... Het 'n bietjie meer in diepte met haar gepraat. [The rehabilitation unit was part of the programme. So, there was a full-time social worker ... Talked a bit more in depth with her.]*

*C1P15: Die beste maatskaplike werk(st)er my gehelp met "mindset change" en so het dit elke dag beter gegaan. [The best social worker helped me with mindset change and so it got better every day.]*

Despite these advantages to social work services, Table 6.3 below shows that the participants from Cohort One did not indicate that they were using all the services offered according to Cohort Two. This could be because the participants from Cohort One did not need all these services, forgot to mention them or were not aware of them being offered.

**Table 6.3: Comparison between social work services offered and used**

SOCIAL WORK SERVICES OFFERED (COHORT TWO)	SOCIAL WORK SERVICES USED (COHORT ONE)
<ul style="list-style-type: none"> <li>• therapeutic services</li> <li>• counselling (empowerment, rehabilitation, grief)</li> <li>• psychosocial support services</li> <li>• health monitoring</li> <li>• referrals to day hospitals, other health professionals, work assessment</li> <li>• residential care placement</li> <li>• application for assistive devices</li> <li>• assistance with job opportunities available to PWDs</li> <li>• life/work skill training</li> <li>• protective workshops</li> <li>• food (meals)</li> </ul>	<ul style="list-style-type: none"> <li>• support group</li> <li>• peer support</li> <li>• assistance with job opportunities</li> <li>• food parcel</li> <li>• counselling</li> </ul>



SOCIAL WORK SERVICES OFFERED (COHORT TWO)	SOCIAL WORK SERVICES USED (COHORT ONE)
<ul style="list-style-type: none"> <li>• support groups to PWDs and families</li> <li>• support to families of PWDs</li> <li>• training to family caregivers of PWDs</li> <li>• mediation</li> <li>• advocacy</li> <li>• community awareness (sensitisation)</li> <li>• community reintegration of PWD</li> </ul>	

Dingana (2012), identified certain barriers to accessing resources such as lack of knowledge and inaccessibility of facilities. Although the major contributors to participants from Cohort One not accessing social work services was not assessed in this study, a lack of knowledge did appear to be a reason (See Category 6.2.3).

#### **6.3.7.2 Sub-theme 6.2: Experiences of social work services**

As can be seen from the apparent paradox between services used (Theme Three) and support needs (Theme Four), participants had different experiences. This was also the case with regards to the social work services that they used. Consequently, this section considers the positive and negative experiences of service users (Cohort One) as well as some of the experiences of Cohort Two.

##### **○ Category 6.2.1: Positive experiences of social work services received from adults with an acquired physical disability**

Most participants had positive experiences in terms of the social work support services that they received. Most of these social work services were provided by NGOs, DPOs, rehabilitation centres and the private sector. The following narratives provide some of the feedback given by participants:

*C1P02: Baie behulpsaam ... die bestuur van die sentrum het glads so ver gegaan om my te help om aan 'n werk te kom. [Very helpful ... the manager of the centre even went so far as to help me to obtain a job.]*

*C1P03: I like the group of social worker I'm with them because they allowed everyone who is disabled to work ... and they get paid during month end, meaning that*

*they can take care of their family not to let them depend on grant, I really like that on our social worker.*

*C1P04: (I found it) helpful especially when have problem with your grant or you (are) not receiving community service help in government Departments. (They provide) guidance in my rights as disabled person.*

*C1P06: Kyk hoe dit saam my gaan en gesels en motiveer ... Die feit dat hulle mense besoek en hulle probeer ondersteun waar hulle kan. [Come to see how I was and chat and motivate ... The fact that they visit people and try and support them where possible.]*

*C1P08: They are always there ... they are cool ... They give me strength sometime ... give me advice.*

*C1P09: The social worker is very well understanding the people with disabilities, what they need ... (social worker) try and listen to us and try at least to fulfil what we ask for ... We are very grateful to have a social worker that is willing to help us ... If (the social worker) cannot help us ... tell us straight: "I don't think I can help" ... Does it from the bottom of her heart ... They must keep doing their job, they are doing a great job.*

*C1P13: Daar (het) 'n persoon (maatskaplike werker) met 'n hele ander oog met 'n mens praat. Ek het dit baie waardeer. Dit het nooit gevoel of sy jou binne 'n raamwerk wou sit. Sy het regtig baie openlik met 'n mens gepraat en 'n bietjie ondersteuning gegee in terme van wat 'n mens kan verwag ... Ek het regtig 'n goeie ervaring met haar gehad ... Sy het geluister ... Sy't ook die insig gehad om te sien of ons ondersteuningsnetwerk goed genoeg is dat sy ... leiding te gee. [There was a person (social worker) that spoke from a completely different view. I appreciated that a lot. It never felt like she wanted to put you in a framework. She really spoke very openly with a person and provided a bit of support on what one could expect ... I really had a good experience with her ... She listened ... She also had the insight to see whether our support network was good enough so she ... (could provide) guidance.*

*C1P15: Die maatskaplike werk(st)er is baie goed ... Was dit nie vir maatskaplike dienste nie sou ek nooit gekom het waar ek nou is nie ... Die feit dat 'n maatskaplike werk(st)er met my 'n pad kon loop tot ek erken het ek is gestrem,*

*my weer deel gemaak het van gemeenskap, my selfbeeld ... Ek haal my hoed af vir maatskaplike werkers wat die werk doen. [The social worker is very good ... if it wasn't for social work services I would never have come to where I am now ... The fact that a social worker could journey with me until I could admit I am disabled, made me part of society again, my self-image ... I take my hat off to social workers that do the work.*

These experiences reiterate the role NGOs and other organisation have played as resources to households with a PWD, particularly where the disability is severe and difficult to manage. These organisations provide additional training, peer groups of support and advice to households (Graham et al., 2014).

○ ***Category 6.2.2: Negative experiences of social work services received from adults with an acquired physical disability***

Despite the majority of participants having positive experiences with social work services, there were some participants that had negative experiences in terms of the social services they received, as can be seen in the narratives below:

*C1P01: I got out of the hospital there was no communication between a social worker and physiotherapist ... (I) discovered ... the social workers employed in fact had ... never work with people with disabilities so they don't understand sometimes emotional, psychological side of the disability. That is my experience and is that is my opinion.*

*C1P04: Sometimes you meet social worker that doesn't make follow up to your problem, ending up you had to struggle to get hold of your social worker.*

*C1P11: Things you say it ... they undermine it ... because here ... I told them (social worker) I have some people who need help here ... but the social worker ... they take time.*

*C1P17: This was 36 years ago and one of the first things the social worker came ... to my mom and said: "Well, your son's going to be in a wheelchair for the rest of his life, so does he like to play chess ... so maybe we can start teaching him playing games." And my mother was so insulted and furious, so she told the social worker to leave. So it was a bit of a misunderstanding at the time.*

Dorsett (2010) stressed the vital role that social workers can play in the rehabilitation of persons with physical disabilities by providing information and reassurance, along with exploring meaning and appraisals, and developing problem-solving skills. They also facilitate access to necessary resources through interventions such as advice, referral, and advocacy that assist both the PWDs and their family members. When this does not happen, it could provide a negative experience for both parties in terms of social work services, while also affecting the reputation of the profession.

○ **Category 6.2.3: Lack of knowledge about social work services**

As could be deducted from Table 6.3, some of the participants of this study identified through snowball sampling (who in many cases made use of private health care services) did not have knowledge of the social work services available in their communities. Accordingly, some of them stated:

*CIP13: Ek weet nie waar om daarvoor (maatskaplike dienste) te soek nie. [I do not know where to look for it (social work services.)]*

*CIP14: Wat ek wel kan sê is ek weet nie van maatskaplike werk wat spesifiek op ons (persone met gestremdhede) gerig is nie ... Ek is dalk net nie bewus van wat is daar buite en wat kan hulle vir 'n ou doen nie. [What I can in face say is that I don't know of social work aimed specifically at us (PWDs) ... I am maybe not aware of what is going on outside and what they can do for a guy.]*

*CIP18: Wat doen 'n maatskaplike werk(st)er? [What does a social worker do?]*

The feedback from these participants could be valuable for identifying potential improvements in service delivery to PWDs in the social work profession, especially, as was the focus of this study, to adults with an acquired physical disability. This coincides with the rationale of this study, as there are few previous studies focusing on social work services to adults with an acquired physical disability (Nexus, 2018). Further, as stated before, knowledge of service users' perspectives is useful in monitoring the services for quality assurance (DOH, 2000). Further analysis of potential recommendations will be discussed in Chapter Seven.

○ **Category 6.2.4: Experiences of social workers**

Apart from the experiences of service users, the experiences of service providers i.e. social workers from Cohort Two must also be considered to identify possible attributes to build on or challenges to address for service delivery. Accordingly, some of these participants state:

*C2P02: My experience in working with persons with disabilities has given some profound things to reflect on. I was very overwhelmed at first with people's experiences and the sober thought that this could actually happen to me at any point of time ... It made me realise that they are not different from me, and that they are people first. My respect for their resilience grew from knowing and learning how they've had to cope with this new way of living especially those that have acquired a disability later on in life. This also helped me to work with them as persons before their disability, which has helped me to tap on their strengths and resilience ... I have a few clients who have been empowered enough to empower others and these are my peer supporters who assist in encouraging others ... I have been angry and extremely saddened when I encounter some clients because of the situation at hand ... At times, I feel helpless too because it seems there isn't much I can do. I have a client with spastic cerebral palsy and all her arms are contracted severely and she needs someone to assist her with daily living activities. I have helped her to apply for learnerships and even though she qualifies, she needs a permanent carer and there is no one available to assist her with that, which means she is just staying at home and becoming despondent ... I have grieved for some, felt very encouraged by some, anguished by some and I guess that's the human journey but overall these experiences have given me some kind of satisfaction on my purpose of enabling others ... Many new clients think that as the social worker, I will be able to solve all their problems, especially financial ones. They do not seem to understand my role in their lives, and this frustrates them at times and I always try to override this challenge by explaining what I do and what our organisation does.*

*C2P04: Ek kan nou een spesifieke geval onthou ... waar die kliënt geval het en haar rug op drie plekke beseer het en ... nou in 'n rolstoel ... Die onkunde van die versorgers by die huis ... en van (persoon met gestremdheid) self, hoe om na*

... self te kyk ... wanneer ... vir terapie moet gaan ... arbeidsterapie moet gaan of fisioterapie toe moet gaan ... “mobility” ... om net te aanvaar dat (hul) gestremd is, want ... nou moes (hul) afhanklik van ander persone wees ... (Die area) het nie “residential facilities” vir ons gestremde persone nie so as hulle na een moet gaan is dit meestal ... na een of ander stad toe ... so as hul daar is, is dit moeilik vir die families om hulle daar te besoek ... Die toeganklikheid is ook ‘n probleem wat ons ondervind byvoorbeeld by banke of by winkels of “even” by hulle huise ... en ons is die enigste organisasie (in die area) wat werkswinkels aanbied. Daar is nie nog enige organisasie wat as “resource” dien vir persone met gestremdhede om ‘n werkswinkel by te woon om hulle bedag besig te hou nie. [At this moment I can remember one specific case ... where the client fell and injured her back in three places and ... now in a wheelchair ... The inexperience of the caregivers at home ... and of (person with disability) self, how to ... take care of themselves ... when ... to go for therapy ... occupational therapy and physiotherapy ... mobility ... to just accept that (they) are disabled because now (they) had to depend on other people ... (The area) does not have residential facilities for our disabled people so if they have to go to one it is mostly ... to one or other city ... so when they are there, it is difficult for families to visit them there ... The accessibility is also a problem that we experience for example the banks or at the shops or even their houses ... and we are the only organisation (in the area) that provides workshops. There is no other organisation that acts as resource for PWDs to attend a workshop to keep them busy during the day.]

C2P05: *The challenge is the lack of resources in the community ... especially transport. They don’t have enough transport.*

Combining both the experiences of service users regarding social work with the experiences of social workers themselves could assist in finding priorities to address to improve social work service delivery to PWDs, especially adults with an acquired physical disability. Dingana (2012) found disparities in the needs mentioned by service users and service providers. This indicates that needs that may seem important to professionals may not always be important to PWDs. Therefore, it is important to involve service users before planning for service delivery i.e. a bottom-up approach.

### 6.3.7.3 *Sub-theme 6.3.: Services aligned with policies*

In Chapter Two, several international as well as South African policies guiding service delivery to PWDs were discussed. This section, on the other hand, makes use of the responses from Cohort Two, where South African social workers themselves identify the policies they align their services to PWDs with. A further analysis of the adherence to these policies will be provided in Chapter Seven.

#### ○ *Category 6.3.1: Services aligned with other international policies*

The UNCRPD covers a wide range of areas including health, education, employment, access to justice, personal security, independent living, and access to information (Equalityini, 2020). During the inauguration of the UNCRPD, South Africa was one of 155 countries that signed the convention (UNICEF, 2013), thereby indicating the government's commitment to protect the rights of its disabled citizens (Roomaney, 2017). One participant identified that they use the UNCRPD as a guiding policy in service delivery to PWDs by stating:

*C2P01: United Nations Convention on the Rights of Persons with Disabilities, ... To educate and empower the clients on their rights while supporting and motivating them in pursuing the realization of their dreams / goals. They are often faced with challenging circumstances on a personal and socio-economic level and by equipping them to believe in themselves and motivating them, some have been able to achieve more than they have expected of themselves.*

Another important international policy is the 17 SDGs. Based on the principle of “leaving no one behind,” these goals emphasise a holistic approach to achieving sustainable development for all (Steenkamp, 2017; UN 2015). Further, the SDGs emphasise that people who are vulnerable must be empowered, which can be applied to PWDs (UN, 2015). The participant narrative above identified similar strategies according to these goals in its focus on empowering and supporting PWDs. A further analysis of services aligned to policies will be conducted in Chapter Seven.

#### ○ *Category 6.3.2: Services aligned with the WPRPD (South Africa)*

In 2016, the DSD launched the WPRPD in South Africa. This policy updates South Africa's 1997 INDS and integrates the obligations of the UNCRPD. and the Continental Plan of Action



for the African Decade of Persons with Disabilities (both of which South Africa has signed), with South Africa's legislation, policy frameworks and the National Development Plan 2030. It further supports mainstreaming for realising the rights of PWDs. All participants from Cohort Two indicated that this is an important guiding policy they used in service delivery to PWDs, as can be seen in the narratives below:

*C2P03: We mainly focus on the White Paper (confirmed by follow-up question that they were referring to this White Paper on the Rights of People with Disabilities).*

*C2P04: Bewusmaking kry ons leiding van die "White Paper on the Rights of People with Disabilities" sodat korrekte inligting weergegee kan word aan die gemeenskap oor gestremdhede. [Awareness raising gets us guidance from the White Paper on the Rights of People with Disabilities so that correct information would be provided to the community about disability.]*

The collaboration of social workers with PWDs (and their families) can assist with increasing access to opportunities and promoting social inclusion and community living (MSF, 2018), which is what the WPRPD aims to work towards, aligned with the 2030 National Development Plan and the UNCRPD (SAHRC, 2015).

### ○ ***Category 6.3.3: Services aligned with other South African policies***

In Chapter Two, several other South African policies were discussed that could guide service delivery to PWDs. These policies include the Constitution (RSA, 1996), Promotion of Equality and Prevention of Unfair Discrimination Act (RSA 2000) mandated by section 9(4) of the Constitution, as well as the national rehabilitation policy (Department of Health (DOH), 2000). Participants in this study also identified the Employment Equity Act, Social Work Profession Code of Ethics, Social Assistance Act, Social Professions Act, Health and Safety Act, Human Rights Act, Older Persons Act and, where necessary, the Domestic Violence Act. All of these acted as guiding policies for service delivery to PWDs, as can be seen in the following narratives:

*C2P01: South African Constitution (inclusive of the Bill of Rights), White Paper on the Rights of Persons with Disabilities ... Employment Equity Act ... It is not*



*always easy but knowing that there are policies and legislation in place to protect them, often makes a difference in their lives.*

C2P02: *I have found myself reading and making use of the Constitution and the White Paper on the Rights of Persons with Disabilities a lot because it gives guidelines on how to ensure that persons with disabilities get what is rightfully theirs by removing barriers that are in their environment. I am also guided by our own profession's Code of Ethics ... I respect my clients and see them as humans like me, as this is engraved in the White Paper and also the Code of Ethics. I do not impose my service to my clients. Firstly, I call them and introduce myself and make an appointment for a home visit. When I meet them for the first time, I tell them about our organisation and what it does with and for persons with disabilities. If they like what they hear and with their consent, I register them and put them on their data base and do an assessment. I explain our confidentiality clause and then develop a care plan which aligns with what they tell me ... I try to advocate for my clients and also empower them to raise their voice constructively and get involved in community engagements ... I encourage my clients to stand up for themselves and not to isolate themselves as they are a part of the bigger community. For my youthful clients, I encourage and challenge them to finish matric and try to apply for university in order to get them to be economically independent.*

C2P04: *... die “Social Assistance Act, Social Professions Act”, “Health and Safety Act, Human Rights Act, Older Persons Act” en so af en toe met die “Domestic Violence Act” ... dit is die meeste van die tyd wat ons met daai “Acts” werk ... Die “Social Assistance Act” gebruik ons wanneer ons persone met gestremdhede help om aansoek te doen vir hul toelae by SASSA of as daar fout kom by die toelae dan kan ... die Act kan jou “guide” daarvolgens. Die “Health and Safety Act” vir ons ... hoe ons “workshops operate”, want jy het ‘n “health certificate” nodig om die “workshops” korrek te laat “operate”. Die “Domestic Violence Act” is, maar in geringe gevalle waar kriminele sake dalk geopen word waar ‘n persoon met ‘n gestremdheid aangerand word deur sy “partner” of ‘n familielid of so. [ ... the Social Assistance Act, Social Professions Act, Health and Safety Act, Human Rights Act, Older Persons Act and now and again the Domestic Violence Act ... this is most of the time the acts we work*

*with ... The Social Assistance Act we use when we assist persons with disabilities to apply for grants at SASSA or if there comes a mistake with the grants ... the Act can guide accordingly. The Health and Safety Act for us ... how we operate the workshops because you need a health certificate to operate the workshops correctly. The Domestic Violence Act is, but in seldom cases where a criminal case may be opened where the person with the disability is abused by their partner or family member or so. ]*

Based on these narratives, it can be seen that participants identified the South African Constitution (RSA, 1996) and the WPRPD (DSD, 2016) as the two main policies that guide them in service delivery to adults with an acquired physical disability. An analysis of how these services aligned with the policies is further discussed in Chapter Seven.

#### **6.3.7.4 Sub-theme 6.4: COVID-19 pandemic impact on social work services**

The spread of the global COVID-19 pandemic brought unique experiences and challenges in different sectors. In Chapter Five, the impact of this pandemic on this research study was discussed extensively. The pandemic also had a profound impact on social work service delivery, as lockdown regulations were initiated across different countries, limiting home visits to minimise virus transmission. It was, therefore, important to consider the experiences of both service users (Cohort One) and service providers (Cohort Two) in terms of the pandemic.

##### **○ Category 6.4.1: Experiences of adults with an acquired physical disability**

The COVID-19 pandemic brought about a general uproar, both globally and on a national level, for the consideration of PWDs in disaster management strategies (McKinney, McKinney & Swartz, 2020; Swinger, 2020). Participants in this study had different experiences in terms of the pandemic, as is apparent in their statements:

*CIP05: I have learned a lot of things but also worried about those who are facing poverty.*

*CIP13: Ek dink met iets wat met 'n mens nou beïnvloed wat nie sou onder gewone omstandighede se geval sou gewees het nie ... Ek mis die mense en om uit te kom. [I think with something that influenced a person now that would not be the case under normal circumstances ... I miss the people and to be able to go out.*

- CIP14: *Voor “lockdown” het ek ‘n helper gehad wat twee keer ‘n week ingekom het en sy sou die hele huis skoonmaak en die klere ophang en stryk ... Die groot ding is die kontak met mense. Daai waar ek heeltemal geïsoleer is ... Daai eerste week en ‘n half het my verskriklik erg gevang. Ek was baie “sad”. Ek was baie eensaam. Dit was vir my baie erg ... ek is in ‘n rolstoel en ek bly op my eie. Dit maak dit soveel moeiliker. Ek kan nie net vinnig uitstap en rond beweeg buite. ‘n Mens besef net weer ... wat jy alleen by die huis sit met geen ander afleiding nie. Dan raak jy weer “sad”, want jy besef jy is verlam. Dan kan ek ook verstaan ‘n mens moet passop vir depressie vir mense wat op hulle eie is. [Before lockdown I had a helper that came in twice a week and she would clean the whole house and hang up the clothes and iron ... The big thing is the contact with people. That where I am totally isolated ... That first week and a half hit me very hard. I was very sad. I was very lonely. It was terrible for me ... I am in a wheelchair and I live on my own. It makes it so much more difficult. I cannot just walk out quickly and move around outside. One just realises again ... w= where you sit alone at home with no other distraction. Then you get sad again, because you realise you are paralysed. Then I can also understand one must be careful for depression for people that are on their own.]*
- CIP15: *Einde Mei toe begin druk die mure ek moet uit. Ek het vroeg die oggend toe President aankondig jy kan gaan stap, my rolstoel gevat en gery. Dit was heerlik. Ek mis verskriklik my kliënte en vriende en ... die natuur, maar ek bly maar in die huis klaar gestrem, kan nie nog ‘n virus gaan haal nie en niemand kom kuier om dit te bring nie. [End of May then the walls started to press on me I must get out. I took my wheelchair and drove early the morning when the President announced we could walk. It was lovely. I miss my clients and friends terribly and ... nature but I stay at home, already disabled, cannot go get a virus or visit someone to get it. ]*
- CIP19: *Ek dink om my loopbaan te probeer laat aangaan was ‘n groot uitdaging. Daarmee moes ek ‘n bietjie werk, maar dit was eintlik ‘n lekker uitdaging gewees ... So tans kan ek by die huis sit en ek kan werk aan my musiek. Ek maak nie geld en dit is die grootste uitdaging. Finansies bly ‘n uitdaging. [I think to try and keep my career going was a big challenge. With that I also had*

*to work a bit, but it was actually a nice challenge ... So currently I can sit at home and work a bit on my music. I don't make money and that is the biggest challenge. Finances remains a challenge.*

Many participants indicated social isolation as a concern due to lockdown restrictions. They also expressed concerns for the economic impact of the lockdown regulations, as certain sectors were not able to work, affecting people's employment. One participant also mentioned that they used to have a helper who could not, at the time of the interview, come to assist them with housework, which, apart from the isolation, caused extra strain on daily functioning.

○ **Category 6.4.2: Experiences of social workers**

The COVID-19 global pandemic re-emphasises the importance of accessibility measures for support services according to Article 11 of the UNCRPD (IDA, 2020). The pandemic also opened discussions for the WPRPD to be adapted into an act to protect PWDs (WCFID, 2020). In this light, some participants stated:

C2P01: *It has negatively impacted the service delivery. Prior to the lockdown we mainly had telephone contact with our clients in an attempt to reduce our risk of possible infection as the circumstances in which we found ourselves during home visits was not always conducive to our holistic well-being. Being of the most vulnerable and marginalized persons within communities, our clients felt even further marginalised as some of them display a degree of dependence on their social workers and expect them to be available in supporting them through their challenges.*

C2P02: *Home visits are an integral part of what we do, hence the fact that we are not out there seeing our clients is a big thing for me ... most of my high risk clients do not have cell phones or phones that can go on social media platforms. I am very worried especially about those who are not reachable. Because of funding and lack of resources, we as social workers do not have work cell phones to make contact with our clients while we are at home and have had to use our personal cell phones for emergencies. This affects my boundary setting with clients and have had to download another WhatsApp so as to continue making contact with clients in a cheaper way but not everyone has WhatsApp which is*

*a challenge. However, this helps even in a small way to keep in touch with clients.*

*C2P03: Clients are really missing out ... we are not allowed to go on home visits since two weeks prior to the lockdown so it is more than a month now (at time of interview) that we have not engaged with clients and deliver any services to them. Only telephonically but ... you can only do so much telephonically.*

*C2P04: Ons kon eers ons deure oopmaak toe “level 4” geïmplementeer word, maar met dit kan ons glad nie tuisbesoeke doen nie so die kliënte kry nie daardie diens ... Ons kan telefonies met die kliënte kontak maak, maar dit is minimaal ... Daardie kliënt voel ook dalk geïsoleerd en hulpeloos en in “a state of depression” ... Ek dink vir elke kliënt is dit moeilik in die COVID-19 pandemie en om nie daardie ondersteuning te kry waaraan hul gewoon was aan of op ‘n gereelde basis gekry het nie, sal ek dink dis baie traumaties ... Ons het ook gevind dat die kliënte nie finansieel sterk genoeg is om na die kantoor toe te “travel” nie. [We could only open our doors when level 4 was implemented, but with this we could not do any home visits at all so the clients do not get that service ... We can make contact with the clients telephonically, but this is minimal ... That client also maybe feels isolated and helpless and in a state of depression ... I think for every client it is difficult with the COVID-19 pandemic and to not receive that support that they are used to or received on a regular basis, I could think it is be very traumatic ... We also found that clients are not financially strong enough to travel to the office.]*

Some of the experiences of social workers related to the experiences of adults with an acquired physical disability, especially in terms of social isolation. Since the pandemic came unexpected and unannounced, most sectors, including social work, were not fully prepared for the long-term impact it could have. Since the onset of the pandemic, many adjustments have been put into place to ensure that most sectors could continue service delivery as best possible. This was mentioned by participants as well in terms of telephonic contact, and later, office visits. These adjustments, however, also come with challenges (i.e. clients not having phones or finances for office visits), which hinders accessible service delivery to adults with an acquired physical disability.

### **6.3.7.5 Sub-theme 6.5: Role of the social worker in rehabilitation of adults with acquired physical disabilities**

Social workers play a vital role in rehabilitation. They conduct psychosocial assessments, psychosocial counselling, discharge planning, case management and psychosocial health education (Springer & Casey, 2013).

It could be argued that some of the most pivotal social work roles included that of broker, enabler and educator. Particular functions that correspond to each of these roles within the rehabilitation team could be articulated. These roles could also be used to analyse the experiences of PWDs regarding the quality of service they receive from the social worker (e.g. in-patient rehabilitation, and rehabilitation in an ambulatory, or a sanatorium etc.) (Sape, 2003; Sapezinskiene, 2000; Miley et al., 1995). In terms of service delivery to PWDs, especially adults with an acquired physical disability, other roles to take note of could include that of counsellor, public relations officer, manager, facilitator, motivator, researcher and advocate.

#### **○ Category 6.5.1: Role of a social worker as seen by Cohort One**

As mentioned earlier, there are various roles a social worker can fill. Participants from Cohort One identified the role of counsellor, broker, educator and researcher in this study.

#### **- Counsellor**

As a counsellor, the social worker can guide the client towards modifying behaviour, empowerment and the acquisition of skills to cope with problem situations (Engelbrecht, 1999). Some participants explained the role of the social worker as a counsellor – the ‘soft cushion’ in the multi-professional rehabilitation team, as can be seen in the following narratives:

*C1P13: (Praat van maatskaplike werker binne rehabilitasie eenheid). Daar is nie ‘n kussing wat sagter is in die eenheid nie ... Waar jy jou kop kan neer sit en beter kan asem haal ... dan was die maatskaplike werk(st)er daar en as ‘n mens met haar gesels is dit soos asem skep. [(Speaking about social worker within rehabilitation unit). There is no cushion that is softer in the unit ... Where you can lay your head and breathe better ... Then the social worker was there and when one speaks to her it is like taking a breath.]*

CIP16: *If maybe they can offer counselling first because other people, they don't really get over it.*

- **Broker**

A broker is supposed to mediate, defend and advocate on behalf of the client and be a case manager (Sape, 2003; Sapezinskiene, 2000; Miley et al., 1995). With some of the recommendations (see category 6.6.1), this role also came out. One of the participants described the role of the social worker as a broker assisting with community integration very comprehensively:

CIP17: *Social workers ... must make us attractive in the environment out there ... engage us into the community ... they must know the community and make a place for us in the community ... The social worker must know is the (various community resources named) accessible. The social worker must take me from my hospital bed back to the community ... I am not going to live in the hospital for the rest of my life ... The social worker is just like an estate agent ... They saw my criteria ... and found me a "house" according to my criteria ... Gave me the keys ... The social worker cannot lurk in the shadows all the time. Then the social worker arrives to says: "Ok, I want to find the right university for you now ... then the social worker find (places for socialising) ... It is a catalyst to taking me the environment where I can ... be independent from my family ... I might be looking at society and say: "Society is not accepting me." The social worker say: "Listen, you are eating too much, you are drinking too much, you are not coping with what has happened to you, you don't dress very well, you have lost your self-image, that is why you are not winning in the social front." ... The social worker arrives back on the stage and gives me a few tips.*

- **Educator**

In the discussion on the need to sensitise the community to ensure rehabilitation of the PWD in the community, two participants also noted the role of the social worker as an educator:

CIP07: *Ook meer die nodige dienste nader wat die kliënt dalk kan belangstel. [Also approach more the necessary services that the client might be interested in.]*



*CIP17: I think communities are naïve and I really think communities need to be sensitised about the needs of persons with physical disabilities ... The social worker can do that by creating awareness in the community ... The social worker really needs to sensitise the community if I am going to be accepted in the community ... I am not talking about hospital, or stepdown ... or even university ... those times come and go ... It is your working environment where you are 20 or 30 years and then the village that you are living in. You are there for 10, 20, 30, 40, 50 years.*

The role of educator encompasses the development of skills by providing relevant information, giving advice, identifying and teaching problem-solving techniques, amongst other elements (Engelbrecht, 1999).

#### **- Researcher**

Lastly, such as is the case with this study, the social worker might act as a researcher to scientifically determine the extent of problems, needs and phenomena and to make recommendation, by analysing related factors (Engelbrecht, 1999). Two participants also identified this role in the social worker:

*CIP07: Die maatskaplike werker moet ook meer ingelig wees oor die gestremdheid en of siekte. [ The social worker should be more informed about that specific disability and or illness].*

*CIP17: They need to be better than Google ... by engaging with others that are in the same environment and knowing what works and doesn't work for them, learn from the experiences of other people and being able to process.*

The role of the social worker as researcher was also identified and described as a need to be informed about the disability and be “better than Google” to identify what works and does not work. There were also motivations for similar research studies that emphasises this role (see Category 6.6.3).



○ **Category 6.5.2: Role of social worker as seen by Cohort Two**

As mentioned earlier, the social worker can have various roles. Some of the roles that were identified by Cohort Two (social workers themselves) include the counsellor, broker, public relations officer, educator, motivator and mediator.

- **Counsellor**

As mentioned with the perspectives of participants from Cohort One, the social worker can take on the role of counsellor to modify behaviour or empower (Engelbrecht, 1999). Likewise, participants from Cohort Two identified services related to this role of the social worker:

*C2P01: Therapeutic services; supportive, empowerment and option counselling; loss and grief counselling*

*C2P02: I have provided therapeutic counselling by listening to the experiences of clients ... and I've done rehabilitation counselling ... I have supported families who seem not to understand at times, and help them to understand that their family member is still the same person as some may start thinking that they are no longer who they used to be.*

*C2P04: Ek het gefokus op die volgende dienste soos uiteengesit in ons diensplan – ondersteuningsdienste ... “psychosocial support services”. Dan het ek ondersteuningsgroepe gehad aan hierdie persone met gestremdhede en dan hulle versorgers. [I focused on the following services according to our service plan – support services ... psychosocial support services. Then I had support groups for these persons with disabilities and then their caregivers.]*

Engelbrecht (1999) stated that a social worker's preference and personality can influence role fulfilment (e.g. being more prone to the role of counsellor than to that activist). This can also be seen in the preferences stated in the narratives above.

- **Broker and Public relations officer**

Another role that was identified by both Cohort One and Two is the role of broker, which coincided sometimes with that of public relations officer, as the social worker had to identify certain services, make referrals and link the PWD with resources (Engelbrecht, 1999). Participants from Cohort Two described these roles as follows:

- C2P01: *Referrals to day hospitals, physiotherapists as well as occupational therapists; referrals for work assessment with a view to job opportunities available to persons with disabilities as well as support to workgroups (participation in forums and activities which provides an opportunity for social interaction).*
- C2P02: *I have also advocated for some clients because suddenly because of a disability, a client may find that his or her own house is no longer accessible. I had to make contact with the Housing Department in order to find an alternative accommodation for a client because she could not go up the stairs ... For my clients who are still economically active ... looking for learnerships around the city ... I have also invited other organisations to my support group so that they can give tips to my clients on how to start a small business. I also monitor my clients' health by asking whether they are attending scheduled hospital visits and doing exercises. For my older clients, I connect them to other organisations within the community who provide activities for older persons like beadworks so that they do not sit at home doing nothing*
- C2P03: *Finding placement for them (PWDs) in residential care, trying to ... reunite families ... we try to get learnerships for them ... we will try to link you (the PWD) up with the necessary resources in the area ... I have a work group where we try to create employment opportunities for our clients ... I liaise with the day hospital ... where they have a stroke club where we take the clients and they assist you with physiotherapy ... and rehabilitate you to get you back on track again ... We do have counselling*
- C2P04: *Aansoek vir hulpmiddels by die provinsiale hospitale (en mobiliteit spesialis besigheid). Ek het baie nou saam gewerk met (rehabilitasie sentrum se naam) ... en dan die "follow-up visits" as die persoon nou terugkom soos van die rehab sentrums ... om hom weer te "reintegrate" in die gemeenskap en ook die gesinne om die versorger op te lei en gereed te kry voor die persoon uit die "rehab" sentrum uit kom. Dan het ek ook nou saamgewerk met die fisioterapeute in die provinsiale hospitale ... om opvolgbesoeke by die hospitale te doen., met die dokters, fisioterapie of arbeidsterapie [Applications for assistive devices at provincial hospitals (and mobility specialist company). I worked very closely with (rehabilitation centre name) ... and then the follow-up visits when the person then returns from the rehab*

*centres ... and to reintegrate him again into society and also the families to train the caregiver to prepare them for when the person returns from the rehab centre. Then I also worked closely with the physiotherapists at the provincial hospitals ... to do the follow-up visits at the hospitals ... with the doctors, physiotherapists or occupational therapists.]*

This role is aligned with the expectation of participants from Cohort One that social workers should find resources for them (See 6.5.1.2).

#### **- Educator**

An educator is expected to provide information, educate and provide preventive care; (Sape, 2003; Sapezinskiene, 2000; Miley et al., 1995). The following participants indicated this role in their methods of service provision:

*C2P02: Parents need to be thoroughly educated about their child's disability in order to equip them with knowledge that will best serve their child. I have seen adults with a physical disability who have gone to special schools and did not even reach grade 10 and yet they have the mental capacity to do so.*

*C2P04: Daar moet meer ondersteuning gegee word of opleiding gegee word aan die versorgers van hierdie persone (persone wat later in hul lewe 'n gestremdheid verkry het) ... die maatskaplike werker kan dan meer met die hulpmiddels "assistance" gee, hoe die rolstoel dalk werk, hoe die hospitaalbed dalk werk en hoe jy dalk die "nappy" aansit by die huis ... .Ek het ook bewusmaking gedoen in die gemeenskap oor verskillende gestremdhede. [There must be more support provided in training for the caregivers of these people (people who acquired a disability later in life) ... the social worker can then provide more assistance with the resources, maybe how the wheelchair works, maybe how the hospital bed works and how the nappy must maybe be put on at home ... I also did awareness in the community about different disabilities]*

As can be seen from the narratives above, participants in this study acknowledged the role social workers play in educating and training individuals, families and communities in managing the acquired disabilities.

### - *Motivator*

Stemming from the engagement with positive experiences of social work services (see 6.2.1), the role of motivator was implied by participants from Cohort One. However, participants from Cohort Two also indicated their role as social workers in motivating PWDs to participate, remove themselves from isolation and build optimism. Generally, this role serves to make people's existence rewarding and productive (Engelbrecht, 1999), as can be seen in the following narratives:

*C2P03 That work group is also a form of support ... where clients speak about their experiences and try and support each other*

*C2P05: I also do workshops ... it is to empower them ... we also do the learnerships with (PWDs).*

The act of motivating PWDs was implemented mostly through support and work skills groups, which focused on empowering them and introducing them back into the labour market.

### - *Mediator*

In this study, participants from Cohort Two indicated that it was also sometimes necessary them to act as mediator between PWDs and their families and act a catalyst in the situation (Engelbrecht, 1999), a term also used earlier by Cohort One (C1P17). Accordingly, one participant stated:

*C2P02: I have intervened on family conflicts where family members sometimes take advantage and abuse a client ...*

Historically, the social work profession has also had the responsibility of working with and advocating for vulnerable groups in society such as PWDs in terms of equity and social justice (Mackelprang, 2013; Stainton, 2010). This includes social policies and practices that provide the same opportunities for PWDs as persons without disabilities (Mackelprang, 2013). Although it was not specifically mentioned, the overall discourse from services used by the PWDs interviewed for this study and role of the social workers in providing these indicated that both Cohorts also acknowledged the role of the social worker as an advocate.

### 6.3.7.6 *Sub-theme 6.6.: Recommendations for future social work services to adults with an acquired physical disability*

As mentioned earlier, people with disabilities have often been marginalised. The WPRPD (DSD, 2016) emphasises PWDs' integration into the community in terms of Pillar 3 and 4 i.e. Supporting Sustainable Integrated Community Life and Promoting and Supporting Empowerment of Persons with Disabilities. According to a study done by van de Ven et al. (2005) the concept of integration as an outcome of rehabilitation consists of five elements i.e. functioning in an ordinary way without receiving special attention; socialising with others; taking part in, and contributing to society; trying to realise one's potential as well as being the director of one's own life (Van de Ven, Post, de Witte & Van de Heuvel, 2005). Participants in this study gave some recommendations based on their experiences of how social workers can improve on service delivery to adults with an acquired physical disability, especially in terms of community integration and rehabilitation.

#### ○ *Category 6.6.1: Recommendations from service users*

Since one aspect of the study focused on the experiences of services users (adults with an acquired physical disability) regarding social work support, it was decided to gain the input of Cohort One on how social work services could be improved to PWDs. Below are some of their suggestions:

*C1P01: As part of social work studies at University level it should be included that people should have an internship ... at the hospital where these things takes place (referring to people acquiring a disability) ... because some of these social workers, they have never been disabled, so they don't know ... what is going on in people's lives. And work at the day hospital. That would be a start.*

*C1P03: I can say what about our government can try and make that peer facilitate job permanent at least we can take it as our job and at least we earn R4 000 that is much, much better.*

*C1P06: Hulle besoek die mense slegs een keer per maand. Ek dink hulle moet dit meer gereeld doen ... My mening is dat hulle kan ondersteuningsgroepe begin, motiveringspraatjies hou en individuele onderhoude voer met persone met gestremdhede. [They visit the people only once a month. I think they must do it more often ... My opinion is that they can start support groups, host*

motivational talks and have individual interviews with persons with disabilities.]

- C1P08: *When people are in a wheelchair, they do not want to talk too much. They do not want people to be ashamed of them ... and when you stay inside it is a lot of damage ... you think about all the things you did before ... so social workers ... they must try and give them something that they have never experienced before ... like take them to the park ... then (they) can talk ... because when you take someone to other place, (they) can experience other things, (they) can see that life goes on ... social workers must try and organise more sports for people.*
- C1P10: *I think the social worker is supposed to do check-up ... even people who are not disabled ... people who are important in their lives, they do need support. It is not only people with disability that need social workers.*
- C1P13: *Alleen by die huis is jy uitgelewer ... So bietjie opvolg na die tyd sou “nice” gewees het ... Ek sal sê dit is die kontak ... iemand wat weet van persone met spinaal koord pasiënte lyk by die huis. Wat in die gemeenskap is ... Om met jou op jou “level” te kan praat met wat is die “challenges” asook die “coping” ... ander “nitty gritty” van aanpas in ‘n huis ... Dit sal dalk “nice” wees. [Alone at home you are extradited ... So a little follow-up afterwards would have been nice ... I would say it is the contact ... someone that knows how persons with a spinal cord patient at home look. Who is in the community ... to be able to speak to you on your level on what the challenges are as well as the coping ... other nitty gritty like adapting at home ... that would be nice.]*
- C1P14: *Dink ek daar is ‘n leemte waar daar nie genoeg gekommunikeer word nie vir ouens in rolstoele of nie, by hulle uit kom nie om te sê dit is wat jy kan doen by hierdie organisasie. Stel jy dalk belang? ... Wat ek dink wel ook belangrik is met mense wat ook gestremd is by mense uit kry wat dalk onlangs gestremd geraak het wat nie wil uitkom nie en hulself toesluit in hulle huise ... Ek weet nie hoe dit werk dat maatskaplike werkers meer sulke ouens betrek ... Ek dink veral in hierdie situasie (pandemie) kan hulle (maatskaplike werkers) regtig betrek word ... As ‘n ou weet wie is hulle en watter organisasies is daar en wat ‘n ou kan “assist”, dan sal ek hulle gebruik in die omstandighede soos hierdie*

... Dit is baie keer “great” om ‘n oproep van iemand te kry wat nie iets aan jou wil verkoop nie ... Ek dink dit is “great” as jy ‘n oproep kry wat niks van jou soek nie en net te hoor of jy “fine” is. Geen mens sal sê dit sal nie lekker wees nie. [ Do think there is a shortage where there is no communication for guys in wheelchairs or not, get to them to say what it is that you can do at the organisations. Are you interested? ... What I think is of importance with people that are also disabled getting them to people who are maybe recently disabled and don’t want to get out and lock themselves in their houses ... I don’t know how it works for social workers to include more people like that ... I think especially in this situation (pandemic), they (social worker) could really be involved ... When one knows who they are and what organisations there are that can assist one, then I will make use of them in situations like this ... It is often great to receive a call from someone who doesn’t want to sell you something ... I think it is great when you receive a call and no one asks anything of you and just wants to know if you are fine. No person would say that this wouldn’t be nice. ]

CIP16: They can just have activities for disabled people ... Like sports or even outings because ... it’s so good to mingle with people like you.

CIP19: (Maatskaplike werkers) moet bewus daarvan wees, want dat hulle “experts” is op my omstandighede nie. Die omstandighede verskil baie, baie drasties ... Net tussen my en my pêle. Daar is een van my pêle wat nie eers ‘n strooitjie se papier afhaal nie of sy koeldrank self oopmaak nie. Maar hy is ook in ‘n rolstoel. Ons kuier ook saam. Maar die verskil tussen my en hom in daardie geval is baie, baie groot ... dit is die grootste frustrasie ... dat daar maatskaplike werkers is wat nie altyd bewus is van die onderliggende verskille tussen ouens in rolstoele nie. [(Social workers) must be aware that they are not experts on my circumstances. The circumstances differ a lot, very drastically ... Just between myself and my pals. There is one of my pals who cannot even take off the paper of a straw or open his own cooldrink. But he is also in a wheelchair. We also socialise together. But the difference between myself and him in that case is very, very big ... it is the biggest frustration ... that there are social workers that are not always aware of underlying difference between guys in wheelchairs.]



○ **Category 6.6.2: Recommendations from service providers**

Another, equally important aspect of the study was to allow the service providers (social workers) to reflect on how they think service delivery could be improved to adults with an acquired physical disability. Accordingly, they stated:

*C2P01: On-going workshops, information / educational sessions and peaceful protests to create an awareness and advocate on behalf of persons with disabilities and to ensure the implementation thereof.*

*C2P02: Rehabilitation is crucial for them to find a means for economic empowerment ... Protective workshops should have a business to enable participants to get a decent wage ... There is need for more advocacy with corporates and business to employ persons with disabilities.*

*C2P04: Daar moet meer ondersteuning gegee word of opleiding gegee word aan die versorgers van hierdie persone (persone wat later in hul lewe 'n gestremdheid verkry het). [There must be more support provided or training given to the caregivers of these people (people who acquired a disability later in life).]*

Based on both Cohorts' responses, the recommendations for social work service delivery could be summarised as follow:



**Table 6.4: Comparison between recommendations from both service user (Cohort One) and service provider (Cohort Two)**

RECOMMENDATIONS FROM SERVICE USERS	RECOMMENDATIONS FROM SERVICE PROVIDERS
<ul style="list-style-type: none"> <li>• Social work studies to include experience with disability</li> <li>• Be more informed about different disabilities – “be better than Google” but know limitations</li> <li>• Visit more often, do check-ups (even telephonic)</li> <li>• Follow-ups after rehabilitation</li> <li>• Have individual interviews</li> <li>• Introduce PWDs to community and inform about services at organisations</li> <li>• Counselling</li> <li>• Sports for PWDs</li> <li>• Let PWDs have new experiences</li> <li>• Send people with the same disability to PWDs</li> <li>• Approach more services for PWDs</li> <li>• Make peer support jobs permanent with higher salary for PWDs</li> </ul>	<ul style="list-style-type: none"> <li>• On-going workshops</li> <li>• Information / educational sessions</li> <li>• Peaceful protests to create an awareness and advocate on behalf of PWDs and to ensure the implementation thereof.</li> <li>• more advocacy with corporates and business to employ persons with disabilities</li> <li>• More support provided or training to the caregivers of PWDs</li> <li>• Provide more assistance with the resources</li> </ul>

Some participants from Cohort Two also identified where they would need more support to be able to deliver more effective services to adults with an acquired physical disability:

*C2P02: Equal opportunity to work and participate in life’s activities. There is also a need to include them in the social and economic activities and help them with opening small businesses so that they are economically emancipated ... Transport is a big impediment as most clients struggle to attend learnerships or work because transport is not accessible ... Accessible accommodation needs to be prioritised for persons with disabilities ... Most of the people that have acquired a disability later on in life find that they cannot always go back to the jobs they used to do. Some are older for learnerships and they cannot easily get formal jobs ... Government needs to be strict on organisations to employ a certain number of persons with disabilities ...*

*C2P03: The white paper (on the rights of persons with disabilities) is brilliant ... but the implementation of it ... everyone is entitled to a house but for a physical disabled person you need a ramp ... and you don’t see the house built with that.*

C2P04: *Dat die hospitaal self ... die gesinslid ... nooit vir ... 'n paar sessies rondom die emosionele ondersteuning en die fisiese ondersteuning wat gebied moet word om hierdie persoon te versorg, dan sal dit ook baie help ... want as die persoon huis toe kom, kan hulle weer 'n besering opdoen deur hul eie onkunde en die versorger se onkunde. [So that the hospital itself ... invites ... the family member ... for a few sessions around the emotional support and physical support that must be given to care for this person, then that will also help ... because when the person returns home, they can obtain an injury again due to their own ignorance.]*

○ **Category 6.6.3: Motivation for similar studies**

In Africa, groups that are particularly vulnerable are children, women, older persons, people with disabilities and people from the LGBTIQ+ community (Australian Association of Social Workers, International Council on Social Welfare & IFSW, 2020). This was expressed by some participants from Cohort One:

C1P9: *I like to share my experience with the world, so they can know that there are people that are strong outside there ... feel free to call me.*

C1P10: *They (social workers) don't go to community to do research, like you are doing now ... I will just find you maybe two more people that you can interview.*

C1P11: *But some things ... like this interview ... you ... care for this people ... I thought this interview will put me in another part to arrange for people ... for our community ... good things here.*

C1P14: *Waar 'n ou deur jou tesis baie kan leer waar maatskaplike werkers baie belangrik is (nou tydens pandemie) as in enige ander normale tyd en kyk hoe hulle opge"gear" kan word. [Where one could learn a lot from your thesis is where social workers are very important (now, during a pandemic) than any normal time and see how they could be geared up.]*

C1P15: *Jy het my dag gemaak. Nou het ek baie lus vir werk. Wanneer laas bietjie gepraat oor gestremdheid. [You made my day. Now I'm eager for again. When last did I talk a bit about disability?]*

As mentioned earlier, many studies focused on the perspectives of the service provider (social worker) rather than the service user (PWD), which is what made this study, which focused both on the experiences of service users along with those of service providers, so invaluable. The positive feedback from participants indicated a need for similar studies providing ‘a voice’ to service users, specifically vulnerable groups such as PWDs. As mentioned earlier, knowledge of service users’ perspectives is useful in monitoring the services for quality assurance (DOH, 2000). By including service users before planning, overall improvement of services can be done, minimising disparities between service user needs and service provider plans (Dingana, 2012).

## **6.4 CONCLUSION**

As discussed in Chapter Five, qualitative research allows the social work profession to learn from those they serve (CSWE, 2012). This chapter provided an overview of service users (adults with an acquired physical disabilities) which could assist the social work profession in improving policy prioritisation and implementation as well as overall service delivery to this target group. Further conclusions and recommendations in terms of the research study will be discussed in detail in Chapter Seven.

## **CHAPTER SEVEN**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **7.1 INTRODUCTION**

This chapter stems from the fifth objective of this research study, namely to make recommendations to policy makers, organisations and social workers on how the social work support to adults with acquired physical disabilities can be further developed to assist with their integration into society. To reach these conclusions, this study made use of the discussions of a literature review, research methodology and empirical study findings. Previous chapters on the nature of the study (Chapter One), research on similar topics (Chapter Two to Four), the research methodology (Chapter Five) and finally, the result from the empirical study of this research study (Chapter Six) were discussed. In so doing, these chapters paved the way for this chapter to provide concluding remarks and recommendations, not only to address the research topic, but also for future studies. The main focus in this chapter will thus be recommendations regarding adults with an acquired physical disability, although in certain cases the more general term PWDs was used to indicate a recommendation that would be beneficial for both adults with an acquired physical disability and other PWDs.

#### **7.2 LESSONS LEARNED FROM THIS STUDY**

This study included different models and perspectives on disability to obtain a better understanding of the experiences of adults with an acquired physical disability regarding social work support services. This might be seen as a limitation in certain cases, but due to the complexity of the concept of disability, this varied analytical frame was decided on to ensure that a more comprehensive understanding of the experiences was possible. To a certain extent, these models and perspectives also linked with one another to form part of the unique bio-psychological perspective within the social work perspective. This is shown in Table 7.1 below, as adapted from the discussions from Chapter Three and the application of the models and perspectives in Chapter Four as utilised within this study.

**Table 7.1: Summary of information used to gain understanding of experiences of participants from a biopsychosocial perspective**

	<b>BIOLOGICAL</b>	<b>PSYCHOLOGICAL</b>	<b>SOCIAL</b>
Psychosocial theory		Life stages and crises	
Social Model			Social aspects
ICF model	Body functions Impairments Activity limitations	Coping strategies Health behaviour	Participation restrictions Barriers Facilitators
Ecological perspective			Microsystems Mesosystems Exosystems Macrosystems
Capabilities Approach	Functionings and capabilities (influenced by both personal and environmental factors)		Commodities Environment (physical, social, economic, cultural, political)
Grief model		Stages of grief	
Other	Age, gender, cause of disability	Resilience Loss of Independence Spiritual experiences	Living area of participants

During this study, there were a number of main findings that could be identified across the different themes of the study. These included the importance of peer support and accessible information about services, the lack of employment opportunities and financial concerns, as well as lack of accessibility and transport within communities. These findings will also be discussed under each theme with the relevant recommendations.

The value of peer support amongst adults who have acquired a physical disability was discussed in terms of support services, assisting with acceptance and resilience, as well as including them with community awareness and sensitisation initiatives. The value of this was described as akin to hearing from someone that is in that specific situation who could empathise and relate to the experiences of others. In terms of accessible information, it was highlighted that, without knowledge of services that are available, it is not possible to utilise these services, which has a significant effect on the rehabilitation process of adults with an acquired physical disability.

Rehabilitation policies and other disability policies such as the UNCRPD and WPRPD aim toward the reintegration of PWDs in society. However, this is hindered by challenges such as lack of employment opportunities, accessibility and transport within their communities. Participants in this study all seemed motivated to be able to form part of their communities, but

were limited in the level of integration possible to them through these challenges. This is concerning, because if a motivated group with a seemingly high level of resilience and acceptance of their life with a disability are struggling, these difficulties will be even more applicable to PWDs who do not have the same levels of resilience and acceptance.

A final lesson that was learnt from this study was the importance of ‘bottom-up’ approaches in planning service delivery and policies for PWDs. Referring to the recommendations provided by the service users in Chapter Six (see Table 6.4), this input was valuable, as it provided hands-on recommendations. One example that comes to mind is a participant from Cohort One instructing social workers not to always conduct interviews at the office or the client’s house, but to conduct them in other places such as the park at times. This is a seemingly simple recommendation, but could make a great difference for the service users, as they would immediately be experiencing something new and feel part of the community, which could in turn have a positive effect on their rehabilitation process. As can be seen from the consideration of PWDs’ recommendations, the idea of a ‘bottom-up’ approach manifests in including PWDs and their families in all aspects that concern them, including recreational and advocacy events. This immediately provides a sense of community integration for them, allows other community members to gain a better understanding of their skills, and could minimise misconceptions and stigmatisations from the community. In so doing, this approach ensure that the outcome of these initiatives will be aligned with their needs.

### **7.3 RECOMMENDATIONS**

This study aimed to answer the research question: What are the experiences of adults with acquired physical disabilities with regards to social work support (especially in assisting them after they acquired the physical disability)?

#### **7.3.1 Research methodology**

Chapter Five discussed how the research methodology was greatly influenced by the COVID-19 pandemic, as it required the study to be redesigned and brought about the need for new ethical considerations. In terms of Mouton’s (2011) guidelines for selecting a research topic, this study met all three criteria i.e. relevance to career, intellectually stimulating as well as researchable, interesting and worthwhile, as discussed in Chapter Five.

### 7.3.1.1 *Summary*

This research study used a combination of descriptive and exploratory research to answer the research question. In the literature review chapters (Chapter Two to Four), descriptive research was used to provide a more comprehensive analysis and understanding of the research topic aligned with the research objectives. The research study was explorative due to the lack of current research on the specific variables included in this topic. The different experiences shared among participants provided understanding for the experiences of adults with an acquired physical disability through their unique narratives (Chapter Six). Participants from both Cohorts provided their experiences on some of the challenges in service delivery to adults with an acquired physical disability and provided recommendations on the matter.

The research study made use of a qualitative approach with some quantitative elements in terms of the identifying particulars of participants. This approach was aligned with some of the purposes of qualitative research in terms of research being done with a vulnerable service user group (adults with an acquired physical disability) regarding their experiences of social work services. Likewise, due to the lack of comprehensive previous research on the experiences of adults with an acquired physical disability, a combination of deductive and inductive reasoning was used in this study. To be more specific, inductive reasoning was used when unanticipated findings emerged during the empirical study, in which case reference was made to previous research studies with similar findings. Deductive reasoning was used by using general findings from previous studies within the literature review and relating it to specific findings of the study.

The literature review in this research study took place over three chapters aligned with the first three objectives. However, although there were no studies available with the same researchable variables as this study, the literature review provided insight on similar topics. Once the literature review was completed, it guided the themes for the interview schedules. It was decided to make use of semi-structured interviews with a planned number of 25 participants over two Cohorts. These were to be divided between service users (Cohort One) and service providers (Cohort Two). Despite these plans, the study only had 24 participants, of which one from each Cohort provided two means of their experiences used for the empirical study, essentially providing 26 interviews (sources) with 24 participants. The first Cohort thus included nineteen adults with acquired physical disabilities and the second Cohort five social workers who has had experience with working with PWDs.

As was the case with the planned number of participants, the planned methods of sampling and data collection were affected due to the COVID-19 implications. Accordingly, the planned purposive sampling had to be complemented by snowball sampling where the gatekeeper organisation was not able to identify enough potential participants by merit of not being able to access their client files. Likewise, the implementation of COVID-19 lockdown regulations just as the research study's empirical interviews were about to start affected the data collection methods, which had to be redesigned and resubmitted to the REC for approval before commencing with interviews (the ethical clearance process was further discussed under 5.4.1 in Chapter Five). Since the WHO identified PWDs as a potential vulnerable group for the COVID-19 pandemic due to a potential weakened immune system, as well as the 'lockdown regulations' put in place under governmental guidelines, it was thus decided to restructure the data collection for the research study to be done remotely through the use of technology such as cell phone calls, or VOIP such as WhatsApp and Zoom.

The study was categorised as a medium-risk study under the REC submission, so the researcher had to be aware of participants' possible feelings and approach the interviews with the notion of not doing any harm to the participants. Interviews were also structured in such a way to begin and end the interviews with the least personal and emotionally sensitive questions to increase the comfort of the participant. All the participants of this study were given the option to be referred for debriefing. During this research, extra effort was made to ensure that the study adhered to the additional ethical considerations of conducting research remotely by means of technology. Participants were given choices regarding the different methods, and all participants participated voluntarily. Should the need have arisen for debriefing, participants would have been referred to a relevant social worker in their area. Three potential independent social workers were identified for debriefing of participants.

One evident advantage of remote interviews due to the COVID-19 pandemic was the ability to be able to interview any participant from any area with minimal costs involved. In the case of face-to-face interviews, interprovincial interviews would have been costly in terms of travelling. The remote interviews allowed for participants to range over different areas within the Western Cape, while also to including participants from Gauteng and KwaZulu-Natal, allowing the research study to be more transferable. For this study, narrative, content, and some elements of discourse analysis were used.



### **7.3.1.2 Recommendations for future studies**

Despite the benefits, there were some limitations to this study. Some of these limitations will be addressed below along with some recommendations for future studies.

#### *A. No face-to-face interviews*

As already discussed extensively, due to COVID-19 restrictions, it was prohibited to conduct face-to-face interviews. This caused limitations in terms of being able to assess participants' facial expressions and body language. Despite this limitation, voice tone and pauses could still be identified and interpreted in most cases. The researcher also attempted to compensate for the lack of face-to-face interviews by having a photo of herself as a profile picture for WhatsApp, and wherever possible, to arrange a Zoom interview. However, most participants were not able to make use of that option due to a lack of access to technology. Overall, the researcher attempted to make the interview process as convenient possible for each participant. As this was a new experience for the researcher, it was also a learning experience to adapt to this way of doing research. Future studies could investigate other alternative ways for face-to-face interviews and weigh up options most convenient for the participants, also bearing in mind the cost of data and their own lack of technological skills.

#### *B. Use of technology for interviews and consent forms*

As social work focuses largely on human relationships and working with people within the community, this limitation required a new approach that would not be traditionally used in social work i.e. making use of technology only in terms of making contact with participants. It was clear from discussions around different continents (as discussed in Chapter Four), that this new approach had vast limitations and required the profession, as a whole, to identify and address the challenges of this new approach. This included various ethical considerations, as discussed in Chapter Five. Future studies could look at various studies that experienced the same limitations and ethical considerations and identify the challenges to best address them for their own studies.

#### *C. Limited information about cultural differences*

Due to the lack of participants, no pilot study was done. This would be recommended for future studies. Although this was not a focus point in this research study, it was only discovered during

the interview process of the study that participants did not disclose a lot of cultural or racial information. In a less precarious time than during a global pandemic, this could have been remedied by locating participants from varying backgrounds. Nonetheless, this lack of diversity meant that no in-depth analysis of cross-cultural experiences could be done. Instead, disability culture was unpacked in general in terms of stigmatisation and acceptance in communities.

The study used open-ended questions within a semi-structured interview process, which provided the participants the opportunity to share as much or little as they felt comfortable disclosing. This manner of interviewing is seen as less invasive than a structured interview. However, combined with no face-to-face interviews, this also meant that data such as participants' race or culture, were not identified. Should future studies want to compare the different experiences across different cultures, this identifying particular should be included in the interview schedule in a sensitive manner that is not imposing on the participants.

Some of the other limitations to the study in terms of the content that was covered will be addressed under recommendations for future studies.

### **7.3.2 Theme 1: Biological experiences of adults with an acquired physical disability**

The first theme of this study was aimed at gaining a better understanding of the biological experiences of participants in terms of the biopsychosocial model. Although this model includes the psychological and social aspects as well, a more detailed discussion of these aspects will be discussed in Themes Two to Four. The biopsychosocial model is also used in the ICF, where disability is defined in terms of impairment, activity limitations and participation restrictions. These three dimensions of disability encompass the sub-themes of this theme. This theme referred to findings from interviews with Cohort One.

#### **7.3.2.1 *Summary***

The types of impairments were discussed under the identifying particulars of Cohort One (see Figure 6.4. in Chapter Six). From the causes of the disability, it was derived that most of the participants' impairment involved not being able to walk. However, many indicated that this would not be the aspect of their life they would most want to change, instead identifying some activity limitations such as being able to lean over, use arms, have stable stomach functioning, move around in small spaces, reach certain things and have certain finer movements. One participant also experienced neuropathic pain which influenced activity.

With everyday activities, participants experienced restrictions in terms of being unable to bath themselves, transfer themselves, take things out of the closet, pick up after the dog, lift and carry things, drive, arrange the fire for a braai, clean the house, turn switches on and off and navigate smart phones. Despite some experiencing activity limitations, there were still many participants that mentioned they were able to do most activities themselves, as they had learnt to adapt i.e. getting dressed, doing hair, washing, cooking, getting into the bath and car, making dinner and doing wheelchair sports. This is aligned with the capabilities approach, where functionings are described as activities (e.g. being able to play sport) as discussed in Chapter Three. How the PWD experiences activity limitations can be affected by contextual factors such as social attitudes, legal and social structures and internal personal factors (DWCPD and UNICEF, 2012). This will be discussed under Theme Two (psychological experiences), Theme Three and Four (societal experiences), as well as Theme Five (cultural experiences). Society could inhibit a PWD's performance by creating barriers (e.g. inaccessible buildings), or not providing facilitators (e.g. unavailability of assistive devices). Participants in this study identified the need for accessibility as a major contributor to their participation restriction. This will be discussed in terms of accessible housing and the accessible community in general.

Both impairment and activity limitation can thus influence PWDs' participation restrictions, which refer to the person not being able to experience full involvement in life situations (compared to a person without a disability). The participation restrictions of participants from this research study included not being able to go to certain places and being dependent on the environment.

According to the ICF model, disability is characterised as the result of a complex relationship between an individual's health condition, personal factors, as well as external factors representing the circumstances in which the individual lives. An environment with barriers, or without facilitators, will restrict the individual's ability to participate within that specific society (WHO, 2001).

### **7.3.2.2 Recommendations**

As mentioned in Chapter Six, this study was not of a medical nature, and therefore medical factors are not mentioned in great detail. However, it was important to identify the impairments and other biological experiences of participants to understand the activity limitations and

participation restrictions they experienced. Some recommendations regarding these two aspects of the ICF model will be discussed below.

#### *A. Activity limitations*

From the empirical study, a paradoxical experience in terms of activity limitations was discussed, as some participants were able to do certain daily activities whilst others still struggled with them. Those that were able to adapt to their life with a disability seemed to develop more activities that they could fulfil independently. This provides a strong motivation for the importance of rehabilitation and support for adults with an acquired physical disability. Generally, rehabilitation is aimed at retaining, restoring and creating function that was lost, such as some of the activity limitations described by participants.

In South Africa, the goal of the national rehabilitation policy is: “[t]o improve accessibility to all rehabilitation services in order to facilitate the realisation of every citizen’s constitutional right to have access to health services [...] and to serve as a vehicle to bring about equalisation of opportunities and enhance human rights for PWDs” (DOH, 2000:2). Conversely, as discussed in Chapter Two, many PWDs rely on public health care services that are overcrowded, which inhibits regular visits. This limitation could be addressed if health professionals such as physiotherapists and occupational therapists could work alongside social workers in communities to support adults with an acquired disability in their rehabilitation process. This recommendation is supported by the empirical study, where both participants from Cohort One (service users) and Cohort Two (service providers) identified this as a need, indicating the importance of these services complementing each other in communities in rehabilitation service delivery.

Ultimately, developing more support for rehabilitation within communities in terms of initiatives such as CBR could assist PWDs with their activity limitations which, as some participants have indicated, are possible to overcome with the right support. Social workers can thus work alongside other health professionals and families of PWDs to teach ‘new’ ways for doing everyday tasks such as dressing and washing where possible. This would have a positive influence on the PWDs’ ability to participate and gain independence, which aligns with various disability policies.

### *B. Participation restrictions*

One of the greatest participation restrictions that participants from both Cohorts identified in this study was accessibility. Despite various initiatives in terms of universal design and accessibility policies (New Urban Agenda, Pillar 1 of WPRPD and UNCRPD Article 9), there are still several challenges in terms of accessibility for PWDs. This could be addressed by advocating for universal design for all to the various stakeholders such as governmental departments, corporate businesses, and community facilities. As became apparent with the conclusion that a ‘bottom-up’ approach in planning service delivery and policies for PWDs is necessary, it is crucial that they be involved with these advocacy strategies to improve accessibility. To this end, one participant from Cohort One (C1P19) explained how there seems to be a general lack of understanding of what is needed in terms of accessibility, and various other participants echoed this by recommending the involvement of PWDs in addressing the participation restriction within communities. Studies such as this one could provide evidence-based motivation for change in communities from a bottom-up approach, as opposed to the traditional top-down approach for setting and implementing policies.

### **7.3.3 Theme 2: Psychological experiences of adults with an acquired physical disability**

As mentioned before, acquiring a disability could lead to different psychological experiences due to the life stage the individuals were in when they acquired the disability, as well as how long they have been living with the disability. This theme referred to experiences from Cohort One. Participants discussed how they had to adapt and come to terms with their life with a disability which, for many, required a lot of reflection. Some participants also explained how they had to come to terms with the realisation that the life they planned was not going to be possible for them anymore. To gain a better understanding of the psychological experiences of adults with an acquired physical disability, the sub-themes of the model of grief, loss of independence, resilience and spiritual experiences were identified.

#### **7.3.3.1 Summary**

Kübler-Ross (1972) identified five stages of grief, which was later adapted by Ross and Deverell (2010) to nine phases of grief i.e. shock/disbelief, relief, denial, bargaining, guilt, depression, anger, anxiety and acceptance. Despite participants experiencing most stages of grief, when analysing the content of the interviews, it could be argued that most participants

had grown to accept their life with a disability at the time of the interview. Social workers play an important role in assisting PWDs and their families in working through the feelings during the different stages of grief. The importance of working through all of these feelings of grief is invaluable in fully socialising PWDs and reintegrating them into society, as is reflected in the goals of policies such as the WPRPD (2016) and the UNCRPD (2006), to name a few. This will be further discussed in Theme Six.

There also seemed to be a correlation between participants who were experiencing acceptance and their level of resilience. Several participants displayed tremendous levels of resilience and an overall ability to be able to cope with acquiring a physical disability. Resilience is described as a powerful personal factor, which plays a pivotal role in the individual's quality of life. Most participants in this study (fourteen) had acquired their physical disability more than ten years prior to the interview, which could be an indicator of why their level of resilience and overall acceptance appeared to be high. They were, however, able to identify previous stages of grief they had experienced. Some participants also indicated that they had a spiritual experience in terms of their disability, although this was not a main discussion point. The spiritual experiences of participants could be identified through the discourse of interviews, indicating a belief in 'greater good' and 'higher power.' Accordingly, some participants identified religious institutions as a source of social support for them.

As discussed earlier, the ultimate goals of rehabilitation include minimising disability, by ensuring equalisation of opportunities, full participation, and independent living. This is important to remember in understanding how the loss of independence could have a psychological impact on the individual. On the other hand, gaining independence again through rehabilitation could have a positive psychological impact on the PWDs. Both the loss of independence and the importance of this right were key discussion points for participants in Cohort One, and also emphasised in service strategies identified by participants from Cohort Two. Several participants indicated that they had difficulty adjusting to a life where they were dependent on other people. Some even expressed how they had experienced people that wanted to assist them, with this not always being helpful. Such narratives contribute to a realisation of the importance for PWDs of gaining back independence.

The psychological impact of loss of independence could be described in terms of how the person must come to the realisation of what they can still do on their own, and conversely, where they may need assistance. Where an individual regained independence, it could be

associated with Maslow's hierarchy of needs (1943), where self-actualisation of reaching one's full potential is the last in the hierarchy of needs. It could also be associated with acceptance (grief model), resilience and improved quality of life. However, where independence is still lost, it could relate with some of the other stages of grief prior to the final, acceptance stage.

### **7.3.3.2 Recommendations**

High levels of resilience and spiritual experiences would be associated with positive psychological experiences, which could be strengthened and supported. Recommendations will be made regarding how to address some of the adverse psychological experiences i.e. loss of independence and feelings of grief.

#### *A. Assistance with feelings of loss of independence*

One of the most significant psychological impacts that acquiring a physical disability brings forth is the loss of independence. Most people strive for independence from a young age, namely the moment in childhood that they learn to do things on their own. It is then understandable that, when a sense of independence is lost, it would have a considerable psychological impact on the individual. Similar to the recommendations on participation restrictions, social workers and other health professionals can assist with loss of independence by strengthening rehabilitation measures within communities. These measures could include access to assistive devices that would fit specific needs as well as access to community resources such as sports, recreational or skills development. By doing this, certain activity limitations and participation restrictions could be addressed, which will minimise the sense of independence lost.

Where activities cannot be regained through rehabilitation, the social worker could support both the adult with an acquired physical disability and their family with regard to how best to find ways to adapt to this change. For example, one participant in Cohort One indicated that, due to the loss of independence, they long for 'alone time' without a caregiver. This is something that caregivers could be alerted to, and arrangements could be made to grant the PWD time without their care. Many participants also indicated that peer support could play a vital role in this psychological aspect. Social workers could liaise with other PWDs to assist in supporting adults who acquired a physical disability, which could feel less like professional intervention and thereby foster a sense of independence. This will also be discussed further in Theme Six.

### *B. Assistance with feelings of grief*

Building on the sense of loss of independence, another psychological aspect of adults with an acquired physical disability is the feeling of grief. The stages of grief are vital in understanding the mourning of a life without a disability that many adults with an acquired physical disability may experience. Participants in this study described how the loss of independence, a planned career and even some activity limitations had an impact on them. Social workers need to support adults with an acquired physical disability throughout the grief process to ensure that they can achieve the final stage of acceptance. This may require long-term emotional support from both the social worker and peers and family members of the PWD.

An essay written in 1987 by Emily Perl Kingsley (*Welcome to Holland*) could be a valuable comparison to assisting adults with an acquired physical disability. Originally written about her child with a disability, this essay describes that, when having a baby, it is similar to planning a trip to one country. However, when getting the disability diagnosis, one discovers you have arrived in another country. Further, the essay explains how one needs to discover what the “different” country needs to offer. This is where social workers need to be the ‘tour guides’ of the “different place”, assisting adults with an acquired physical disability to identify their abilities beyond the disability. This is only one example of an analogy, and from the empirical study of this research, it is evident that making use of PWDs themselves as a form of peer support would be one of the best ways to support an adult with an acquired physical disability. They are, in more ways than one, the experts which social workers can tap into.

#### **7.3.4 Theme 3: Support services used by adults with an acquired physical disability**

The environment in which an individual finds themselves has a considerable effect on the prevalence and extent of disability. It was decided to make use of Bronfenbrenner’s ecological model as a theoretical framework for this study, as it considers the influence that the environment has on the individual depicted as a series of systems which fits into one another. As applied to social workers who work on individual, familial and community levels, this model provides a good guide to understanding the PWD in relation to their (social) environment. This theme refers to the experiences of participants from Cohort One. The nested systems of this perspective represented the sub-themes.



### 7.3.4.1 *Summary*

Within the microsystem of the ecological perspective as applied to this study, participants made use of the spousal/partner, parental, sibling and child sub-system as support networks. In the mesosystem, on the other hand, these support networks comprised extended family, friends and professionals. Further, participants identified social work/welfare organisations, health facilities and other community facilities – such as religious institutions, workplaces and community sport groups – as their exosystem support networks. Finally, their macrosystem included the South African Health Care System as well as other support services including assistive devices, insurance and social grants.

In terms of assistive devices, participants mostly made use of mobility devices and devices that assist with finer motor skills, accessibility and continence. Since most of the participants acquired a spinal cord injury, the primary mobility devices used were wheelchairs. Related to this, one participant noted that people tend to think that all wheelchairs are alike, although essentially they are specifically customised to the person using them. There were, however, also participants that made use of other mobility devices such as crutches, a quadropod and a walking cane. One participant indicated that, as part of their sport group, they buy different sport equipment that are adapted and shared. This is done not only to save on the cost, but also to allow people to be able to use them to participate in different sports. In addition to their mobility devices, a few participants were also able to further their mobility by adapting their cars to still be able to drive it despite their disability.

As mentioned before, one of the primary assistive devices participants used were those that assist with finer motor skills, accessibility and continence. One participant with an SCI specifically made use of several assistive devices that assisted with fine motor skills in terms of typing, writing and even painting. Other participants indicated that they made use of continence devices, especially those who experienced some form of SCI, as the injury affected this aspect of their life. In addition, many participants adjusted their own home to make it more accessible through means of ramps. Accessibility is an important aspect in terms of inclusion and independence for many persons with physical disabilities. The impact of lack of accessibility will be further discussed in Theme Four.

Related to accessibility is the individual's access to financial resources. A few participants specifically made mention of the disability grant as a support mechanism. There were also a

small number of participants who indicated that insurance played a big role in supporting them. One participant noted an insurance policy of a deceased spouse as a support system, and another noted an incapacity insurance policy. Yet another participant stated that social insurance played a role in supporting them with both monetary and physical resources.

#### **7.3.4.2 Recommendations**

Recommendations in terms of improving the experiences of adults with an acquired physical disability on social work support, as can be derived from the background above, involve mobility and accessibility. Some participants did make recommendations, as indicated in Table 6.4 in Chapter Six. More related recommendations would also be made in Theme Four. There was a general thread amongst the narratives of participants, stating the importance of family and peer support in their lives. Recommendations would be to ensure that especially these two support systems are available and strengthened for adults with an acquired physical disability. Strengthening this support would reinforce rehabilitation and reintegration of this group into society.

#### **7.3.5 Theme 4: Support needs of adults with an acquired physical disability**

This theme also refers to the experiences of participants from Cohort One. As was the case with Theme Three, the nested systems of the ecological perspective represented the sub-themes within this theme.

##### **7.3.5.1 Summary**

The need identified in this study within the microsystem of adults with an acquired physical disability was for intimate relationships. This was not explicitly mentioned, but rather an implied need that could be identified through analysing the discourse of interviews, which entailed conversations about failed marriages and deceased spouses, as well as the general value participants put on their spouses.

The support needs within mesosystem include the need for extended family support and professional support and understanding. Although some participants indicated that their extended family is their support network, others indicated that the support was not the same as before and could almost be described as fading. In Theme Three it was identified that participants made use of professionals. However, not all the participants had positive

experience. There were several participants that indicated that they did not feel they received adequate support and understanding from professionals in terms of their circumstances.

Under the exosystem, participants identified social work/welfare organisations, post-discharge rehabilitation, community support services, community safety, as well as transport systems as a need. There were a few participants in this study that felt that there were not sufficient community support services available. Transport to services was also a concern. Many participants did not have their own, private transport and relied on public transport, which in most cases failed to accommodate them. Transport was thus identified as one of the biggest needs in this study. This need also links with concerns for accessibility, participation and independence. Related to this, a few participants mentioned their concern for community safety, which often prevented them from leaving their homes.

Finally, the needs identified within the macrosystem by adults who acquired a physical disability included disability-friendly employment and financial concerns. Nine participants in this study were unemployed, and many identified employment for PWDs as a critical need. Some identified that they were employed prior to acquiring the disability, but struggled to find employment since. Understandably, the lack of employment opportunities for participants in this study lead to financial concerns. These concerns, however, were not only expressed by participants who were unemployed. Many employed participants also expressed a concern for their finances and the cost of different services, equipment and other support.

### **7.3.5.2 Recommendations to address support needs**

There were various support needs identified by participant in this study i.e. relationship, extended family support, professional support and understanding, post-discharge rehabilitation facilities, community support services, transport systems, community safety, disability-friendly employment and financial concerns. Recommendations to address these needs will be made to relevant stakeholders.

#### *A. Relationships*

As mentioned earlier, the need for intimate relationships were not always explicitly mentioned but, were identified as a theme through the discourse of the interviews. Having an intimate relationship is personal, and thus might not be directly influenced by professional support. However, where professionals, and more specifically social workers, can assist with this would

be in terms of helping adults with an acquired physical disability, as well as other PWDs, become more integrated into society. Where an adult with an acquired physical disability was in a relationship prior to acquiring the disability, sufficient support in terms of counselling could be provided to both the PWD and their partner to ensure that the relationship could also adjust to the life with a disability.

### *B. Extended family support*

Many of the adults with an acquired physical disability that took part in this study identified that, although they initially received support from extended family members, this support faded over time. Ongoing family support and involvement in community activities with PWDs could ensure that the family members stay involved and keep supporting adults with an acquired physical disability. One such example could be to involve both PWDs and their families in planning and implementing advocacy-, support-, or even recreational activities such as World Disability Day. Both parties could then share in the responsibilities and the enjoyment, which could strengthen the relationship and understanding between them.

### *C. Professional support and understanding*

In Chapter Four, it was discussed that within a multi-professional rehabilitation team, social workers must often act as mediators and advocate on behalf of the PWD and the family to ensure that their needs are addressed with other professionals as well. Participants in this study mentioned that other professionals did not always consider their circumstances and support needs. Sometimes, with the necessary intervention, information was provided in a manner that was empathetic, such as ensuring that the adult with an acquired physical disability understood the full extent of their diagnosis. In examples like these, the social worker would thus act as the liaison between the PWDs and their families and other health professionals to ensure that the PWD felt that their needs were understood and supported. The social worker also needs to support the PWD and the family in finding the balance between spiritual beliefs and realism in terms of the prognosis, while simultaneously developing their capabilities. This would also assist with the adjustment from life without a disability to living with a disability through the different stages of grief.

#### *D. Post-discharge rehabilitation facilities*

As mentioned in Chapter Two, few of the health care and rehabilitation facilities in South Africa offer affordable services. Services within the private sector are often expensive, which makes them inaccessible for a large portion of the South African population. It was also noted by participants from Cohort Two that some of the governmental rehabilitation facilities are not located within the communities of adults with an acquired physical disability, which makes it difficult for families to visit them during the process. The lack of post-discharge facilities and general referral between the rehabilitation facility and the community poses certain considerations for different sectors.

Firstly, the governmental support in terms of more community-based rehabilitation initiatives should be addressed to make rehabilitation (and post-rehabilitation) services more accessible. This is aligned with the 2030 Call for Rehabilitation by the WHO, but also the South African National Rehabilitation Policy. Secondly, with more facilities available in different, more wide-spread, communities, the referral between these facilities and community services such as social work services should be improved to ensure continuity of rehabilitation care. This will, in turn, improve the reintegration of adults with an acquired physical disability into the community. Finally, segregated service delivery between professions should be minimised, and focus should be given to more multi-professional collaborative service delivery.

#### *E. Community support services*

Similar to the recommendations for post-discharge rehabilitation facilities, improved support from government for the establishment of more community support services that are affordable and accessible to adults with an acquired physical disability and their families is recommended. Social workers, along with PWDs and their families, can actively advocate for more of these services. Another consideration is to mobilise PWDs and their families to create the community support services that are required themselves, not only to assist themselves but also others in similar situations. This is often how DPOs are developed, as they focus on the needs of PWDs within different communities. This enhancement could assist with community reintegration of adults with an acquired physical disability, as it could both provide support needs and create some form of employment opportunity for adults with an acquired physical disability.

### *F. Transport systems*

Despite the availability of some transport systems for PWDs, these are not sufficient for the current need in communities. Studies in the past (Muller-Kluits, 2017 & Dingana, 2012) identified the same needs, which indicates that initiatives that have been taken since are not fully addressing this need. As with many other support service needs, transport to PWDs should be addressed with the assistance of governmental support to ensure accessibility and affordability. Social workers could advocate and suggest policy reforms so that these do not merely remain guidelines and policy goals, but become mandated for public transport systems. This would also have to be done as a collaboration between public transport stakeholders, PWDs and governmental stakeholders to ensure success.

### *G. Community safety*

Several participants identified community safety as a concern for them. The concern for community safety could be twofold. Firstly, it could cause injuries such as spinal cord injuries that could cause a disability, and secondly, the lack of community safety could limit community reintegration for PWDs, as they might fear going to different places in the community. As indicated in Figure 6.4 in Chapter Six, many participants acquired their disability through means of violence i.e. gunshot or stabbing, indicating a potential lack of safety in their community. Many of the disabilities of participants could have been avoided with lower crime rates and prevention of the spread of certain illnesses that could lead to an impairment e.g. TB which could, in some cases lead to spinal TB (paralysis). Social workers, along with other health professionals, could educate the community on the risks of certain illnesses that could cause impairments. Along with law enforcement officials and other community organisations, they could also address the crime rate within communities with early interventions to minimise youth gangster involvement.

### *H. Disability-friendly employment*

As discussed earlier, employment of PWDs are not reaching policy goals at the moment. Despite the findings in this study, which identified several learnerships and training workshops available to them, PWDs are still not included in the general labour market. Consequently, social workers could liaise with SETAs of different sectors to identify what is required for PWDs to filter into the labour market. Although in South Africa the unemployment rate is high in general (estimated at 30% from various sources), and would possibly increase after severe

job losses during the COVID-19 pandemic, it would still be beneficial to assess why PWDs do not seem to be fully included in the labour market. The difficulty experienced by PWDs seeking employment prevalent, despite initiatives where the inclusion of PWDs are considered a priority. Involving different sectors in these discussions could help to identify where improvements need to be made to assist with employment of PWDs. Focusing specifically on adults with an acquired a physical disability, who in many cases were employed prior to acquiring the disability, the social worker could assess what skills they still have to be able to assist them in integrating back to the labour market. This could be done with the assistance of an occupational therapist who could do a 'job-readiness' assessment. From this assessment, a personal rehabilitation plan could be set up in liaison with the PWD and their family to work towards reintegration.

### *I. Financial concerns*

In South Africa, it is estimated that almost one in five people rely on the social grant. This is a significant percentage for a country that also has high unemployment rates. This would indicate that relying solely on social grants as a long-term income for PWDs is not sufficient, and that the focus should rather be on enabling them in earning their own income. Many participants in this study discussed their concerns regarding finances. There are two possible recommendations for addressing these concerns. The first, as discussed earlier, would be to include more PWDs, especially adults who acquired a physical disability and likely had employment before, into the labour market. Employment could begin to address some of the financial concerns experienced. Another recommendation would be to make assistive devices, equipment and other resources more accessible and affordable for PWDs. As one participant (C1P19) mentioned, among their peers, they bought a single item of adjustable equipment for wheelchair sports that they could share to save on cost. The participant further mentioned that they raise funds to be able to purchase some of these resources. This is an example of an initiative that social workers could support PWDs in. In terms of gaining more accessible and affordable devices, social workers may need to liaise more with governmental stakeholders to identify this as a priority that is not only related to policy, but also to budget.

### **7.3.6 Theme 5: Cultural experiences of adults with an acquired physical disability**

This theme included the experiences of participants from Cohort One, and discussed their experience with both lack of understanding and acceptance within the community.

### **7.3.6.1 Summary**

Participants in this study identified that they experienced stigmatisation and a need for sensitisation in the community, where it is assumed that if the person is disabled in one way, they are disabled in all ways e.g. a person with a physical disability is assumed to also have an intellectual disability. The experience of stigmatisation (combined with some of the needs discussed in Theme Four) brought about a need for sensitisation within communities, such as refraining from parking on wheelchair parking and using wheelchair bathrooms. Negative experiences such as stigmatisation could have an influence on adults with an acquired physical disability's psychological experience as discussed in Theme Two.

It is evident that a lot of the stigma experienced was due to the community not having enough information about disability, inhibiting PWDs' acceptance within a community. Not all participants, however, had negative experiences within their community, with some indicating that they felt accepted. As stated before, how the community is experienced by the PWDs (i.e. stigmatisation or acceptance), could influence their ability to be able to fully participate in society. This could then be identified as a barrier, under the ICF model, that can hinder priorities of policies like the UNCRPD and WPRPD for disability inclusion.

### **7.3.6.2 Recommendations to reduce stigmatisation through sensitisation of communities**

As many of the participants from Cohort Two indicated, one of the best ways to minimise stigmatisation is through educating and sensitising the community on different types of disabilities and their needs. However, what could also add to this, would be to involve PWDs themselves in these activities. The disability rights slogan often used is “nothing about us without us,” which emphasises the importance of not only advocating on behalf of PWDs, but also including them in these practices. Many participants in this study indicated the difference speaking to someone who also acquired a physical disability made in the process of their coming to terms with their diagnosis. The same could be argued for the community. When a professional such as a social worker is educating or sensitising a community about different disabilities, the impact may not be as significant as when the community hears the same information from a PWD, and even more so, if the PWD is someone who may have had the same misconceptions prior to acquiring a disability.



### **7.3.7 Theme 6: Social work support services to adults with an acquired physical disability aligned with policies**

Many participants made use of social work support services through means of DPOs and other welfare/social work organisations. This theme explored social work services to adults with acquired physical disabilities by combining experiences of both the service user (Cohort One) and the service provider (Cohort Two).

#### **7.3.7.1 Summary**

Although the study mostly considered how the service delivery of social workers were aligned with policies and the roles of social workers as experienced by adults with an acquired physical disability, it is worthwhile to note that the organisation that was represented in this study through Cohort Two fulfilled the functions of DPOs as described earlier. These functions included contributing to the evaluation and monitoring of services and collaborating with researchers to contribute to service development, promoting public awareness and understanding by professionals about the rights of PWDs, as well as conducting audits of environments, transport, and other systems and services to promote the removal of barriers.

#### *A. Services delivered according to policies*

The study considered both the services offered by social work organisations as described by service providers (Cohort Two), and services used as described by service users (Cohort One). In the empirical study, Table 6.3 shows that the participants from Cohort One did not indicate that they were using all the services offered according to Cohort Two. This could be because the participants from Cohort One did not need all these services, did not mention these services or were not aware of the services being offered

In Chapter Two several international as well as South African policies guiding service delivery to PWDs were discussed. The UNCRPD covers a wide range of areas including health, education, employment, access to justice, personal security, independent living, and access to information. The Chapter also identified several other South African policies that could guide service delivery to PWDs, including the Constitution (RSA, 1996), Promotion of Equality and Prevention of Unfair Discrimination Act (RSA, 2000) mandated by section 9(4) of the Constitution, as well as the national rehabilitation policy (DOH, 2000).

Along with the policies summarised above, participants from Cohort Two of this study also identified the Employment Equity Act, Social Work Profession Code of Ethics, Social Assistance Act, Social Professions Act, Health and Safety Act, Human Rights Act, Older Persons Act as well as the Domestic Violence Act (where necessary), as guiding policies for service delivery to PWDs. It was not possible to analyse in detail how social work services were aligned with all of these policies, so only a brief discussion in terms of the WPRPD will be done in terms of the services identified by Cohort Two, as the main beneficiaries of the successful implementation of the WPRPD included PWDs and their families as rights-holders. Accordingly, Table 7.2 shows the different pillars of the WPRPD, how it relates to the UNCRPD and which services are aligned with it.

As an international policy on service delivery to PWDs, the UNCRPD is a fundamental document in this study. Within South African context, the WPRPD serves that purpose as it specifically focusses on the rights of PWDs providing guidance from a South African (social work) perspective in consideration with previous policies. It was decided to only focus analysis on service delivery according to policy within these two policies. The other policies are acknowledged but no in-depth analysis was done in terms of compliance to these policies. Table 7.2 below shows that services offered at the participating organisation, as represented by Cohort Two, were aligned with the WPRPD and the UNCRPD policy priorities for service delivery to PWDs and their families.

**Table 7.2: Comparison of social work services delivered according to WPRPD and UNCRPD**

<b>PILLARS OF WPRPD</b>	<b>RELEVANT UNCRPD ARTICLE</b>	<b>SOCIAL WORK SERVICES OFFERED</b>
Removing Barriers to Access and Participation	Article 9: Accessibility Article 11: Situations of Risk and Humanitarian Emergencies Article 20: Personal Mobility Article 21: Freedom of Expression and Opinion and Access to Information Article 30: Participation in Cultural Life, Recreation, Leisure and Sport	Community awareness (sensitisation) Community reintegration of PWD Application for assistive devices Assistance with job opportunities available to PWDs
Protecting the Rights of Persons at risk of Compounded Marginalisation	Article 10: Right to life Article 12: Equal Recognition Before the Law Article 13: Access to Justice Article 14: Liberty and Security of the Person. Article 15: Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment. Article 16: Freedom from Exploitation, Violence and Abuse. Article 17: Protecting the Integrity of the Person Article 21: Freedom of Expression and Opinion, and Access to Information.	Mediation Advocacy Community awareness (sensitisation) Utilisation of Domestic Violence Act where abuse is Present Residential care placement Protective workshops
Supporting Sustainable Integrated Community Life Independent Living	Article 8: Awareness Raising Article 11: Situations of Risk and Humanitarian Emergencies Article 19: Living Independently Article 20: Personal Mobility Article 23: Respect for the Family Article 30: Participation in Cultural Life, Recreation, Leisure and Sport	Community awareness (sensitisation) Application for assistive devices Life/work skill training for PWDs Assistance with job opportunities available to PWDs Support groups to PWDs and families Support to families of PWDs Training to family caregivers of PWDs Community reintegration of PWDs Residential care placement
Promoting and Supporting Empowerment of PWDs	Article 13: Access to Justice Article 24: Education Article 25: Health Article 26: Rehabilitation	Mediation Advocacy Health monitoring

PILLARS OF WPRPD	RELEVANT UNCRRPD ARTICLE	SOCIAL WORK SERVICES OFFERED
		Referrals to day hospitals and other health professionals, Work assessment Life/work skill training for PWDs Therapeutic services Counselling (empowerment, rehabilitation, grief) Psychosocial support services
Reducing Economic Vulnerability and Releasing Human Capital	Article 27: Work and Employment Article 28: Adequate Standard of Living and Social Protection	Community awareness (sensitisation) Community reintegration of PWDs Life/work skill training for PWDs Assistance with job opportunities available to PWDs Application for social grants Food (meals)
Strengthening the Representative Voice of PWDs	Article 29: Participation in Political and Public Life Article 33: National Implementation and Monitoring	Advocacy
Building a Disability Equitable State Machinery	Article 4: General obligations Article 9: Accessibility Article 13: Access to Justice Article 20: Personal Mobility Article 24: Education Article 25: Health Article 26: Rehabilitation Article 33: National Implementation and Monitoring Article 35: Reports by States Parties	Advocacy
Promoting International Co-operation	Article 32: International Cooperation States Parties Article 40: Conference of States Parties	Advocacy
Monitoring and Evaluation	N/A	Follow up research studies such as this study to assess service delivery in terms of policies Monitoring and evaluation of different systems according to disability inclusion compliance

Ultimately, most participants from Cohort One had positive experiences in terms of the social work support services that they received. However, a few indicated that there were some negative experiences including no communication between a social worker and physiotherapist, no follow up appointments, social workers taking their time to visit and finally, social workers not always understanding the emotional and psychological aspects of their disability. There were also some participants who made use of private health care services which did not have knowledge of social work services in the community. The feedback from participants could be valuable for the social work profession in terms of identifying potential improvements in service delivery to PWDs, especially adults with an acquired physical disability. Even the feedback from participants that they were not aware of where to find social workers or what social workers could do to assist them could be an indication that the profession needs improvement in terms of awareness of its role in service delivery to PWDs. This coincides with the rationale of this study, as there are few previous studies focusing on social work services to adults with an acquired physical disability (specifically in terms of rehabilitation and community integration).

Social workers from Cohort Two also identified some challenges they faced in terms of service delivery to adults with an acquired physical disability and other PWDs. These challenges included clients not understanding their role, inexperience of caregivers and PWDs themselves, and a lack of community resources, accessibility and transport for PWDs. These challenges aligned with the challenges discussed in Chapter Four in a previous study done by Strydom (2015).

Combining the experiences of service users of social work services with the experiences of social workers themselves could assist in finding priorities to address in order to improve social work service delivery to PWDs, especially adults with an acquired physical disability.

### *B. Roles of social workers*

Social workers play a vital role in rehabilitation, conducting psychosocial assessments, psychosocial counselling, discharge planning, case management and psychosocial health education (Springer & Casey, 2013).

As mentioned earlier, it could be argued that some of the most pivotal social work roles include that of broker, enabler and educator. Particular functions that correspond to each of these roles

within the rehabilitation team could be articulated. In terms of service delivery to PWDs, especially adults with an acquired physical disability, other roles to take note of could include that of counsellor, public relations officer, manager, facilitator, motivator, researcher and advocate. These roles, in terms of the services identified by Cohort Two will briefly be discussed. While some of these were identified explicitly in Chapter Six (See 6.5.1 and 6.5.2), others were indirectly mentioned through examples given during interviews:

- Broker: Mediate, defend and advocate on behalf of PWDs and be a case manager liaising between different health professionals in terms of referrals and follow-ups.
- Enabler: Consulting to encourage or facilitate self-sufficiency through workshops and training to encourage community integration of PWDs.
- Educator: Providing information and educating PWDs and their families, as well as providing information to communities on prevention of further disabilities.
- Counsellor: Counselling and other therapeutic services to guide the client, towards modifying behaviour, empowerment and acquiring skills to cope with problem situations.
- Public relations officer: Referring and liaising of different resources within the community.
- Manager: Ensuring adherence to different policies by planning and organising decision making, co-ordination and communication on different aspects of service delivery to PWDs according to different policies.
- Facilitator: Accelerating social change through inclusion of PWDs, their families, other community members and other stakeholders to advocate for the needs of PWDs.
- Motivator: Encouraging participation by minimising isolation, building optimism through support groups. as well as individual therapeutic services to PWDs and their families.
- Advocate: Continuing to Advocate for the rights of PWDs to governmental stakeholders as well as corporate businesses and other community stakeholders.
- Researcher: Getting involved with studies such as this one to scientifically determine the extent of problems, needs and phenomena (such as the influence of

the COVID-19 pandemic) on disability and to make recommendations along with developing and planning further service development.

### *C. Experiences during a pandemic*

As discussed in Chapter Six, some of the experiences of social workers related to the experiences of adults with an acquired physical disability, especially in terms of social isolation. The restrictions put in place during the pandemic included the limitation of certain services, such as home visits from social workers, as well as a limitation on the availability of community caregivers or domestic workers, which all provided service and assistance to PWDs and their families. Despite the fast onset of the pandemic not allowing much time to plan for adjustments in service delivery, some adjustments have been put into place since to ensure that most sectors could continue service delivery as best possible. This was mentioned by participants as well, with some stating that they could make telephonic contact with service providers, and later, as the restrictions lessened, office visits. These adjustments, however, also came with challenges (i.e. clients not having phones or finances for office visits), which hinders accessible service delivery to adults with an acquired physical disability. Consequently, participants from Cohort One indicated that there was some level of caregiver burden for their families, and, for those living alone who were used to receiving assistance from a carer, significant challenges in terms of daily functioning.

#### **7.3.7.2 Recommendations**

As mentioned earlier, there were some negative experiences of social work support services, and both the service users (Cohort One) and service providers (Cohort Two) had some recommendations on how to improve further on service delivery to PWDs, especially adults with an acquired physical disability. A summary of these recommendations was indicated in the empirical study in Table 6.4. Some participants from Cohort Two also identified where they would require more support to be able to deliver more effective services to adults with an acquired physical disability. These support needs included the implementation of the WPRPD from all stakeholders; the provision of equal opportunity to work and participate in life's activities such as helping PWDs with opening small businesses and strict governmental enforcement for employment of PWDs; accessible transport and accommodation for PWDs, as well as for the hospital or rehabilitation centres, to include family caregivers in the programme to provide them with training on how to provide emotional support and physical support to the

PWD. These recommendations were considered as a point of departure for the recommendations on service delivery according to policies, the roles of a social worker and social work support during a pandemic.

#### *A. Services according to policies*

As discussed earlier, the participating organisation's service delivery indicated by Cohort Two was aligned with policies such as the WPRPD and the UNCRPD. This study only provided a point of departure in assessing the implementation of policies on service delivery to PWDs in South Africa. The distribution of participants from Cohort Two (social workers from the participating gate-keeper organisation) across two opposing areas i.e. urban and rural does provide some transferability of the study, but by no means could this be a definite conclusion. An in-depth analysis would be recommended where each of the services delivered would be assessed in terms of efficiency and effectiveness as well. It would also be recommended that the same be done in terms of other policy implementation for other organisations and even governmental stakeholders. More frequent monitoring and evaluation studies would also be recommended to ensure that there is continuous adherence to the policies to ensure effective and efficient implementation.

#### *B. Roles of social workers*

There are various roles a social worker can play and only some were highlighted within this study in terms of service delivery to PWDs, especially adults with an acquired physical disability. These roles were fulfilled by the participating organisation, but as indicated with the discussion on adherence to policies, a more in-depth analysis would be required with more participating organisations to assess the true roles fulfilled by the social worker in terms of this service delivery. All these roles discussed as indicated by the service delivery also required some improvements, as not all the experiences from the participants from Cohort One were positive. It would be recommended to consider these experiences from Cohort One as well as the recommendations on improving service delivery as indicated in Table 6.4. from both Cohort One and Two as a point of departure when planning future service delivery to PWDs. Social work is one of the few professions that act as advocates for their clients. It would be further recommended to emphasise this role more in terms of representing clients (PWDs) in different environments. These environments could include governmental such as policy making and reforms; academic such as curriculum development, skills development, research, conferences



and publications; corporate such as employment inclusion and community in terms of awareness and sensitisation, to name only a few. Social work, as a profession, could contribute a unique perspective on different aspects of service delivery, including to PWDs, but this expertise needs to be shared and utilised more over different environments. The finding that some of the participants from the snowball sampling were not even aware of the role of the social worker in supporting PWDs indicated a need to reflect on how actively these roles are being portrayed and shared across different environments. Social work is often underrepresented within health-related discussions, such as service delivery to PWDs, including rehabilitation for adults who acquire a physical disability later in life.

### *C. Social work support during a pandemic*

Although a pandemic is not an experience that would be considered an everyday occurrence, its presence during the time of this study indicated a need to reflect on the role of social work during a pandemic. The limitations on service delivery that implemented with the pandemic identified the need to develop contingency plans for such emergency situations within the profession, especially for vulnerable groups such as PWDs. The pandemic allows organisations, governmental structures and other stakeholders in service delivery to PWDs to identify the challenges currently being experienced and develop service plans that would, at least to a great extent, overcome these challenges. It would be recommended that these discussions take place to develop contingency plans for possible future emergency situations, such as pandemics or even natural disasters. One recommendation provided by the participants from Cohort One was that organisations should make communities aware of the services available and make constant contact. This would allow for increased participation of PWDs, and for them to be able to benefit from continuous (in this case, telephonic) contact to address social isolation during pandemic restrictions. As discussed earlier, social work is often underrepresented within health-related discussions, such as service delivery to PWDs. This also seemed to be the case with strategic service plans during the pandemic, as there were limitations to social work service delivery. A comprehensive contingency plan could be set up within the profession to ensure that social workers are also included in service planning to vulnerable groups such as PWDs during emergencies whilst still ensuring their own safety with the necessary precautions, equipment and support. Again, the valuable expertise and skills of the profession need to be advocated more in different environments to address this.

### **7.3.8 Recommendations for future study**

As mentioned before, there were some limitations to this study. Some of these will be addressed below in terms of recommendations for future studies.

#### **7.3.8.1 *Lack of research on the topic and dated sources***

The study had to rely on previous studies that had similar variables. This brought about the limitation that some of the sources used were dated. The research study countered this limitation with the inclusion of more recent sources. This poses a potential for further studies to be done on similar variables as this study.

#### **7.3.8.2 *No fixed measuring tool for disability***

As discussed in Chapter Two, the concept ‘disability’ is extraordinarily complex, and although there are some popular definitions and models used to describe disability, there is no universal consensus on the term. This filters down to the measuring tools for surveys and other research methods, making statistical data inconsistent and limited. Although it might be idealistic to aspire to a uniform definition and measuring tool for disability, this limitation could be minimised through further similar studies and more regular statistical censuses where the criteria for inclusion is clearly defined. With more available findings of disability research, more comparable data would also be available, making it easier to focus on specific inclusion criteria when measuring disability in different contexts.

#### **7.3.8.3 *Small sample size***

Due to the qualitative nature of the study which included lengthy interviews, only 24 participants were included in this study. This meant that the study’s findings were based on only 24 adults with acquired physical disabilities. Although, as mentioned before, there is also a limitation on recent, exact statistics on the number of adults with an acquired physical disability, it would in most certainty be more than 24 people. This study also only included participants over three of the nine provinces. This provides an opportunity for further research to be done with more participants, either through quantitative measures to include more people, or with more focus in terms of qualitative research.

#### **7.3.8.4 *Various themes within the study***

This study included various themes to obtain an overview of the experiences of adults with an acquired physical disability on social work support services. This was done to be able consider various aspects that could contribute to their experiences. However, this could also be a limitation, because it limits the depth in which the research can focus on each theme. Effectively, this also provides an opportunity for further studies to be done on only one or a few of these themes to be able to go into more in depth concerning each of these.

#### **7.3.8.5 *Recommendations for future studies based on study results***

Based on the findings of this study and some limitations to the study, the following recommendation are made for future studies:

- As mentioned earlier, some participants indicated a lack of understanding for the needs of PWDs, specifically adults with an acquired physical disability. This motivates for further studies done with service users, especially vulnerable groups, to obtain an understanding of their experiences to better support them.
- Due to the limitations of the research study topic, it was not possible to conduct a full analysis of the services that the participants used. Therefore, future studies that focus only on the extent and efficiency of the service utilisation would be recommended. It is suggested that future studies could also focus on identifying whether other services are used. Future studies could also analyse the efficiency and effectiveness of these services through the experiences of service users.
- One of the ways to integrate PWDs, especially adults with an acquired physical disability who might have been employed before, is through long-term employment. From the findings in this study, this seems to be a challenge. It is therefore suggested that research be done on the skills and expertise of PWDs, feedback from occupational therapists on work readiness of PWDs and different SETAs on the requirements for employment from different sectors.
- According to various researchers as discussed in Chapter Three, there is a bi-directional link between poverty and disability. It is suggested that more studies analyse this phenomenon in terms of the capabilities approach. It is further

suggested to combine this research with employment opportunity and outcome studies on PWDs.

- This study could be utilised as a point of departure for future studies in terms of assessing social work services aligned with policies on disability service delivery in South Africa, as well as the roles that a social worker plays in the rehabilitation of PWDs, specifically adults with an acquired physical disability. It is further recommended that more in-depth studies be done on the services aligned with different policies, including different organisations, governmental and other service delivery stakeholder. It is further recommended that these studies be done in terms of the experiences of service users with different socio-economic, geographical and cultural backgrounds. These studies might have to be broken down into various smaller studies and would need to be done on a regular basis, to ensure that the results remain relevant.
- Participants in this study indicated high levels of resilience and acceptance for living with a disability. It would be recommended that a similar study be done with a sample that does not have the same level of resilience and acceptance to perhaps identify more support needs for adults with an acquired physical disability.
- There has also been an increase in research studies since the onset of the COVID-19 pandemic, specifically focusing on the challenges and experiences of social workers. It is recommended that more studies also be done with service users. The results of these studies could then be utilised for long-term contingency plans where emergencies arise.
- Due to the lack of previous research on adults with an acquired physical disability, it is recommended that more similar studies be conducted.
- It suggested that future studies seek to determine whether there are any other needs that should be addressed for adults with acquired physical disabilities.
- Future studies should also be done to analyse whether any of the mentioned needs were addressed and whether the significance of the need has decreased or increased. This should be done on a regular basis.
- Besides studies on general positive and negative feelings of adults with an acquired physical disability, it is recommended that a specific focus is also placed on the

stages of grief and the relation that each stage has to the feelings experienced by the adult who acquired a physical disability.

- It is suggested that research be conducted that seeks to further investigate the coping mechanisms of adults with an acquired physical disability in terms of developing stronger resilience and acceptance of living with a disability.
- Mention was made of Erikson's psychosocial development theory and the effect the different stages in which adults who acquired a physical disability could have on their personality development. Further studies on this could also be done to assess this more.
- As stated earlier, this research study could be beneficial in social work, especially in terms of service delivery to PWDs and their families. In considering the limitations of the study, one main recommendation for future studies is to have more similar studies which are both descriptive and explorative. These studies should then focus on different variables such as different research areas, different age groups of PWDs, different disabilities, different socio-economic conditions of participants and the use of public and/or private health care. Once there are enough studies considering the different variables, commonalities between these studies could be assessed, which could emphasise the common needs of family caregivers of persons with physical disabilities. These research outcomes could then potentially be used to raise awareness of the role players involved to aim at addressing the needs of family caregivers of persons with physical disabilities.

## 7.4 CONCLUSION

As a concluding remark to this study, the importance of doing research with service users, especially those who are also vulnerable groups could provide a vital contribution to service development, advocacy and policy initiatives. A bottom-up approach does not only provide a unique perspective, but also some assurance that initiatives would be aligned with the needs of the specific target group. The willingness of participants to participate – along with the length of the interviews and the comments from some of the participants in terms of gratitude for being able to form part of the study – indicates the necessity for more similar studies. The experiences and recommendations for future service delivery from both Cohorts are valuable for developing the social work profession's role within rehabilitation. As mentioned earlier, social workers can

play a vital role within the multi-disciplinary rehabilitation team, but their expertise and skills must be shared more on different platforms e.g. academia, corporate, governmental and policy. This will work towards addressing the frequent underrepresentation of social workers within these discussions on service delivery. As participants in this study acquired their disability through community violence, communicable diseases and road accidents, social workers, as social educators and advocates, can also play a central role in communities in the prevention of many types of acquired physical disabilities.

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# ADDENDUM A:

## APPROVAL FOR STUDY



UNIVERSITEIT  
STELLENBOSCH  
UNIVERSITY

### NOTICE OF APPROVAL

REC: Social, Behavioural and Education Research (SBER) - Initial Application Form

2 April 2020

Project number: 13290

Project Title: Experiences of adults with acquired physical disabilities of social work support in a South African context

Dear Mrs Noreth Muller-Kluits

Your REC: Social, Behavioural and Education Research (SBER) - Initial Application Form submitted on 26 March 2020 was reviewed and approved by the REC: Social, Behavioural and Education Research (REC: SBE).

Please note the following for your approved submission:

#### Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
10 February 2020	9 February 2021

## **ADDENDUM B:**

### **CONSENT TO PARTICIPATE IN RESEARCH (COHORT 1 - ENGLISH)**



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvennoot • your knowledge partner

#### **STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH**

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#### **Experiences of adults with acquired physical disabilities of social work support in a South African context**

You are asked to participate in a research study done by Mrs Noreth Muller-Kluits, from the Department of Social Work at Stellenbosch University. The research will be in line with requirements for the degree of Doctor of Philosophy in Social Work. You were selected as a possible participant in this study because you are an adult with a physical disability that only occurred after the age of 16 (hereafter referred to as an acquired physical disability).

#### **1. PURPOSE OF THE STUDY**

The goal of this study is to understand what the experiences of adults with acquired disabilities are on social work support in South Africa. This goal will be achieved through the following objectives:

- To provide an overview of disability as well as exploring relevant South African policies and legislation which focus on support to persons with disabilities;
- To discuss different views and models of disability with specific focus on those relevant to the social work profession;
- To analyse the social work profession and how social work support to persons with acquired physical disabilities have been experienced from previous, similar studies;
- To investigate the experiences of adults with acquired physical disabilities on social work support in South Africa; and
- To make recommendations to policy makers, organisations and social workers on how the social work support to adults with acquired physical disabilities can be further developed to assist with integration into society.

#### **2. PROCEDURES**

Should you volunteer to participate in this study, you would be asked to do the following things:

- Agree that the researcher may contact you to set up an interview date.
- Indicate a time (and place) where researcher can interview you. During time of COVID-19 outbreak, interviews will be done electronically or telephonically through cell phone, Zoom or WhatsApp.
- Sign this consent form.
- Be interviewed regarding your experience of social work support services in South Africa (interview is estimated to be between 30-60 min).

### 3. POTENTIAL RISKS AND DISCOMFORTS

During the interview process, you will be asked to discuss your experiences regarding social work support to yourself, as a person with acquired physical disabilities. Should you feel the need to be debriefed (counselled) after the interview, you can be referred to a social worker identified in your area.

Social Worker Name: .....

Area: .....

Contact details: .....

### 4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The study is voluntary, and participants would not get any form of payment. The research study would however give participants the opportunity to share their experience of social work support services in South Africa.

### 5. REMUNERATION FOR PARTICIPATION

No payment will be provided for participation in the study but to minimize expenses to the participants, the researcher will do the interviews at a place comfortable to the participant e.g. participants' homes or a communal place of interest that still provide privacy to adhere to the consideration of confidentiality e.g. the participating organisation. During time of COVID-19 outbreak, interviews will be done electronically or telephonically through cell phone, Zoom or WhatsApp, minimising cost to the participant.

### 6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

Any information that is given in connection with this study and that can be identified with you will remain confidential and will be shared only with your permission or as required by law. Confidentiality will be maintained by means of storing the interviews in a locked safe place and all data will be stored in encrypted (password-protected) files. Although the research will be published for educational or professional purposes, no personal information will be shared or published. Coding of participants (e.g. Participant 1) will be used so to not refer to identifying particulars of the participants. It will further be stressed to not use participants' names in audiotaped interviews. Recordings of interviews will be locked up and erased after five years. Only the researcher and the supervisor will have access to these recordings.

### 7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and whilst still remaining in the study.

### 8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about the research, please feel free to contact:

Noreth Muller-Kluits (researcher)  
(c) 076 589 5404

Dr I Slabbert (supervisor)  
(w) 021 808 2075

### 9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw from participating at any time without penalty or consequences. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouché@sun.ac.za; 021 808 4622] at the Division for Research Development.

<b>DECLARATION OF CONSENT BY THE PARTICIPANT</b>
--

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I ..... (*name of participant*) agree to take part in this research study, as conducted by Noreth Muller-Kluits.

.....	.....
<b>Signature of Participant</b>	<b>Date</b>

<b>DECLARATION BY THE PRINCIPAL INVESTIGATOR (RESEARCHER)</b>
---

As the **principal investigator**, I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition, I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this “Consent Form” is available to the participant in a language in which the participant is fluent.

.....	.....
<b>Signature of Principal Investigator</b>	<b>Date</b>

## **ADDENDUM C:**

### **CONSENT TO PARTICIPATE IN RESEARCH (COHORT 2 - ENGLISH)**



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvennoot • your knowledge partner

#### **STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH**

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#### **Experiences of adults with acquired physical disabilities of social work support in a South African context**

You are asked to participate in a research study done by Mrs Noreth Muller-Kluits, from the Department of Social Work at Stellenbosch University. The research will be in line with requirements for the degree of Doctor of Philosophy in Social Work. You were selected as a possible participant in this study because you are a registered social worker with experience in service delivery to persons with a disability.

#### **1. PURPOSE OF THE STUDY**

The goal of this study is to understand what the experiences of adults are with acquired disabilities on social work support in South Africa. This goal will be achieved through the following objectives:

- To provide an overview of disability as well as exploring relevant South African policies and legislation which focus on support to persons with disabilities;
- To discuss different views and models of disability with specific focus on those relevant to the social work profession;
- To analyse the social work profession and how social work support to persons with acquired physical disabilities have been experienced from previous, similar studies;
- To investigate the experiences of adults with acquired physical disabilities on social work support in South Africa; and
- To make recommendations to policy makers, organisations and social workers on how the social work support to adults with acquired physical disabilities can be further developed to assist with integration into society.

#### **2. PROCEDURES**

Should you volunteer to participate in this study, you would be asked to do the following things:

- Agree that the researcher may contact you to set up an interview date.
- Indicate a time and place where researcher can interview you. During time of COVID-19 outbreak, interviews will be done electronically or telephonically through cell phone, Zoom or WhatsApp.
- Sign this consent form.
- Be interviewed regarding your experience of social work support services in South Africa (interview is estimated to be between 30-60 min).



### 3. POTENTIAL RISKS AND DISCOMFORTS

During the interview process, you will be asked to discuss your experiences regarding social work support to yourself, as a person with acquired physical disabilities. Should you feel the need to be debriefed after the interview, you can be referred to a social worker identified in your area.

Social Worker Name: .....

Area: .....

Contact details: .....

### 4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The study is voluntary, and participants would not get any form of payment. The research study would however give participants the opportunity to share their experience of social work support services in South Africa.

### 5. REMUNERATION FOR PARTICIPATION

No payment will be provided for participation in the study but to minimize expenses to the participants, the researcher will do the interviews at a place comfortable to the participant e.g. participants' homes or a communal place of interest that still provide privacy to adhere to the consideration of confidentiality e.g. the participating organisation. During time of COVID-19 outbreak, interviews will be done electronically or telephonically through cell phone, Zoom or WhatsApp, minimising cost to the participant.

### 6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

Any information that is given in connection with this study and that can be identified with you will remain confidential and will be shared only with your permission or as required by law. Confidentiality will be maintained by means of storing the interviews in a locked safe place and all data will be stored in encrypted (password-protected) files. Although the research will be published for educational or professional purposes, no personal information will be shared or published. Coding of participants (e.g. Participant 1) will be used so to not refer to identifying particulars of the participants. It will further be stressed to not use participants' names in audiotaped interviews. Recordings of interviews will be locked up and erased after five years. Only the researcher and the supervisor will have access to these recordings.

### 7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and whilst still remaining in the study.

### 8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about the research, please feel free to contact:

Noreth Muller-Kluits (researcher)  
(c) 076 589 5404

Dr I Slabbert (supervisor)  
(w) 021 808 2075

### 9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw from participating at any time without penalty or consequences. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouché@sun.ac.za; 021 808 4622] at the Division for Research Development.

<b>DECLARATION OF CONSENT BY THE PARTICIPANT</b>
--

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I ..... (*name of participant*) agree to take part in this research study, as conducted by Noreth Muller-Kluits.

.....	.....
<b>Signature of Participant</b>	<b>Date</b>

<b>DECLARATION BY THE PRINCIPAL INVESTIGATOR</b>
--

As the **principal investigator**, I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition, I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this “Consent Form” is available to the participant in a language in which the participant is fluent.

.....	.....
<b>Signature of Principal Investigator</b>	<b>Date</b>

## **ADDENDUM D:**

### **CONSENT TO PARTICIPATE IN RESEARCH (COHORT 1 - AFRIKAANS)**



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvennoot • your knowledge partner

#### **UNIVERSITEIT VAN STELLENBOSCH VRYWARINGSVORM VIR DEELNAME AAN NAVORSINGSTUDIE**

#### **Ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike ondersteuning binne 'n Suid-Afrikaanse konteks.**

U word gevra om deel te neem aan 'n navorsingstudie wat uitgevoer word deur Me. Noreth Muller-Kluits, van die Departement van Maatskaplike Werk aan die Universiteit Stellenbosch. Die navorsingstudie sal voorgelê word vir die verkryging van 'n Doktorsgraad in Maatskaplike Werk. U was gekies as 'n moontlike deelnemer in die studie omdat u 'n volwassene is wat 'n fisiese gestremdheid verkry het.

#### **1. DOEL VAN DIE STUDIE**

Die doel van die studie is om die ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike ondersteuning binne Suid-Afrika, te verstaan. Die doel sal bereik word deur middel van die volgende doelwitte:

- Om 'n oorsig van gestremdheid te bied en die relevante Suid-Afrikaanse beleide en wetgewings wat fokus op die ondersteuning van persone met gestremdhede, te ondersoek;
- Om die verskillende perspektiewe en modelle van gestremdheid, met spesifieke fokus op die wat relevant is op die maatskaplike werk professie, te bespreek;
- Om die maatskaplike werk professie en hoe maatskaplike ondersteuning vir persone wat 'n fisiese gestremdheid verkry ervaar is in vorige, soortgelyke studies, te analiseer;
- Om die ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike werk ondersteuning in Suid-Afrika, te ondersoek; en
- Om voorstelle te maak aan beleidmakers, organisasies en maatskaplike werkers oor hoe die maatskaplike werk ondersteuning vir volwassenes wat 'n fisiese gestremdheid verkry het verder ontwikkel kan word om integrering in die gemeenskap te ontwikkel.

#### **2. PROSEDURES**

Indien u in stem om deel te vorm van die studie, sal u gevra word om die volgende te doen::

- Stem in dat die navorser u kan kontak.
- Dui die tyd en plek aan waar die navorser u kan ondervra. Gedurende die COVID-19 pandemie sal onderhoude telefonies of elektronies deur middel van selfoon, WhatsApp of Zoom gedoen word.
- Teken die vrywaringsvorm.

- Om ondervra te word rakende u ondervinding oor maatskaplike werk ondersteuning in Suid-Afrika (die onderhoud sal ongeveer 30-60 minute lank wees)

### 3. MOONTLIKE RISIKO'S EN ONGEMAKLIKHEID

Gedurende die onderhoudproses, sal u gevra word om u ondervindings in verband met maatskaplike ondersteuning wat aan u, as 'n volwassene wat 'n fisiese gestremdheid verkry het, te deel. Indien u voel u benodig berading na die onderhoud, kan u verwys word na 'n maatskaplike werker wat geïdentifiseer is in u area.

Maatskaplike werker Naam: .....

Area: .....

Kontakbesonderhede: .....

### 4. MOONTLIKE VOORDELE VIR DEELNEMERS EN/OF VIR DIE SAMELEWING

Die studie is vrywillig en geen finansiële vergoeding sal aan deelnemer gegee word nie. Die navorsingstudie sal die deelnemer die geleentheid gee om hul ondervindings oor maatskaplike werk ondersteuning in Suid-Afrika te deel.

### 5. VERGOEDING VIR DEELNAME

Geen betaling sal gegee word aan enige deelnemer nie, maar ten einde die kostes vir deelnemer te verminder, sal die navorser die onderhoude doen op 'n tyd en plek wat die deelnemer verkies bv. Deelnemer se huise of 'n gemeenskaplike plek wat steeds privaatheid het en voldoen aan vertroulikheidsooreenkomste. Gedurende die COVID-19 pandemie sal onderhoude telefonies of elektronies deur middel van selfoon, WhatsApp of Zoom gedoen word om sodoende die koste van die deelnemers te verminder.

### 6. BESKERMING VAN U INLIGTING, VERTROULIKHEID EN IDENTITEIT

Enige inligting wat deur middel van die navorsing verkry word en wat met u in verband gebring kan word, sal vertroulik bly en slegs met u toestemming bekend gemaak word of soos deur die wet vereis. Vertroulikheid sal gehandhaaf word deur onderhoude in 'n kluis en alle data in 'n lêer met 'n geheime kode, te stoor. Alhoewel die navorsing gepubliseer sal word vir opvoedkundige of professionele redes, sal geen persoonlike inligting gepubliseer of gedeel word. Daar sal gebruik gemaak word van kodes (bv. Deelnemer 1) om deelnemer te identifiseer sonder om hul persoonlike inligting te gebruik. Daar sal verder gepoog word om nie die naam van die deelnemer in die klankbaan opgeneemde onderhoude te noem nie. Die opnames van die onderhoude sal in 'n kluis gestoor word en vernietig word na vyf jaar. Slegs die supervisor en die navorser sal toegang hê tot hierdie opnames.

### 7. DEELNAME EN ONTTREKKING

U kan self besluit of u aan die studie wil deelneem of nie. Indien u inwillig om aan die studie deel te neem, kan u te eniger tyd u daaraan onttrek sonder enige nadelige gevolge. U kan ook weier om op bepaalde vrae te antwoord, maar steeds aan die studie deelneem.

### 8. NAVORSERS SE KONTAKBESONDERHEDE

Indien u enige vrae of besorgdheid omtrent die navorsing het, staan dit u vry om in verbinding te tree met:

Noreth Muller-Kluis (navorser)  
(s) 076 589 5404

Dr I Slabbert (supervisor)  
(w) 021 808 207

## 9. REGTE VAN DEELNEMERS

U kan te eniger tyd u inwilliging terugtrek en u deelname beëindig, sonder enige nadelige gevolge vir u. Deur deel te neem aan die navorsing doen u geensins afstand van enige wetlike regte, eise of regsmiddel nie. Indien u vrae het oor u regte as deelnemer by navorsing, skakel met Me. Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] van die Afdeling Navorsingsontwikkeling, Universiteit Stellenbosch.

### VERKLARING DEUR DEELNEMER

As die deelnemer, bevestig ek dat:

- Ek die bogenoemde inligting en dat dit geskryf is in 'n taal waarin ek gemaklik is.
- Ek het 'n geleentheid gehad om vrae te vra en al my vrae was beantwoord.
- Al die kwessies rondom privaatheid en die vertroulikheid en die gebruik van inligting wat ek verskaf, is verduidelik.

Deur te ken hier onder, bevestig ek, ..... (naam van deelnemer) dat ek instem om deel van die navorsingstudie te vorm, gevoer deur Noreth Muller-Kluis.

.....  
**Handtekening van Deelnemer**

.....  
**Datum**

### VERKLARING DEUR DEELNEMER

As die **hoof navorser**, bevestig ek hiermee dat die inligting in hierdie dokument deeglik aan die deelnemer verduidelik is. Ek bevestig ook dat die deelnemer aangemoedig (en deeglike tyd gegee) om vrae te vra. Ek sal ook die volgende opsie wil kies:

	Die gesprek met die deelnemer was gedoen in 'n taal waarin hul gemaklik is.
	Die gesprek met die deelnemer was gedoen met die hulp van 'n vertaler (wat 'n vertroulikheidsdokument onderteken het) en die Vertraulikheidsvorm is beskikbaar vir die deelnemer in 'n taal waarin hul gemaklik is.

.....  
**Handtekening van Deelnemer**

.....  
**Datum**

## **ADDENDUM E:**

### **CONSENT TO PARTICIPATE IN RESEARCH (COHORT 2 - AFRIKAANS)**



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvennoot • your knowledge partner

#### **UNIVERSITEIT VAN STELLENBOSCH VRYWARINGSVORM VIR DEELNAME AAN NAVORSINGSTUDIE**

---

#### **Ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike ondersteuning binne 'n Suid-Afrikaanse konteks.**

U word gevra om deel te neem aan 'n navorsingstudie wat uitgevoer word deur Me. Noreth Muller-Kluits, van die Departement van Maatskaplike Werk aan die Universiteit Stellenbosch. Die navorsingstudie sal voorgelê word vir die verkryging van 'n Doktorsgraad in Maatskaplike Werk. U was gekies as 'n moontlike deelnemer in die studie omdat u 'n geregistreerde maatskaplike werker is met ondervinding in ondersteuningsdienste aan persone met 'n fisiese gestremdheid.

#### **1. DOEL VAN DIE STUDIE**

Die doel van die studie is om die ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike ondersteuning binne Suid-Afrika, te verstaan. Die doel sal bereik word deur middel van die volgende doelwitte:

- Om 'n oorsig van gestremdheid te bied en die relevante Suid-Afrikaanse beleide en wetgewings wat fokus op die ondersteuning van persone met gestremdhede, te ondersoek;
- Om die verskillende perspektiewe en modelle van gestremdheid, met spesifieke fokus op die wat relevant is op die maatskaplike werk professie, te bespreek;
- Om die maatskaplike werk professie en hoe maatskaplike ondersteuning vir persone wat 'n fisiese gestremdheid verkry ervaar is in vorige, soortgelyke studies, te analiseer;
- Om die ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike werk ondersteuning in Suid-Afrika, te ondersoek; en

Om voorstelle te maak aan beleidmakers, organisasies en maatskaplike werkers oor hoe die maatskaplike werk ondersteuning vir volwassenes wat 'n fisiese gestremdheid verkry het verder ontwikkel kan word om integrering in die gemeenskap te ontwikkel.

#### **2. PROSEDURES**

Indien u in stem om deel te vorm van die studie, sal u gevra word om die volgende te doen::

- Stem in dat die navorser u kan kontak.
- Dui die tyd en plek aan waar die navorser u kan ondervra. Gedurende die COVID-19 pandemie sal onderhoude telefonies of elektronies deur middel van selfoon, WhatsApp of Zoom gedoen word.
- Teken die vrywaringsvorm.
- Om ondervra te word rakende u ondervinding oor maatskaplike werk ondersteuning in Suid-Afrika (die onderhoud sal ongeveer 30-60 minute lank wees).

### 3. MOONTLIKE RISIKO'S EN ONGEMAKLIKHEID

Gedurende die onderhoudproses, sal u gevra word om u ondervindings in verband met maatskaplike ondersteuning wat aan u, as 'n volwassene wat 'n fisiese gestremdheid verkry het, te deel. Indien u voel u benodig berading na die onderhoud, kan u verwys word na 'n maatskaplike werker wat geïdentifiseer is in u area.

Maatskaplike werker Naam: .....

Area: .....

Kontakbesonderhede: .....

### 4. MOONTLIKE VOORDELE VIR DEELNEMERS EN/OF VIR DIE SAMELEWING

Die studie is vrywillig en geen finansiële vergoeding sal aan deelnemer gegee word nie. Die studie is vrywillig en geen finansiële vergoeding sal aan deelnemer gegee word nie. Dit kan bydra tot u professionele doelwitte.

### 5. VERGOEDING VIR DEELNAME

Geen betaling sal gegee word aan enige deelnemer nie, maar ten einde die kostes vir deelnemer te verminder, sal die navorser die onderhoude doen op 'n tyd en plek wat die deelnemer verkies bv. Deelnemer se huise of 'n gemeenskaplike plek wat steeds privaatheid het en voldoen aan vertroulikheidsooreenkomste. Gedurende die COVID-19 pandemie sal onderhoude telefonies of elektronies deur middel van selfoon, WhatsApp of Zoom gedoen word om sodoende die koste van die deelnemers te verminder.

### 6. BESKERMING VAN U INLIGTING, VERTROULIKHEID EN IDENTITEIT

Enige inligting wat deur middel van die navorsing verkry word en wat met u in verband gebring kan word, sal vertroulik bly en slegs met u toestemming bekend gemaak word of soos deur die wet vereis. Vertroulikheid sal gehandhaaf word deur onderhoude in 'n kluis en alle data in 'n lêer met 'n geheime kode, te stoor. Alhoewel die navorsing gepubliseer sal word vir opvoedkundige of professionele redes, sal geen persoonlike inligting gepubliseer of gedeel word. Daar sal gebruik gemaak word van kodes (bv. Deelnemer 1) om deelnemer te identifiseer sonder om hul persoonlike inligting te gebruik. Daar sal verder gepoog word om nie die naam van die deelnemer in die klankbaan opgeneemde onderhoude te noem nie. Die opnames van die onderhoude sal in 'n kluis gestoor word en vernietig word na vyf jaar. Slegs die supervisor en die navorser sal toegang hê tot hierdie opnames.

### 7. DEELNAME EN ONTTREKKING

U kan self besluit of u aan die studie wil deelneem of nie. Indien u inwillig om aan die studie deel te neem, kan u te eniger tyd u daaraan onttrek sonder enige nadelige gevolge. U kan ook weier om op bepaalde vrae te antwoord, maar steeds aan die studie deelneem.

### 8. NAVORSERS SE KONTAKBESONDERHEDE

Indien u enige vrae of besorgdheid omtrent die navorsing het, staan dit u vry om in verbinding te tree met:

Noreth Muller-Kluis (navorser)  
(s) 076 589 5404

Dr I Slabbert (supervisor)  
(w) 021 808 207

## 9. REGTE VAN DEELNEMERS

U kan te eniger tyd u inwilliging terugtrek en u deelname beëindig, sonder enige nadelige gevolge vir u. Deur deel te neem aan die navorsing doen u geensins afstand van enige wetlike regte, eise of regsmiddel nie. Indien u vrae het oor u regte as deelnemer by navorsing, skakel met Me. Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] van die Afdeling Navorsingsontwikkeling, Universiteit Stellenbosch.

### VERKLARING DEUR DEELNEMER

As die deelnemer, bevestig ek dat:

- Ek die bogenoemde inligting en dat dit geskryf is in 'n taal waarin ek gemaklik is.
- Ek het 'n geleentheid gehad om vrae te vra en al my vrae was beantwoord.
- Al die kwessies rondom privaatheid en die vertroulikheid en die gebruik van inligting wat ek verskaf, is verduidelik.

Deur te ken hier onder, bevestig ek, ..... (naam van deelnemer) dat ek instem om deel van die navorsingstudie te vorm, gevoer deur Noreth Muller-Kluits.

.....  
Handtekening van Deelnemer

.....  
Datum

### VERKLARING DEUR DEELNEMER

As die **hoof navorser**, bevestig ek hiermee dat die inligting in hierdie dokument deeglik aan die deelnemer verduidelik is. Ek bevestig ook dat die deelnemer aangemoedig (en deeglike tyd gegee) om vrae te vra. Ek sal ook die volgende opsie wil kies:

	Die gesprek met die deelnemer was gedoen in 'n taal waarin hul gemaklik is.
	Die gesprek met die deelnemer was gedoen met die hulp van 'n vertaler (wat 'n vertroulikheidsdokument onderteken het) en die Vertroulikheidsvorm is beskikbaar vir die deelnemer in 'n taal waarin hul gemaklik is.

.....  
Handtekening van Deelnemer

.....  
Datum



# ADDENDUM F:

## SEMI-STRUCTURED INTERVIEW SCHEDULE (COHORT 1 – ENGLISH)



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

**UNIVERSITY OF STELLENBOSCH  
DEPARTMENT OF SOCIAL WORK**

### **Experiences of adults with acquired physical disabilities on social work support in a South African context**

Interviewer: Noreth Muller-Kluits  
Dissertation for PhD in Social Work

*All the information recorded in this questionnaire will be regarded as confidential.*

PARTICIPANT NUMBER: .....	INTERVIEW DATE: .....
PHASE OF INTERVIEW PROCESS: .....	COHORT 1

#### **IDENTIFYING PARTICULARS**

- Tell me about yourself (gender, age, marital status, live/work area, work).

#### **THEME 1: BIOLOGICAL EXPERIENCES OF ADULTS WITH AN ACQUIRED PHYSICAL DISABILITY ACCORDING TO BIOPSYCHOSOCIAL AND ICF MODEL**

- Could you tell me more about your disability? (type, age acquired)
- How would you say did the disability affect your life? (health, activity limitations, activities of daily living (ADLs) and Instrumental Activities of Daily Living (IADLs))

#### **THEME 2: PSYCHOLOGICAL EXPERIENCES OF ADULTS WITH AN ACQUIRED PHYSICAL DISABILITY ACCORDING TO THE BIOPSYCHOSOCIAL MODEL AND PHASES OF GRIEF**

- Would you be willing to tell me about the day you acquired the disability? (feelings)

#### **THEME 3: SOCIAL SUPPORT TO ADULTS WITH AN ACQUIRED PHYSICAL DISABILITY ACCORDING TO THE ECOLOGICAL PERSPECTIVE (BRONFENBRENNER)**

- Could you tell me about your family/home life? (living arrangements, accessibility, support from family)

- What social support services did you receive?
- How would you describe your community life?
- Who/what do you find the most helpful/supportive currently in your life?

**THEME 4: SUPPORT NEEDS OF ADULTS WITH AN ACQUIRED PHYSICAL DISABILITY)**

- Are there any challenges you experience within your family/home life? (support, resources, accessibility)
- What challenges regarding resources and general life within the community have you experienced? (challenges, lack of resources)

**POSSIBLE THEME 5: CULTURAL EXPERIENCES OF ADULT WITH AN PHYSICAL ACQUIRED DISABILITY**

- How do you feel about the general attitude your community has towards PWDs, including yourself?

**THEME 6: SOCIAL WORK SUPPORT SERVICES TO PERSONS WITH ACQUIRED PHYSICAL DISABILITIES ALIGNED WITH POLICIES IN SOUTH AFRICA**

- What social work services did you receive?
- How did you experience these social work services?
- What did you find most helpful about the social work services you received?
- What did you find least helpful/successful about the social work services you received?
- Are there any recommendations or comments you would like to make regarding the social work support given to adults who have acquired a physical disability? What role can the social worker play?

**CONCLUSION**

- How did you experience the COVID -19 regulations?
- How do you think social workers could assist with similar situations in the future?

*Thank you for participating in the research study*

## ADDENDUM G:

### SEMI-STRUCTURED INTERVIEW SCHEDULE (COHORT 2 – ENGLISH)



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner  
**UNIVERSITY OF STELLENBOSCH**  
**DEPARTMENT OF SOCIAL WORK**

#### **Experiences of adults with acquired physical disabilities on social work support in a South African context**

Interviewer: Noreth Muller-Kluits  
Dissertation for PhD in Social Work

*All the information recorded in this questionnaire will be regarded as confidential.*

PARTICIPANT NUMBER: .....	INTERVIEW DATE: .....
PHASE OF INTERVIEW PROCESS: .....	COHORT 2

#### **IDENTIFYING PARTICULARS**

- Tell me about yourself. (gender, age, marital status, live/work area)

#### **THEME 6: SOCIAL WORK SUPPORT SERVICES TO ADULTS WITH ACQUIRED PHYSICAL DISABILITIES ALLIGNED WITH POLICIES IN SOUTH AFRICA**

- What support services have you provided to persons with a disability, specifically adults who have acquired a physical disability later in life?
- Which policies did you make use of to guide you in supporting persons with an acquired physical disability?
- In what way did you align your services to these policies?
- What was the most challenging in providing these services?
- What role do social workers play in the rehabilitation process of adults with acquired physical disabilities
- What would your suggestion(s) be in improving the implementation of policies supporting service delivery to adult who have acquired a physical disabilities and general service delivery to them?

#### **CONCLUSION**

- How did the COVID-19 regulations influence service delivery to persons with disabilities?

*Thank you for participating in the research study*

## ADDENDUM H:

### SEMI-STRUCTURED INTERVIEW SCHEDULE (COHORT 1 – AFRIKAANS)



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

**UNIVERSITEIT VAN STELLENBOSCH  
DEPARTEMENT VAN MAATSKAPLIKE WERK**

#### **Ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike ondersteuning binne 'n Suid-Afrikaanse konteks.**

Navorsers: Noreth Muller-Kluits  
Proefskrif vir Doktoraal in Maatskaplike Werk

*Al die inligting wat in die vraelys opgeneem word, sal as vertroulik hanteer word.*

DEELNEMERNOMMER: .....	ONDERHOUD DATUM: .....
FASE VAN ONDERHOUDPROSES: .....	KOHORT 1

#### **IDENTIFISERENDE BESONDERHEDE**

- Vertel my van uself (geslag, ouderdom, huwelikstatus, leef/werksarea, werk).

#### **TEMA 1: BIOLOGIESE ONDERVINDINGS VAN VOLWASSENE WAT 'N FISIESE GESTREMDHEID VERKRY HET VOLGENS DIE BIOPSIGOSOSIALE EN ICF MODEL**

- Kan jy my vertel van u gestremdheid? (tipe, ouderdom verkry)
- Hoe sou u sê het u gestremdheid jou lewe beïnvloed? (gesondheid, aktiwiteitsbeperkings, aktiwiteite van daaglikse lewe en instrumentale aktiwiteite van daaglikse lewe)

#### **TEMA 2: SIELKUNDIGE ONDERVINDINGS VAN VOLWASSENE WAT 'N FISIESE GESTREMDHEID VERKRY HET VOLGENS DIE BIOPSIGOSOSIALE MODEL EN DIE FASES VAN ROU**

- Sal u bereid wees om my te vertel van die dag wat u die gestremdheid verkry het? (gevoelens)

**TEMA 3: MAATSKAPLIKE/OMGEWINGSONDERVINDINGS VAN VOLWASSENE WAT 'N FISIESE GESTREMDHEID VERKRY HET VOLGENS DIE EKOLOGIESE PERSPEKTIEF (BRONFENBRENNER)**

- Kan u my vertel van u familie/huislewe? (lewensomstandighede, toeganklikheid, ondersteuning van familie)
- Watter gemeenskapsdienste het u ontvang?
- Hoe sal u, u betrokkenheid in gemeenskapslewe beskryf?
- Wie/Wat vind u die mees hulpvaardig/ondersteunend in u lewe tans?

**THEME 4: ONDERSTEUNINGSBEHOEFTE VAN VOLWASSENES MET 'N VERKRYGDE FISIESIE GESTREMDHEID**

- Is daar enige uitdagings wat u ondervind in u familie/huislewe (ondersteuning, hulpbronne, toeganklikheid)
- Watter uitdagings in terme van hulpbronne en algemene gemeenskapsbetrokkenheid het u al ondervind? (uitdagings, tekort aan hulpbronne)

**TEMA 5: KULTURELE ONDERVINDINGS VAN VOLWASSENE WAT 'N FISIESE GESTREMDHEID VERKRY HET**

- Hoe voel u oor die algemene houding wat die gemeenskap het teenoor persone met 'n gestremdheid, insluitend uself?

**TEMA 6: MAATSKAPLIKE ONDERSTEUNINGSDIENSTE AAN VOLWASSENES MET 'N VERKRYGDE FISIESIE GESTREMDHEID IN TERME VAN BELEIDE IN BINNE 'N SUID-AFRIKAANSE KONTEKS**

- Watter maatskaplike ondersteuningsdienste het u ontvang?
- Hoe het u die ondersteuningsdienste ondervind?
- Wat het u die mees hulpvaardigste gevind in terme van die maatskaplike ondersteuningsdienste wat u ontvang het?
- Wat het u die minste hulpvaardig gevind in terme van die maatskaplike ondersteuningsdienste wat u ontvang het?
- Is daar enige aanbevelings of kommentaar wat u het in terme van maatskaplike ondersteuningsdienste wat aan volwassenes wat 'n fisiese gestremdheid verkry het? Watter rol kan die maatskaplike werker speel?

**GEVOLGTREKKING**

- Hoe het u die COVID-19 regulasies ervaar?
- Hoe dink u kan maatskaplike werkers in soortgelyke situasies in die toekoms help?

*Dankie dat u deelgeneem het aan die navorsingstudie.*

# ADDENDUM I:

## SEMI-STRUCTURED INTERVIEW SCHEDULE (COHORT 2 – AFRIKAANS)



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvenoot • your knowledge partner

**UNIVERSITEIT VAN STELLENBOSCH  
DEPARTEMENT VAN MAATSKAPLIKE WERK**

### Ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike ondersteuning binne 'n Suid-Afrikaanse konteks

Navorsers: Noreth Muller-Kluis

Proefskrif vir Doktoraal in Maatskaplike Werk

*Al die inligting wat in die vraelys opgeneem word, sal as vertroulik hanteer word.*

DEELNEMERNOMMER: .....	ONDERHOUD DATUM: .....
FASE VAN ONDERHOUDPROSES: .....	KOHORT 2

#### IDENTIFISERENDE BESONDERHEDE

- Vertel my van uself. (geslag, ouderdom, huwelikstatus, leef/werkarea, werk)

#### TEMA 6: MAATSKAPLIKE ONDERSTEUNINGSDIENSTE AAN VOLWASSENES MET 'N VERKRYGDE FISIESIE GESTREMDHEID IN TERME VAN BELEIDE IN BINNE 'N SUID-AFRIKAANSE KONTEKS

- Watter ondersteuningsdienste het u aan persone met 'n gestremdheid verskaf, spesifiek volwassenes wat 'n fisiese gestremdheid later in hul lewe verkry het?
- Watter beleide maak u gebruik van as 'n handleiding vir ondersteuning aan persone wat 'n fisiese gestremdheid verkry het?
- Hoe het die dienste ooreengestem met die beleide?
- Wat was die grootste uitdagings wat u ondervind het in hierdie dienslewering?
- Watter aanbeveling(s) het u om die implementering van beleide wat ondersteuning aan persone met gestremdhede en algemene dienslewering aan volwassenes wat 'n fisiese gestremdheid verkry het, te verbeter?

#### GEVOLGTREKKING

- Hoe het die COVID-19 regulasies dienslewering aan persone met gestremdhede beïnvloed?

*Dankie dat u deelgeneem het aan die navorsingstudie.*

## **ADDENDUM J:**

### **INFORMATION PAMPHLET (ENGLISH)**



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvennoot • your knowledge partner

#### **DEPARTMENT OF SOCIAL WORK**

You are invited to participate in a qualitative study to explore  
**Experiences of adults with acquired physical disabilities on social work support in a South African context**

Who would be eligible to participate:

- Adults (over 18 years old) who have acquired a physical disability at no younger than 11 years old.
- You must be able to communicate in either English or Afrikaans.
- You must have received social support services in terms of your disability.

OR

- You must be a registered social worker under the South African Council for Social Service Professions (SACSSP).
- You must have experience in providing social support services (rehabilitation or after care) to persons with a disability, specifically adults who have acquired a physical disability within a South African context.
- You must be able to communicate in either English or Afrikaans.

Should you be interested to participate in this study, please contact:

**Noreth Muller-Kluits**  
(c) 076 589 5404  
e-mail: [mnoreth@gmail.com](mailto:mnoreth@gmail.com)

## **ADDENDUM K:**

### **INFORMATION PAMPHLET (AFRIKAANS)**



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvenoot • your knowledge partner

#### **DEPARTEMENT VAN MAATSKAPLIKE WERK**

U word uitgenooi om deel te neem aan die kwalitatiewe studie om die volgende te ondersoek

#### **Ondervindings van volwassenes wat 'n fisiese gestremdheid verkry het oor maatskaplike ondersteuning binne 'n Suid-Afrikaanse konteks**

Wie kan deel vorm van die studie:

- Volwassenes (ouer as 18 jaar) wat 'n fisiese gestremdheid verkry het nie jonger as op die ouderdom van 11 jaar oud.
- U moet kan kommunikeer in Engels of Afrikaans.
- U moet maatskaplike ondersteuningsdienste in terme van u gestremdheid ontvang het.

OF

- U moet geregistreer wees as 'n maatskaplike werker onder die SACSSP.
- U moet ondervinding hê om maatskaplike ondersteuningsdienste (rehabilitasie en nasorg) aan persone met 'n gestremdheid te gee, veral volwassenes wat 'n fisiese gestremdheid verkry het, binne 'n Suid-Afrikaanse konteks.
- U moet kan kommunikeer in Engels of Afrikaans.

Indien u instem om deel te vorm van die studie, kontak asseblief:

**Noreth Muller-Kluits**  
(s) 076 589 5404  
e-pos: [mnoareth@gmail.com](mailto:mnoareth@gmail.com)



## **ADDENDUM L:**

### **EXAMPLE OF DEBRIEFING OF PARTICIPANTS FORM**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

To whom it may concern

Doctoral degree student: Noreth Muller-Kluits

Topic: Experiences of adults with acquired physical disabilities of social work support  
in a South African context

I hereby confirm that I will be available to offer any debriefing services for  
participants taking part in abovementioned study.

Kind regards

\*Signatures omitted to protect identity

## ADDENDUM M:

THEME VERIFICATION FORM FOR  
INDEPENDENT CODER

UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

I, [REDACTED], hereby declare to agree to act as Independent Coder for the research study of:

**Noreth Muller-Kluits**

**Research for PhD in Social Work**

**Topic: Experiences of adults with acquired physical disabilities of social work support in a South African context**

As an independent coder I will not disclose any information that I obtain from the research study in order to adhere to the confidentiality requirement of the study.

Signed at Quetzshorn on the 3 day of August 2020.

THEMES	SUB-THEMES	CATEGORIES
Theme 1 Biological experiences of adults with an acquired disability	1.1 Activity limitations (ADLs)	
	1.2 Participation restriction	1.2.1 Accessible housing 1.2.2 Accessibility challenges in community
Theme 2 Psychological experiences of adults with an acquired disability	2.1 Model of Grief	2.1.1 Shock, numbness and disbelief 2.1.2 Relief 2.1.3 Denial 2.1.4 Bargaining and guilt 2.1.5 Depression 2.1.6 Anger 2.1.7 Anxiety 2.1.8 Acceptance
Theme 3 Support services used by adults with an acquired disability according to ecological perspective	3.1 Microsystem	3.1.1 Spousal/ partner subsystem 3.1.2 Parental sub-system 3.1.3 Sibling sub-system 3.1.4 Child sub-system
		3.2.1 Extended family 3.2.2 Friends and peers 3.2.3 Health professionals
	3.3 Exosystem	3.2.1 Social work/ Welfare Organisations 3.2.2 Health facilities 3.2.3 Other community facilities
		3.4.1 The SA Health Care System 3.4.2 Other support services 3.4.3 Financial assistance
	3.4 Macrosystem	
Theme 4 Support needs of adults with an acquired disability according to ecological perspective	4.1 Microsystem	
	4.2 Mesosystem	4.2.1 Extended family support 4.2.2 Professional support and understanding
		4.3.1 Post-discharge rehabilitation facilities 4.3.2 Community support services 4.3.3 Transport systems
	4.3 Exosystem	

		4.3.4 Community safety
	4.4 Macrosystem	4.4.1 Disability-friendly employment
		4.4.2 Financial concerns
Theme 5 Cultural experiences of adults with an acquired disability within their community	5.1 Lack of understanding in community	5.1.1 Stigmatisation
		5.1.2 Need for sensitisation in communities
	5.2 Acceptance in community	5.2.1 Experience of acceptance
		5.2.2 Recommendations for improving acceptance as depicted by participants
Theme 6 Social work support services to persons with acquired physical disabilities aligned with policies in South Africa	6.1 Social work support services used	6.1.1 Social work services offered at an organisation
		6.1.2 Social work services used by adults with an acquired physical disability
	6.2 Experiences of social work services	6.2.1 Positive experiences of social work services received
		6.2.2 Negative experiences of social work services received
		6.2.3 Lack of knowledge about social work services
		6.2.4 Experiences from social workers
	6.3 Services aligned with policies	6.3.1 Services aligned with other international policies
		6.3.2 Services aligned with WPRPD (South Africa)
		6.3.3 Services aligned with other South African policies
	6.4 Impact of COVID-19 pandemic on social work services	6.4.1 Experiences of adults with acquired physical disabilities
		6.4.2 Experiences of social workers
	6.5 Role of social worker in rehabilitation of adults with acquired physical disabilities	6.5.1 Role of social worker as seen by Cohort 1
		6.5.2 Role of social worker as seen by Cohort 2
	6.6 Recommendations for future social work services to adults with acquired physical disabilities	6.6.1 Recommendations from service users
		6.6.2 Recommendations from service providers
		6.6.3 Motivation for similar studies

I hereby agree that the above-mentioned themes and sub-themes were clearly identified within the transcribed interviews of the empirical study.

\*Signatures omitted to protect identity

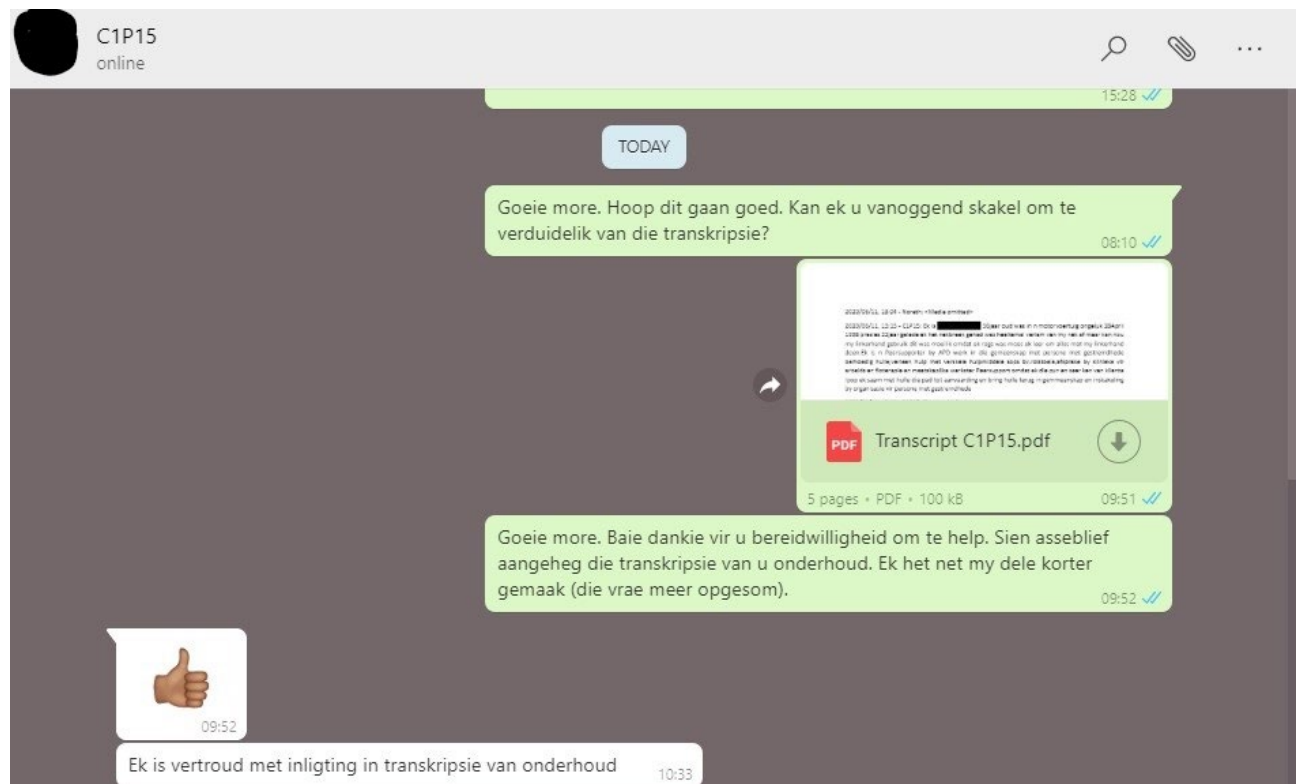
# ADDENDUM N:

## MEMBER CHECKING FORM FOR PARTICIPANTS



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jou kennisvennoot • your knowledge partner

### COHORT ONE



Participant Number

C1P13

I hereby declare that I have read the transcribed interview done for this research study:

Yes



No

I hereby declare that I agree with the content of the transcribed interview:

Yes



No

COHORT TWO

Participant Number C2P3

I hereby declare that I have read the transcribed interview done for this research study: (Mark correct one with "x")

Yes x

No

I hereby declare that I agree with the content of the transcribed interview: (Mark correct one with "X")

Yes x

No

\*Signatures omitted to protect identity

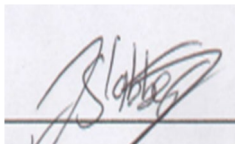
## **ADDENDUM O:**

### **LANGUAGE EDITOR DECLARATION**

To whom this may concern

I, Janie Slabbert of ID number 9303200115086, hereby declare that I have personally edited the dissertation titled "Experiences of adults with acquired physical disabilities of social work support in a South African context" by Noreth Muller-Kluits of Student Number 15430111, highlighting language errors and improving formulation where necessary. The research assignment was submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD) in Social Work in the Faculty of Arts and Social Sciences (Department of Social Work) at Stellenbosch University on 11 August 2020.

Sincerely,



9/08/2020

**Contact Details:**

Cell: 076 320 7827

E-mail: [j.a.slabbert93@gmail.com](mailto:j.a.slabbert93@gmail.com)

**Address:**

28 Ganzekraal Road

Oak Glen

Belville 7530

**Qualifications:**

Master of Arts in English (SU) (Cum Laude),

Published Poet at TypeCast Literary Journal (<http://typecast.org.za>),

Trained Teacher with a Postgraduate Certificate in Education (SU),

Trained Writing Lab Consultant at Stellenbosch University's Language Centre,

Three years' experience in editing postgraduate papers and dissertations.

## **ADDENDUM P: TECHNICAL EDITOR DECLARATION**

### **TECHNICAL FORMATTING**

☎ +27+21-886 5672

☎ +27+82 757 8708  
email address: [cdp@sun.ac.za](mailto:cdp@sun.ac.za)

Postal address: 2 Constantia Ave, Stellenbosch 7600, South Africa

---

### **DECLARATION**

I hereby certify that the dissertation by  
**NORETH MULLER-KLUITS**  
was formatted by me.

*Title of dissertation:*

**EXPERIENCES OF ADULTS WITH ACQUIRED  
PHYSICAL DISABILITIES OF SOCIAL WORK SUPPORT  
IN A SOUTH AFRICAN CONTEXT**

*University:*

**Stellenbosch University**

*CD Park*

.....  
**CD PARK**

10 August 2020

.....  
**DATE**

## **ADDENDUM Q:**

### **REFLECTIVE REPORT**

This research study was inspired by both my professional and personal experience within the field of disability. I was born with Spina Bifida Myelomeningocele, and years later, a close family member had a stroke at the age of 44 years. Both of us had a poor initial prognosis, but a strong support network. Our ability to surpass our initial prognosis can be attributed to this support network. This realisation only came later in my life, as I began to learn more about Bronfenbrenner's ecological perspective during my undergraduate social work training.

My first job as a social worker was with an organisation delivering social work services to persons with disabilities and their families. During this time, I again experienced the valuable role of an individual's support network(s). This specific community had developed many structures to support persons with disabilities and their families, where these families also help one another. This experience has influenced both my personal and professional development. Once I started my post-graduate research, I first explored the experiences of family caregivers of persons with physical disabilities, which at the time, was based on my experiences at my first job. During this time, I realised the valuable role that qualitative research could play in 'sharing stories' and 'giving voice' to people that might not have the opportunity to speak often. I also realised that I enjoy doing research, and from there gained the opportunity for this study. Through the guidance of my admissions committee, after the realisation of the role social workers play in service delivery, the topic for this research study – an exploration of the experiences of adults who have acquired a physical disability regarding social work services – started to develop.

During research on this topic, I had to put my own perspectives and experiences aside, since all of the variables of the study, namely being a person with a disability, having a family member who had acquired a physical disability, and being a social worker who has worked with persons with disabilities, applied to me. During the interviews, I was cautious to ensure that my own background would not influence the study, as I could relate to similar experiences. This is where my training as a social worker guided me, as I have learnt to separate my personal and professional life. I could, however, relate to the sense of 'loss' that was felt by the family



member who had to seek an alternative career choice due to the disability. There were also some of the challenges that I could relate to myself.

During the interviews, I was humbled by how willing participants seemed to be in sharing their experiences with me. Due to the COVID-19 pandemic, it was difficult to access enough participants through purposive sampling, and snowball sampling had to be used. Many participants from this study referred other possible participants. This again showed the willingness to participate in the study and assist with rendering ‘voices heard’ and ‘stories shared.’ So many participants shared their gratitude for being able to share their experiences, and a few asked me: “What are you going to do with this research?” This emphasised our responsibility as researchers to never keep research to ourselves, but to share what was found.

A critical realisation came in terms of the correlation between the experiences of family caregivers and persons with an acquired disability. In both cases, an adjustment had to be made from life without a disability to living with a disability. This did not necessarily mean a negative outcome. The focus on adults with an acquired physical disability also assisted in maintaining an objective stance during the research process, as I was born with a disability. Therefore, despite having some shared experiences, I never had to make any adjustments in my life, as this was always my life.

During this research study I had learnt from the participants, from other thought leaders on the topic, and from different workshops and training opportunities that developed my professional understanding of the disability sector. Remembering how resilient the participants of this study have been, along with the people from the community I worked in years ago, I am increasingly convinced of the importance of a bottom-up approach in service delivery planning. Consequently, it is crucial to involve service users in community events that take place on their behalf. Both of these are recommendations I made for this study.