Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province

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DECLARATION

I, Johannah Motsei Paledi, hereby declare that the work contained in this thesis is my own original work and that I have not previously, in its entirety or in part, submitted it at any university for a degree.

Paledi

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Johannah Motsei Paledi

23 November 2022

DEDICATIONS

I dedicate this thesis to the following people:

- My late father, Tlhabaki Abbyziah Moalusi, and my late mother, Rosinah Konana Moalusi. Papa and Mama, your “little” girl has made it. Thank you very much for the values that you instilled in me. I could not have chosen better parents.

- My “kid” brother, Moagabo Kenneth Moalusi. You left us so tragically and so unexpectedly. Going through this study was, in a way, therapeutic for me. May your beautiful soul continue to rest in peace – until we meet again.

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ABSTRACT

The aim of this study was to explore whether inclusive citizenship education could address the needs of families with members living with cerebral palsy in the rural parts of the Bojanala District in the North West Province. Cerebral palsy comprises a heterogeneous group of conditions that involve permanent non-progressive central motor dysfunction. These conditions affect muscle tone, posture and movement. People living with disabilities such as cerebral palsy in South Africa are usually faced with attitudinal challenges, such as prejudice, stereotyping and discrimination, which lead to the exclusion and isolation of those affected by the disability.

The research followed a qualitative approach with three methods being used to collect data, namely a literature review, document analysis and in-depth interviews. Semi-structured interviews were conducted with nine biological parents and two caregivers who were members of the extended families of children with cerebral palsy, as well as six community members who had some affiliation with the families of the children with cerebral palsy. The initial plan was to have two parents or caregivers per household, but unfortunately, one family had only one participant instead of the anticipated two. The participants were selected purposefully, as they possessed rich information on and experience and understanding of the phenomenon of cerebral palsy. The data gathered were analysed through thematic analysis, which led to five themes and 17 sub-themes emerging. The five themes were knowledge about cerebral palsy, the impact of cerebral palsy on families, resources for families with members living with cerebral palsy, psychosocial experiences and support, and possible interventions. The theoretical framework that grounded this study was Bronfenbrenner's bio-ecological systems theory.

The researcher discovered that the families of children with cerebral palsy and close community members did not have proper knowledge of cerebral palsy and its impact on the lives of those who must contend with it. However, she believes that inclusive citizenship education can address the needs of the families of children with cerebral palsy in the rural parts of the Bojanala District in North West. The various role players can be educated about the concept of cerebral palsy, its causes and how it affects those who have to contend with it. The researcher strongly believes that with knowledge comes understanding, empathy, support and, ultimately, inclusion.

Keywords

Bojanala District; cerebral palsy; citizenship; inclusive citizenship education; inclusive education; North-West Province

ABBREVIATIONS

CP	Cerebral palsy
EDACS	Eating and Drinking Ability Classification System
GMFCS	Gross Motor Function Classification System
MACS	Manual Ability Classification System
CFCS	Communication Function Classification System
EWP6	Education White Paper 6
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WPF	White Paper on Families in South Africa
WPF-R	Revised White Paper on Families in South Africa
WPRPD	White Paper on the Rights of Persons with Disabilities

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CHAPTER 1 INTRODUCTION AND OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Cerebral palsy (CP) comprises a diverse group of disorders that involve central motor dysfunction of a permanent, non-progressive nature (Duke *et al*., 2020:625). These diverse conditions usually affect muscle tone, posture and movement (Duke *et al*., 2020:625). Thus, CP can be identified when limited or no activity is seen in a person or when someone has abnormal muscle tone, posture and movement. Along with these motor disorders, CP is often comorbid with disturbances that influence sensation, perception, cognition, communication, behaviour, epilepsy and secondary musculoskeletal problems (Rosenbaum *et al*., 2007, as cited in Stavsky *et al*., 2017:2). Accardo *et al*. (2007, in Stavsky *et al*., 2017:2) point out that "cerebral palsy is the most common motor disability in childhood", a notion that is supported by Donald *et al*. (2015:963) and Zuurmond *et al*. (2018:46). These authors also suggest that this childhood physical impairment is estimated to occur in about two in 1 000 live births globally. There are four types of CP, namely spastic, athetoid-dyskinetic, ataxic and hypotonic CP (Newman, 2017). Gulati and Sondhi (2018:1007) have a different view and suggest that the three predominant types – spastic, dyskinetic and ataxic CP – are more applicable. Children who are diagnosed with hypotonic CP early in life, later develop spastic, dyskinetic or ataxic CP (Gulati & Sondhi, 2018:1007-1008). However, this is rare, and an improvement with time also sometimes occurs (Gulati & Sondhi, 2018:1007-1008).

1.2 BACKGROUND

In considering CP in the global context, it is noted that this impairment affects a large proportion of children. As seen previously, there is little consensus on CP, leaving much to be discussed. Furthermore, in the African and, more specifically, the South African context, this impairment is further clouded by people's cultural beliefs and understandings.

To provide a background to this study, the point of departure taken is that of Donald *et al*. (2015:969), who suggest that CP is an umbrella concept. Furthermore, at the core of CP, early static brain lesions and motor disability reflect a diverse condition that can have a multitude of potentially associated disorders, as well as further medical complications (Donald *et al*., 2015:969). This point is supported by Bax *et al*. (2005:574) and, more recently, Blair and Cans (2018:13), who state that the clinical expressions or indications of CP are different, as many children with CP differ clinically, and each classification used alone tends to present as incomplete. In considering the South African context, very little has been done regarding CP (Donald *et al*., 2015:963). The term "cerebral palsy" is often used in the African context to describe all motor disability syndromes (Donald *et al*., 2015:965).

Bearden *et al*. (2016:23) argue that CP remains a challenge in Africa, as children with CP tend to experience more severe degrees of disability than other cohorts worldwide. The African Child Neurology Association, a subgroup of the International Child Neurology Association, states that CP is regarded as synonymous with birth asphyxia or neonatal encephalopathy, which is evident in many African countries (Donald *et al*., 2015:965).

In developed countries, if the causes of CP are considered postnatally, a good profile is provided of the proportion of reported CP in the total population (Donald *et al*., 2015:966). In contrast, no accurate profile of CP is available for reported cases in Africa, due to secondary postnatal complications that include meningitis, cerebral malaria and traumatic brain injury (Donald *et al*., 2015:966). Unfortunately, due to these conditions, which are usually identified at birth and include but are not limited to abnormal tone, other diagnostic classifications, which are usually seen to be more appropriate for care and treatment purposes, are given (Ngoveni, 2018:9). Because CP is a type of brain damage that occurs before a child is five years old (Fieger Law, 2017), this can be regarded as the “ceiling” age and “cut-off” mark for attributing CP to a child’s physical condition. In Africa, and even in South Africa, many children are not monitored closely, and ages and conditions are often not documented precisely due to minimal or no medical support, which creates the perception of a greater number of children with CP in the African context (Donald *et al*., 2015:966).

In support of the abovementioned argument, Bunning *et al*. (2017:1) state that communities in underdeveloped countries are not conversant with the causes of disabilities. This may be as a result of limited support services and limited access to resources that can provide such knowledge (Bunning *et al*., 2017:1). These communities are disadvantaged by many of their cultural beliefs, which tend to be rigidly traditional and isolating, and Shakespeare (2014, in Bunning *et al*., 2017:2) states that such views and beliefs influence the way people with disabilities view themselves, as well as the way other people view them. This ultimately influences how they are treated. The way people with disabilities are perceived and treated in the communities in which they live can either promote or constrain their abilities, rights and even their needs (Bunning *et al*., 2017:2), and in many rural communities, this presents great challenges. Zuurmond *et al*. (2018:45) support this view, stating that more than half of the approximately 150 million children who are afflicted with disabilities live in resource-poor settings. Furthermore, research shows that many caregivers of children with disabilities themselves often experience a range of difficulties. These difficulties include exhaustion and high levels of stress, being anxious and depressed and facing stigma and discrimination, much of which arises from traditional beliefs and poverty (Zuurmond *et al*., 2018:46).

Globally, people living with disabilities are also faced with attitudinal challenges, such as prejudice, stereotyping and low expectations with regard to their abilities (Rohwerder, 2018:4), and South Africa is no different. These negative attitudes, which are usually based on a lack of correct information and incorrect beliefs about disability that are not based on facts, can result in stigma. Stigma is defined as “an attribute possessed by a person or group that is regarded as undesirable or discrediting” (Division of Services for People with Disabilities, 2016:6, cited by Rohwerder, 2018:4). Stigma often produces negative responses (Scior, 2016:5), such as pity, avoidance and anxiety, as well as hostility, hatred and even disgust. Inguanzo (2017, in Rohwerder, 2018:7) argues that stigma towards people with disabilities can lead to them and their families being rejected. That contact is an important factor in combatting stigma is undisputed, and special schools, care centres and homes have brought advantages and benefits in this regard. However, the introduction of services that are meant exclusively for people with disabilities has probably encouraged stigmatisation (Rohwerder, 2018:11).

Within the negativity of stigma, a further challenge entails awareness and understanding of the condition (Mostert, 2016:9). Mostert (2016:9) suggests that the stigma experienced by people with disabilities in Africa is the result of a general absence of knowledge and information about the causes of the disability and its characteristics. A literature review by Stone-MacDonald and Butera (2014:5) found evidence that, among Africans, tradition and culture still play a dominant role in describing and defining disability, resulting in some Africans still believing that disabilities are caused by witchcraft and are punishment for bad deeds. Mutlaneng (2020:1) argues that each culture has a unique way of perceiving and treating disabled people and agrees that, in most cases, indigenous Africans single out witchcraft as the cause of disability. She posits that in South Africa, where her research took place, disability continues to be seen as a punishment by God for a particular sin committed by the disabled person or his or her parents or ancestors (Mutlaneng, 2020:7). Similarly, Aley (2016:6) states that people with disabilities are usually rejected and condemned, especially if their condition is viewed as punishment for something morally wrong. Berghs (2017:3) shares a similar sentiment, arguing that the segregation, exclusion and marginalisation of people living with disability have become rampant in African societies.

To put this study into context, it is suggested that the quality of life and the potential of people living with disabilities continue to be limited because of their exclusion and segregation from society. This exclusion also encourages negative stereotyping (Scior *et al*., 2015:101, in Rohwerder, 2018:11). According to the Division of Services for People with Disabilities (2016:5, in Rohwerder, 2018), it is worth noting that beliefs can change and develop over time. Thus, even though inaccurate beliefs and perceptions regarding a disability are often difficult to overcome, there is hope that understanding can be developed and stereotypes changed. Further research has found that many traditional beliefs are declining, especially in countries where disability advocates, civil society and governments aim to dispel negative attitudes and traditional practices (Groce & McGeown, 2013:8).

Furthermore, Njeri (2018:3) argues that, even in the 21st century, many societies remain caught in traditional, obsolete beliefs and mentalities. These antiquated perspectives tend to hamper the lives of people with disabilities (Njeri, 2018:3). Consequently, having a disability is not really a problem; the problem that is usually the most serious is the social and non-inclusive environment in which so many of these individuals live (Njeri, 2018:3). Living in such an environment dismantles self-esteem and discourages achievement (Njeri, 2018:3).

1.3 PROBLEM STATEMENT

The North West Province of South Africa is divided into four district municipalities, one of which is Bojanala. This district falls mostly in the mid-socioeconomic quintile. According to Census 2011, it has a population of 1 665 222. Its rural makeup is "Black African 91,4%, Coloured 0,7%, Indian/Asian 0,6% and White 7,0%" (Bojanala District Municipality www.hst.org.za). The district has 14 special schools, of which 12 cater for children with CP, as well as 66 full-service primary schools and five full-service secondary schools. There are also 11 daycare centres in Bojanala that are registered with the Department of Social Development. According to the Bojanala Platinum District Municipality (Municipalities of South Africa, 2022), there are five hospitals, one central or tertiary hospital and 115 health centres in the district. The economic sectors of the district are "mining (30-35%), community services (15-20%), finance (10-15%), trade (10-15%), transport (5-10%) and manufacturing (5-10%)" (Municipalities of South Africa, 2022). However, while these numbers are satisfactory, most special schools and hospitals are located far from rural areas. In order to access them, the families need to be economically sound enough to be able to pay for transport to take their children to school. The aspect of transport is imperative when considering CP and the complications of the medical condition, such as spasticity, which occurs in the majority of children, as well as significant mobility problems (Donald *et al*., 2015:968). Evidence of these transport challenges is provided by Conchar *et al*. (2016:152), who also list this as one of a number of reasons for the poor health status of people with disabilities. Thus, physical access to healthcare facilities, along with transport to them, is typically difficult when considering rural environments. Thus, financial aspects, influenced by geographical distances, which are compounded by access to suitable healthcare facilities, all form part of the complicated and dynamic problem facing children and parents with CP children.

It is easy to speak of inclusive education, but, as Andrews *et al.* (2020:6) posit, the lack of an acceptable level of resources, including human, technical and infrastructural resources, to facilitate such inclusion remains a challenge. Furthermore, these challenges are compounded in rural areas. The Auditor-General of South Africa (Department of Basic Education, 2019:2) indicates that in most full-service schools, their designation as such is not followed by processes to resource, convert and build their capacity. Because of this, a child with CP may not receive the necessary help or attention in class because teachers are either not trained sufficiently or are preoccupied with other learners (Rohwerder, 2018:18), especially in the full classes that are usually encountered in these schools.

Furthermore, many children suffering from CP in the Bojanala District are not exposed to options that would be more accessible in larger urban areas, such as healthcare facilities where specialist services, wheelchairs or other ambulatory aids are available (Donald *et al*., 2015:968). This notion is supported by Andrews *et al*. (2020:454), who argue that the unique needs of children with CP are not met by the services provided in many low- and middle-income countries. The reason for this can be that many children who present with developmental disabilities are often neglected, excluded or even discriminated against by primary healthcare and education services. Bright *et al*. (2018:27) contend that low- and middle-income countries are characterised by low numbers of health professionals who have specialised in childhood disability. Even when treatment is available, many families in African countries fail to seek treatment and support, resulting in children with neurological disorders suffering higher levels of social stigma (Donald *et al*., 2015:968). This issue is evident in the Bojanala District of the North West Province as well. In addition, there is evidence that some healthcare workers view people with disabilities negatively, which influences their attitudes towards them, as they may feel that caring for disabled people puts extra pressure on the already restricted resources at their disposal (Mall & Swartz, 2012, as cited in Conchar *et al*., 2016:152). Moreover, many of the available care centres in the Bojanala District do not have facilities that can optimally support and improve the well-being of a child with CP, resulting in these facilities becoming centres where only the child’s physical needs are taken care of, with no extra stimulation or therapy.

Following the problem statement above, it seems that research is needed to explore how CP affects the families of people with CP in the Bojanala District and devise plans to address these challenges. During this exploration, other aspects of importance must be included, for example how inclusive the education system is and how cultural beliefs and values influence the families of children with CP. Furthermore, solutions to these problems and ways in which inclusive citizenship education may assist in relieving the plight of children with CP, their families and their communities must be investigated.

1.4 CENTRAL ARGUMENT

The researcher argues that, although there are good policies in the educational support system, they tend to be paper-based and do not filter down to the individual on the street and into the communities where they are needed. Examples of these policies that are sound and positively support and influence the educational system are for example, the Constitution of the Republic of South Africa, the Inclusive Education Policy (*Education White Paper 6*), the *White Paper on the Rights of Persons with Disabilities*, the *White Paper on Families in South Africa* and the *South African Schools Act.*

Furthermore, the families of people living with CP are not getting the social, economic, and psychological support that is needed to cope with their situation or what is advocated by the government and these policies. From the researcher's own experiences, working in the field of education, the researcher strongly believes that the issue of the inclusion and exclusion of people with CP and their families touches on core questions of human rights, justice, and equality. If all policies were fair and objective and implemented properly, communities would be educated about CP, attitudes towards people with CP and their families would be all-encompassing and the necessary support and assistance would be available to all. The researcher concurs with the sentiment expressed by Capri *et al*. (2018:2), namely that “what disables people – what makes people disabled – is how society responds to the impairments”.

The central argument that one can pose is that what is written in the policy documents does not become a reality on the ground and at these grassroots levels, especially in rural areas, people are suffering injustices.

1.5 PURPOSE OF THE STUDY

In relation to the problem statement, the main resolution of this study was to explore the effect of CP on the families of those who have to contend with it. In obtaining a holistic picture of this situation, further aspects were pursued in an attempt to establish how inclusive citizenship education can assist all role players in their plight to cope effectively with CP in their daily lives.

1.5.1 Research aim

In order to ground this study in present-day reality, current, relevant and applicable South African policies were considered. Thus, to extract the core South African legal stance on this topic, the following legislation was explored:

- The policy documents of the Department of Education on inclusion.
- The *White Paper on Families* (WPF).
- Legal acts regarding children and school matters.

More specifically, this study aimed to explore CP in the Bojanala District, North West, and thus it was necessary to explore the following:

- The effect of CP on families and individuals.
- The attitudes of communities towards the families of people living with CP.
- Applicable interventions as suggested by families and community members to change communities’ attitudes to and perceptions of CP.

- Support interventions for families of people living with CP, as suggested by the families and the community.

1.5.2 Research objectives

The objectives that framed the structure of the study were:

- to conceptualise CP based on the literature;
- to explore the effect of CP on families in the Bojanala District, North West Province;
- to explore the perceptions of communities on CP in the Bojanala District, North West Province;
- to determine whether and how inclusive citizenship education can be used to bridge the gap in order to change people's perceptions of CP in the Bojanala District, North West Province;
- to initiate intervention strategies for the families of people living with CP; and
- to make recommendations on how the families of people living with CP can be incorporated inclusively.

1.5.3 Research questions

Based on the earlier submission, the following primary research question was ultimately formulated:

Can inclusive citizenship education address the needs of families with members living with CP in the Bojanala District, North West Province?

The secondary questions were as follows:

- What are the current practices and policy regarding inclusive education in the Bojanala District, North West Province?
- How does CP affect the families of people living with CP?
- What perceptions are evident in communities within which there are people living with CP?
- How can communities be assisted to transform their attitudes toward the families of people living with CP?
- What are the various role players' experiences of the support that is given to the families of people living with CP in order to accommodate them inclusively?
- What guidelines can be developed for a framework to support all role players?

1.6 THEORETICAL FRAMEWORK

1.6.1 Ontological and epistemological paradigm

Maree (2019:58) defines a paradigm as a set of assumptions or beliefs about fundamental aspects of reality. These assumptions or beliefs provide a sense of realism to a particular worldview (Maree, 2019:58). Guba and Lincoln (1994:107) and Makombe (2017:3364) also suggest that a paradigm is a set of basic beliefs that deal with principles representing a worldview. The nature of the world and an individual's perception of his or her place in the world are a part of a paradigm (Guba & Lincoln, 1994:107; Makombe, 2017:3364). This includes possible relationships within that world or parts thereof; thus, a researcher's paradigm would reflect his or her worldview (Mackenzie & Knipe, 2006:5). Therefore, this worldview would, in general, be regarded as the perspective of the researcher and his or her research on his or her thinking or school of thought, beliefs and meanings, all of which inform the perspective when making meaning or interpreting the data from the research (Kivunja & Kuyini, 2017:26).

Lincoln and Guba (1985:15) cite four elements that are present in a paradigm, namely epistemology, ontology, methodology and axiology. The interest of epistemology lies in basic knowledge and the acquisition thereof, while ontology examines the belief system relating to the nature of being and existence (Kivunja & Kuyini, 2017:27). Methodology refers to the approach to data collection or production (Ellen, 1984, in Rehman & Alharthi, 2016:52). Axiology refers to ethical issues encompassing the planning of the research (Kivunja & Kuyini, 2017:26). This view is supported by Maree (2019:58), who states that a paradigm addresses fundamental assumptions relating to faith and beliefs about the nature of reality (ontology).

According to Rehman and Alharthi (2016:52), there are three types of research paradigms, namely positivism, interpretivism and critical theory. However, Nieuwenhuis (2019:58) has a different view; he believes that paradigms are often categorised into a number of broad approaches, such as postpositivist, interpretivist, critical theory or symbolic interactionism. For this study, a constructivist approach with an interpretive paradigm was followed. The constructivist approach underpins the concept of reality being constructed by a person from within his or her own unique reality (Merriam & Tisdell, 2016:9), thereby creating an observed reality that is unique and personal, implying that knowledge is not founded but constructed.

In relation to this study, the researcher endeavoured to gain an understanding of the world of families that have to deal with CP daily in the Bojanala District, North West, by considering the subjective feelings and experiences of these individuals. It is the constructed reality from which they negotiate their world socially that is imprinted on their frame of reference and formed through interaction with others, the environment and their own existence. Furthermore, the participants were involved actively in the research so that the researcher could interpret these perceptions (see Cohen *et al*., 2007, in Rehman & Alharthi, 2016:56). Therefore, this ontological position guided the researcher to understand the research problem by providing access to and interpreting the data, as well as make meaning of these individuals' worlds (see Kivunja & Kuyini, 2017:27).

1.6.2 Bronfenbrenner's bio-ecological systems theory

The theoretical framework of Bronfenbrenner's bio-ecological systems model, namely the process-person-context-time model (Bronfenbrenner & Morris, 1998), guided this study. The process-person-context-time model includes the processes of human development (Bronfenbrenner & Morris, 1998). This theoretical framework facilitated the paradigm, approach and methods of the study, as it postulates that human interaction and development can be captured from a transactional and systemic process that is influenced by the interactions and reactions of the various role players within the spheres of their environments (Patel, 2011, in Hapunda *et al*., 2017:4). As noted by Killian (2004, in Tabane, 2014:86), a child is in a family, the family is in a community, and the community, in turn, develops its own cultures, and then subcultures. These all influence the developing individual. When specifically considering the child, the interaction between factors of the child's biology, family and the community and the greater social landscape either fuel or steer his or her development (Paquette & Ryan, 2011:1).

In the African context, Tabane (2014:92) argues that the relationship between different systems over time is very important from the African ecological perspective, which he links to the famous African saying "it takes a village to raise a child". This illustrates how an individual's development is moulded on and influenced by the numerous ecological levels on which a child finds him- or herself (Tabane, 2014:82). He further argues that the Afrocentric view of Botho or Ubuntu, in terms of which people respect one another and are cognisant that they are linked to one another within individual systems, resonates deeply with this system (Tabane, 2014:92). Therefore, to study CP with a special emphasis on the rural parts of the Bojanala District, it is necessary to look at not only the affected person and his or her immediate environment but also the person's interaction with the larger environment.

Hence, the researcher felt that Bronfenbrenner's theoretical framework could provide a suitable lens through which one could look to better understand the environment and the biological factors that contribute to the development and psychosocial well-being of people with CP. The bio-ecological systems model thus helped the researcher to identify and highlight strategic points of contact and interaction among the different ecological systems involving a person with CP. According to Betancourt *et al.* (2013, in Hapunda *et al*., 2017:6), a very useful preventative strategy that can be considered for identifying childhood problems would be to look at the child's contextual situation. Consequently, one must consider the interactions the child has with other people, and the influence of institutions and policies in the immediate and broader environment on the child. Therefore, it is useful to appreciate the use of the bio-ecological systems model in understanding the needs of people living with CP, their families and the environment. Furthermore, this model can serve as a base to initiate support regarding the needs within the community and society in general.

1.7 EXPLANATION OF TERMINOLOGY

In light of the theoretical framework discussed in Section 1.6.2, the following meanings are defined for the central concepts used in the study.

1.7.1 Cerebral palsy

"Cerebral palsy" is defined as a permanent disorder of the development of movement and posture that causes limitations to activity (Rosenbaum *et al*., 2007, as cited in Diseko, 2017:12). These limitations can be attributed to a static (non-progressive) problem that occurred in the brain of the developing foetus or infant.

1.7.2 Citizenship

"Citizenship" is defined as a sequence of responsibilities and individual rights of a person within a community (Nowhereisland, 2019:1). This includes civic, political, social and economic rights, which describe the relationships between all role players in communities (global and local) and people's multiple identities.

1.7.3 Inclusive citizenship

Forst (2017:1) describes inclusive citizenship as a government policy or rules that provide all members of that society with equal access to public services, public funds and democratic rights, as well as the ability to be represented in government. Inclusive citizenship aims to remove segregation and promote inclusivity and equal rights, despite any difference in colour, cultural background, religious affiliation, gender or creed.

1.7.4 Inclusive education

Inclusive education is an ideal that promotes the quest for equity, social justice, participation and the realisation of citizenship (National College for Teaching and Leadership, 2018:3). Inclusivity is aimed at removing any barriers that may discriminate against or oppress an individual; hence, it is in favour of promoting the well-being of all learners, including those who are disabled (National College for Teaching and Leadership, 2018:3).

1.7.5 Inclusive educational citizenship

Inclusive educational citizenship includes and combines the abovementioned concepts. Grossman (2008:35) defines "inclusive educational citizenship" as a combination of citizenship, education and inclusion that share common grounds, namely ethos and language. Citizenship, education and inclusion include and are based on concerns for human rights, social justice and a sense of community, which are all aimed at building democratic relationships, communities, societies and environments.

1.7.6 Inclusive citizenship education

The concept of inclusive citizenship education can be distinguished from the abovementioned concept by regarding it as the process that encompasses the educational aspects of including all citizens. According to Lange and Kleinschmidt (2016:1), inclusive citizenship education can be seen as referring to the education of the individual to accomplish or enhance aspects of inclusive citizenship.

1.7.7 Family

Olawale *et al.* (2013:160) define "family" as a unit or grouping that consists of parents and their children. In this study, a family will be looked at in terms of a typical African society, where parents enjoy some level of support from members of the extended family (Olawale *et al*., 2013:161).

1.8 RESEARCH PARADIGM, DESIGN AND METHODOLOGY

The research design and research methodology that were used in this study are discussed in the following sections.

1.8.1 Research design

A research design is the manner or path that one uses to move from fundamental philosophical assumptions or paradigms to a research level on which meaning can be made of the data collected. The research design specifies the choice of participants, the data-gathering techniques used and the method of data analysis (Maree, 2014:70), which together produce a comprehensive research study.

A qualitative research design was used in this study, since it entailed an interpretive, naturalistic approach to the study (see Creswell & Poth, 2018:7). According to Creswell and Poth (2018:7), phenomena, ideas or events are studied in their natural settings in qualitative research. Denzin and Lincoln (2011, in Creswell & Poth, 2018:7) posit that in this type of research, attempts are made to make sense of or interpret phenomena in terms of discovering the unique meanings people attach to them. In line with this, Hammarberg *et al*. (2016:499) state that qualitative methods are usually applied when exploring questions about experience, meaning and perspective. This method is usually seen from the standpoint of the participant (Hammarberg *et al*., 2016:499).

In this study, participants reported on their experiences, engagements, perceptions and attitudes regarding CP. The use of qualitative research techniques reflects experiences or events as seen from a personal perspective (Hammarberg *et al*., 2016:499). These techniques include individual interviews or in-depth interviews that facilitate the understanding of a condition (Hammarberg *et al*., 2016:499). Researchers use qualitative research techniques to seek or obtain views on a specific topic. Regarding this study, interviewing the families of people living with CP and members of the communities in which they lived allowed the researcher to obtain such views and uncover new aspects regarding this topic. This supports the notion that qualitative research is exploratory and that new knowledge can be constructed from the data that are collected (Johnson & Christensen, 2012, in Hammarberg *et al*., 2016:499).

In addition, knowledge gained from this study was used to propose ways in which people living with CP and their families can be supported. This is in line with the work of Hammarberg *et al*. (2016:499), who state that clinical practice can be informed by knowledge gained from qualitative research methods. This suggests that such knowledge can be used to support people living with disabilities and can contribute to community learning and development. Besides being used as support, it can also assist in educating the families and communities that are affected by this phenomenon. Kim *et al*. (2017:1) explain that qualitative data are descriptive and produce comprehensive, descriptive summaries and accurate details of the data collected. These descriptive results are presented in a clear, concise and understandable manner.

1.8.2 Research methods

Research methods comprise a variety of techniques a researcher uses for data generation to answer the research question (Johnson & Christensen, 2012, in Hammarberg *et al*., 2016:499). These methods explain how the researcher selects the study population and how data will be collected

(Hammarberg *et al*., 2016:499). In this study, three types of methods were used, namely a literature review, document analysis and in-depth interviews.

1.8.2.1 Literature study and document analysis

The first phase of this study was a detailed and thorough review of the available and relevant literature. This was done to contextualise the study, grounding it in the most recent and relevant research that is pertinent to CP. Along with this, a document analysis of the relevant South African policies and legal acts was undertaken to ascertain the government's stance on disabilities, support and related topics. This provided a framework that is unique to South Africa and a comparative grounding for the study.

1.8.2.2 Semi-structured interviews

After the necessary background information was gathered, semi-structured interviews were conducted with the participants. These semi-structured interviews were a personal and unstructured formal or informal conversation that aimed to identify and explore a participant's emotions, feelings and opinions about a particular research subject (Langkos, 2014:38). This is in line with Rutledge and Hogg's (2020:1) argument that the purpose of semi-structured interviews is to obtain detailed information, and that this information is aimed at shedding light on an individual's perspective, experiences and feelings to derive meaning from the responses from the interview regarding a particular topic or issue. An advantage that arises from semi-structured interviews is that there is direct contact between the researcher and the participant during the personal interview, which allows the researcher to become involved with the participant and facilitates responses from the participant (Langkos, 2014:38).

1.8.3 Selection of participants

Purposeful selection of the participants was done, and purposive sampling was used to obtain suitable participants. According to Freedman *et al.* (2007, in Langkos, 2014:40), purposeful sampling is a non-probability technique; in other words, participants are selected based on their knowledge, relationships and expertise regarding a research subject. Ritchie and Lewis (2003, in Nieuwenhuis, 2019:93), state that the members of a survey sample are chosen specifically so that they are representative of a phenomenon, group, incident, location or type in relation to an important criterion.

1.8.3.1 Inclusion criteria

The sample that was selected met specific inclusion criteria. In determining these criteria, the researcher was guided by Diseko's (2017:19) inclusion criteria in her study of the experiences of caregivers caring for children with CP in Mahalapye, Botswana. As with Diseko's study, the current study stipulated that a parent should be the biological parent of a child living with CP. Any members of the extended family who take care of the person with CP (caregivers) would also be considered, although the primary caregiver must have had a familial connection with the child with CP. The second aspect that was considered was close community members, namely those who reside in the same locality. These participants were interviewed to provide a community perspective; however, they should also have had some affiliation with the family or the child with CP.

Other deciding inclusion criteria were that all participants must reside in the rural part of the Bojanala District and had to be able to sign a letter of informed consent as a way of agreeing to participate in the study. As the main source for obtaining participants was the Department of Health registry and as this study was conducted with the acknowledgment, knowledge and written consent of this department, all participants had to be on the Department of Health registry.

1.8.3.2 Exclusion criteria

Exclusion criteria are factors that disqualify potential participants from participating in a study. These individuals may meet the inclusion criteria but do not or cannot add informational value to the study. As Langkos (2014:40) notes, these additional characteristics can interfere with the success of the study, for instance by increasing the risk of an unfavourable outcome.

The exclusion criteria of the study were as follows:

- Participants and their families who are not on the Department of Health registry and do not live in the specified district, namely the rural part of the Bojanala District, even though they may have a child with CP.
- Any person who is not on the Department of Health registry, even though he or she may have a child with CP.
- Any person who is under the age of 18 years or is mentally incapacitated, as such a person represents a vulnerable population and needs extra care and consideration.

1.8.4 Qualitative data generation and analysis

For this study, data were generated by using semi-structured interviews. According to Clarke and Braun (2013:78), this type of interview is conducted to collect data by providing the participants with an opportunity to express their personal perspectives and opinions and enabling them to discuss issues that they feel are important. McMillan and Schumacher (2014:364) posit that data in qualitative research are analysed as they are collected, because the collection and analysis cycles are usually interactive and overlapping. This point is supported by Ngulube (2015:132), who states that one cannot always separate data analysis from data collection, as analysing sometimes occurs during data collection. In line with this, the data analysis in this study started as soon as the data were collected to avoid forgetting and missing out on emerging patterns that could be relevant.

To analyse the data, thematic analysis was done according to Clarke and Braun’s (2013:78) guidelines, as this method offers a clear and usable framework. Through this process, the researcher will be able to identify themes, that is, patterns in the data that are significant (Maguire & Delahunt, 2017:3353). These themes will “tell the story” of the phenomenon being researched as perceived by the participants (Maguire & Delahunt, 2017:3353). A good thematic analysis makes sense of the data collected and highlights the themes and interesting or important aspects.

1.9 TRUSTWORTHINESS OF THE DATA

The trustworthiness of qualitative research is an important aspect that makes the study credible and reliable. A researcher must ensure that the following issues are taken care of to ensure trustworthiness: credibility, transferability, dependability, confirmability and validity (Korstjens & Moser, 2018:121). All these aspects were considered in the study.

Credibility was ensured through prolonged engagement and triangulation. The researcher collected data from various family members of a person living with CP and other close community members by using triangulation (using more than one method to collect data on the same topic), and then compared the data with other, collateral information to be able to make sense of and derive meaning and draw conclusions from the data. The engagement with the participants was for a prolonged period of time to ensure a true reflection of the phenomenon under study.

Transferability was ensured by retaining all records of the research from beginning to end (see Korstjens & Moser, 2018:2). This was done to ensure that the study could be replicated if necessary.

Confirmability was ensured by basing all findings on the data and not on the personal bias or imagination of the researcher (see Korstjens & Moser, 2018:3). Korstjens and Moser (2018:3) explain that confirmability is about neutrality and the ability of the results to be confirmed or corroborated by others.

Validation was ensured by the researcher keeping all records, notes, minutes of meetings, interview transcriptions and any other information relating to the research process, as suggested by Korstjens and Moser (2018:2). This ensured the transparency and dependability of the study.

1.10 ETHICAL CONSIDERATIONS

According to Mouton (2008, in Babedi, 2013:13), ethical considerations or ethics are a widely accepted set of moral principles. These principles define the rules, correct conduct and behavioural expectations of a researcher towards participants and participants. Hence, research procedures should always be ethical, legal and reflect the integrity of the researcher (Tetzner, 2021:1). The researcher should, at all times, focus on active care of and respect for participants and ensure their confidentiality, which entails not discussing any aspect of the participants who are involved in the research without their written consent (Tetzner, 2021:1). In this study, confidentiality was ensured by not disclosing the identity of the participants but referring to them by using letters and numbers. Also, the participants were not forced or coerced into taking part in this research, and it was emphasised continuously that their participation was voluntary.

Before conducting this research, ethical clearance was obtained from the EMTEL Ethics Committee of the North-West University (NWU-01117-20-A2). The researcher also obtained permission from the head of the North-West Department of Health to conduct research in the Bojanala District, North West, on people who were afflicted with CP.

1.11 LIMITATIONS OF THE STUDY

Limitations foreseen in this study could include non-participation by individuals who were not affiliated with the Bojanala District of the North-West Department of Health. These individuals are those who do not use local health facilities and are unknown to the Department of Health. Furthermore, information and communication can be seen as a barrier, especially in the rural areas.

1.12 CONTRIBUTION OF THE STUDY

This study makes contributions on the following three levels:

- The study contributes to the theory, practice and policy formulation and implementation of support for people living with CP and their families in the Bojanala District of North West.
- The study informs the families of people living with CP and other role players on ways to include and support people with CP in different programmes in the Bojanala District of North West.

- This study educates communities and professionals on CP and informs them of ways through which they can assist in supporting those directly affected by CP in the Bojanala District of North West.

1.13 OUTLINE OF CHAPTERS

The proposed chapter layout for this study is as follows:

Chapter 1: Introduction and overview of the study

Chapter 2: Literature review and theoretical framework

Chapter 3: Document analysis

Chapter 4: Research paradigm, design, methodology and ethical considerations

Chapter 5: Data analysis and interpretation

Chapter 6: Findings, recommendations and conclusion

1.14 SUMMARY

Several studies (e.g., Conchar *et al*., 2016; Ngubane & Chetty, 2017; Pretorius & Steadman, 2017; Thuketana, 2018), have been conducted on CP in South Africa, but none in the rural parts of the Bojanala District, North West, where inclusive citizenship education is proposed to address challenges concerning this disability. Through this study, the researcher hopes to address the needs of families that include people living with CP in the Bojanala District through inclusive citizenship education. In Chapter 2, an in-depth literature review is done on CP.

CHAPTER 2 LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 INTRODUCTION

Twenty-five years after the advent of democracy, little, if any, improvement has been made in the way the South African government deals with people living with a disability; those living with CP are no different, as they have also been overlooked. Furthermore, the situation is no different in the rural parts of the Bojanala District, where, if anything, it seems to be worse. In this chapter, the literature on the conceptualisation of CP is reviewed. This review entails the definition, characteristics, types, causes, risk factors and classifications of CP. Furthermore, problems associated with CP and CP in the context of Africa and South Africa are discussed as well.

2.2 CONCEPTUALISATION OF CEREBRAL PALSY

According to the South African National Council for Persons with Physical Disabilities (in Ferreira, 2017:1), CP is the single largest cause of childhood disability. Since earlier times, “cerebral palsy” has been recognised and is still recognised as an umbrella concept (Donald *et al*., 2015:969; Mahendra *et al*., 2017:76). As mentioned earlier, CP is seen as an early static brain lesion with a motor disability at its core, presenting as a diverse condition with associated multiple potential disorders that can lead to medical complications (Donald *et al*., 2015:969; Mahendra *et al*., 2017:76). Mahendra *et al*. *(*2017:76) further posit that the term “cerebral” refers to the brain and “palsy” means a lack of control in muscle reactions. Problems associated with CP thus entail muscle weakness, shakiness, balance problems and slow responses, ranging from mild to severe. Shih *et al*. (2018:543) add that, even though CP is clearly observed in the musculoskeletal system, it involves damage to the central nervous system.

According to the *Cerebral Palsy Guide* (2019:1), the most common signs of CP are usually observable. These symptoms include spastic and involuntary movements and a general lack of coordination, combined with difficulties experienced with motor skills. Furthermore, as there are different levels of severity and types of movement problems, CP can manifest in various ways. As a result, people with CP experience different complications based on the location of their movement problems. Indications of CP are found in terms of the types of CP, along with neurological and secondary factors (*Cerebral Palsy Guide*, 2019:1). The *Cerebral Palsy Guide* (2019:5) states that a person with CP may have muscular and movement problems, including poor muscle tone. They also achieve their developmental milestones late, including crawling, walking and speaking, and common challenges experienced by people with CP include seizures, loss of hearing and impairment of eyesight, as well as poor control of bladder and bowel movements (*Cerebral Palsy Guide*, 2019).

Salie *et al.* (2022:4674) state that people with CP experience pain in their lower limbs and CP should be regarded as a life-long condition.

Figure 2-1 provides an overview of the conceptualisation of CP for Chapter 2, which is discussed in depth in the chapter.

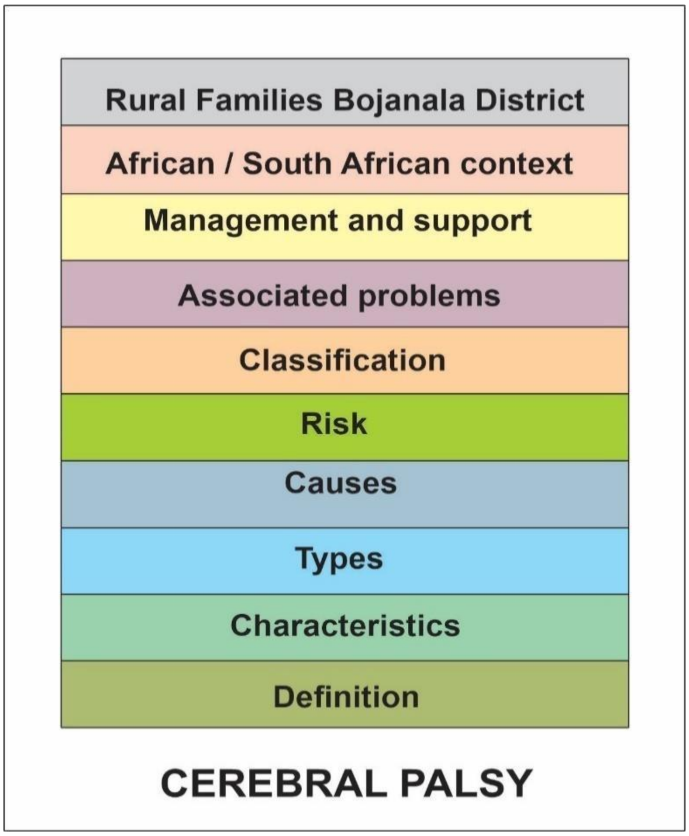


Figure 2-1: Placing CP in context: An overview.

2.2.1 Definition of cerebral palsy

Bax *et al*. (2005:571) posit that William Little was the first to describe CP as early as 1843, and since then, it has been defined slightly differently by different authors and researchers. According to Newman (2017), the term "cerebral palsy" is used to define and explain a group of neurological conditions that mostly affect movement. McLennan *et al*. (2019:472), on the other hand, posit that CP can be described as a nonprogressive disorder that results in permanent movement and posture afflictions. These afflictions can be attributed to disturbances that occurred in the developing brain of an infant (McLennan *et al*., 2019:472).

CP is the most common form of childhood disability and is caused by damage to the cerebrum before, during or within five years of birth (Newman, 2017). Mahendra *et al*. (2017:76) further define CP as a diverse, permanent neurological disorder caused by non-progressive damage to the developing brain. Three common characteristics of CP that are observable are body movement, posture disorders and static abnormalities, all resulting from a brain disorder acquired early in life (Mahendra *et al*., 2017:76). On the other hand, Bertule and Vetra (2020:1) suggest that CP is a disability that describes a collection of permanent disorders that limit activity and are observable in the development of movement and posture. This limitation is ascribed to non-progressive disruptions that occurred during the development of the foetal brain. Patel *et al*. (2018:125) view CP as a disorder that is characterised by abnormal tone, posture and movement. However, Patel *et al*. (2018:125) agree with Bertule and Vetra (2020:1) that, although the initial neuropathologic lesion is nonprogressive, many comorbid conditions may develop at a later stage, which will always be elements that affect the individual's functional abilities.

As mentioned earlier, Donald *et al*. (2015:965) state that the term "cerebral palsy" is often used in the African context to describe all syndromes that involve motor disability. Thus, one may argue that, while some authors define CP, others simply describe it. The different authors do not clarify the age at which CP develops, and one can argue that the foetal or infant's brain may have different meanings for different people. As a result, some children with CP may go undetected. However, Novak *et al*. (2017:897) suggest that, when one is unsure of a CP diagnosis, especially in young infants, a provisional clinical diagnosis of "high risk of CP" should be made. This interim diagnosis can then pave the way for preliminary interventions to be initiated. For the current study, Newman's (2017) more generally used definition provided above was adopted.

2.2.2 Characteristics of cerebral palsy

The characteristics of CP have been studied for a long time (Papavasiliou, 2009:387) and are still acknowledged to this day (Gunel *et al*., 2019:63). Children with CP have difficulty with various academic and social requirements, such as problem solving, communication and socialisation (Gunel *et al*., 2019:63; Papavasiliou, 2009:387). To compound this matter, further physical challenges are also evident, as children with CP usually also experience spasticity, dystonia, joint contracture, abnormal bone development, poor balance, a loss of selective motor control and a lack of strength (Gunel *et al*., 2019:63; Papavasiliou, 2009:387). According to Varni (2005, as cited by Gunel *et al*., 2019:63), health-related quality of life worsens with a decrease in children's motor functional level. This results in reduced quality of life, especially for children with quadriplegia compared to children with hemiplegia (Gunel *et al*., 2019:63).

This study focuses on rural parts of the Bojanala District, where access to health and other basic requirements of life, such as running water, remains a challenge. Therefore, the stated characteristics are already an indication of the possible challenges that may be faced by the parents and caregivers of children with CP.

2.2.3 Types of cerebral palsy

Newman (2017) posits that there are four types of CP, namely spastic, athetoid or dyskinetic, ataxic and hypotonic CP. CP patients are clinically subdivided according to the predominant motor disorder (Eggink *et al.*, 2017:704; Newman, 2017; Patel *et al*., 2018:125). The CP classifications are spastic hemiplegia, spastic diplegia, spastic quadriplegia and extrapyramidal or dyskinetic CP (Eggink *et al*., 2017:704; Newman, 2017; Patel *et al*. 2018:125). While Newman (2017) lists spastic hemiplegia, spastic diplegia and spastic quadriplegia as three types of spastic CP, Patel *et al.* (2018:125) view them as the main ones in that they are not subsections of the spastic CP.

2.2.3.1 Spastic cerebral palsy

According to the Cerebral Palsy Guide (2022:1), spastic CP is a developmental disorder caused by damage to the motor cortex and the pyramidal tracts of the brain. Spastic CP is characterised by an impairment of the coordination of goal-directed movement, resulting in gait and trunk disturbances, intention tremor and slurred speech (Rouberties *et al.,* 2002, in Eggink *et al*., 2017:705). The neurological explanation for this type of spastic CP brain is that distorted brain signals are sent that direct both opposing muscle sets to engage at the same time, which causes the opposing muscles to lock up and become rigid (Rouberties *et al.,* 2002, in Eggink *et al*., 2017:705). According to Jones *et al*. (2007:150), it has been acknowledged for a long time that spastic CP appears in approximately 70 to 80% of children who have been diagnosed with CP, and that it is the most common ailment. This argument is supported by Diseko (2017:22).

2.2.3.1.1 Spastic hemiplegia

Newman (2017) contends that a child with a spastic hemiplegia condition presents with spasticity or muscle stiffness on one side of the body, such as the hand and arm. Speech is usually affected, although intelligence may not be affected (Newman, 2017). Mahendra *et al*. (2017:77) approach this from a different angle and posit that the upper limbs are affected more severely than the lower limbs in this type of CP and that the impaired voluntary movements that are observed mostly affect hand functions. According to Gulati and Sondhi (2018:1008), behavioural problems are common among children with hemiplegic CP; these problems include anxiety, oppositional defiance and specific phobias.

2.2.3.1.2 Spastic diplegia

Newman (2017) describes that the lower limbs are affected in spastic diplegia, making the leg and hip muscles tight and the legs cross at the knees, resulting in walking being more difficult. Gulati and

Sondhi (2018:1008) agree with this description and add that the fine motor functions in the upper limbs in this type of CP usually are retained. The risk factors for spastic diplegia are associated with prematurity and low birth weights in infants (Mahendra *et al*., 2017:77).

2.2.3.1.3 Spastic quadriplegia

According to Mahendra *et al*. (2017:77), spastic quadriplegia is the most severe form of CP and affects all four limbs. The upper limbs are usually more affected than the lower ones. This description is supported by Newman (2017), who adds that the person's condition may involve cognitive deficits and that walking and talking are difficult and seizures may occur. Eyong *et al*. (2018:3248) found a number of comorbidities, such as epilepsy, microcephaly and speech and hearing impairments, to be common in children with spastic quadriplegia, compared to those presenting with athetoid and diplegia CP types.

2.2.3.2 Athetoid or dyskinetic cerebral palsy

Dyskinesia is a movement disorder in which involuntary or intermittent muscle contractions are caused, resulting in the individual twisting, presenting with abnormal postures or having repetitive movements (Eggink *et al*., 2017:704). Eggink *et al*. (2017:705) state that dystonic CP is the most common cause of childhood dystonia. Diseko (2017:22), on the other hand, contends that dyskinetic CP is a consequence of an abnormality in the group of brain cells that assist in movement coordination. According to Newman (2017), dyskinetic CP is the second most common type of CP. Intelligence, according to him, is usually normal, but muscle problems affect the whole body and cause random and uncontrolled body movement. Drooling may occur due to the inability to control facial muscles (Newman, 2017).

2.2.3.3 Ataxic cerebral palsy

Ataxic CP is caused by a defect of the cerebellum at the base of the brain (Diseko, 2017:23). According to Coombe (2017:28), ataxic CP is when there is a loss of coordination that affects the individual's force, accuracy and rhythm of movement. Gulati and Sondhi (2018:1009) posit that this type of CP is rare and usually improves with time.

2.2.3.4 Hypotonic cerebral palsy

Muscle problems appear earlier in hypotonic CP, with the infant's head and body flopping and with breathing difficulty often being experienced (Newman, 2017). According to the Cerebral Palsy Guide (2021:1), hypotonic CP is caused by damage to the cerebellum and is characterised by limp and droopy muscle tone, hyper-flexibility and poor stability. The instability of muscles can cause children to miss important developmental milestones, such as rolling over, sitting up, crawling and walking (Cerebral Palsy Guide, 2021:2).

While this study focuses on the impact of CP on the families of people with CP and those who have to contend with it, the different types of CP outlined above indicate that different families face different challenges, attitudes and perceptions. This happens because of the type and severity of the disability. These differences guided the intervention strategy that the researcher developed in this study, as it had to take cognisance of the different levels of CP and the effects they have on the families of people with CP.

2.2.4 Causes of cerebral palsy

The aetiology of CP differs in developed and developing countries, which can be due to changes in prenatal and paediatric care over the years (Aisen *et al*., 2011, in Lourens, 2016:13). Furthermore, Campbell *et al*. (2008, in Lourens, 2016:13) argue that most cases of CP in developed countries are linked to occurrences before labour. Prenatal genetic and environmental risk factors are linked to 70% of CP cases, and intrapartum asphyxia is linked to 10 to 20% of CP cases (Campbell *et al*., 2008, in Lourens, 2016:13). Abd Elmagid and Magdy (2021:2) posit that the aetiology of CP is multifactorial, heterogenous and characterised by an injury to the immature brain. According to Sondrum *et al.* (2005, in Lourens, 2016:13) and Hall (1996:82), a higher prevalence of post neonatally acquired CP cases is found in developing countries. Sondrum *et al.* (2005, in Lourens, 2016:13) believe that these cases can be attributed to central nervous system infections, birth asphyxia, hypoxia ischaemic encephalopathy and bilirubin toxicity.

According to Newman (2017), damage to the upper part of the human brain, called the “cerebrum”, before, during or within five years of birth can cause CP. This damage to the brain usually occurs before birth, during the first six months of pregnancy, and possible causes are periventricular leukomalacia, abnormal development of the brain or intracranial haemorrhage (Newman, 2017).

Periventricular leukomalacia is damage that affects the white matter of the brain because of a lack of oxygen in the womb (Newman, 2017). According to Newman (2017), this may occur when the mother has an infection during pregnancy or has low blood pressure. This notion is, however, contradicted by Honan *et al.* (2021:49), who posit that CP is caused by non-progressive damage to the developing brain before two years of age.

Newman (2017) further states that abnormal development of the brain can be caused by mutations in the genes responsible for brain development or infections and intracranial haemorrhage as a result of head trauma. Some newborn babies are deprived of oxygen during labour and delivery, which may also cause CP. Another factor that can be the cause of CP is bleeding in the brain that can stop the supply of blood to vital brain tissue, resulting in damaged tissue or the tissue dying off (Newman, 2017). However, research has shown that less than one in 10 cases of CP stems from oxygen deprivation during birth (Newman, 2017). Nevertheless, bleeding in the brain can also happen because of an infection, such as meningitis, or a head injury (Newman, 2017).

Fahey *et al*. (2017:462) contend that even though prematurity, hypoxia-ischemia, placental insufficiency and prenatal infection are well-documented causes of CP, the root cause of the condition remains unclear. For other patients, especially those born full term and without a clearly identifiable cause of the affliction, even by magnetic resonance imaging, the cause of CP remains a mystery. Mahendra *et al*. (2017:67) agree that the aetiology of CP remains unknown. According to Mahendra *et al*. (2017:67), other complications that are associated with this disability include low birth weight, asphyxia at or during the birth process, premature separation of the placenta and an abnormal foetal position. There are numerous risk factors for CP that are important. These risk factors are discussed below.

2.2.5 Risk factors pertaining to cerebral palsy

Some of the risk factors pertaining to CP include effects on the cerebrum, which is the part of the brain that is responsible for muscle control, memory and communication skills (Newman, 2017) Damage to this part of the brain can result in people with CP having difficulty with communication, learning, muscle control and, at times, vision and hearing (Newman, 2017). O'Shea *et al*. (2009:719) identified premature birth, especially before 28 weeks of gestation, as a leading risk factor in the development of CP. This is supported by Stavsky *et al*. (2017:3), who further posit that congenital malformation, foetal growth restriction, multiple gestations, infection during the foetal and neonatal period, birth asphyxia, perinatal stroke and untreated maternal hypothyroidism are all regarded as risk factors for CP. Abd Elmagid and Magdy (2021:1) agree that CP has various risk factors and add that many risk factors pertaining to CP are identified during the antenatal, natal and post-natal periods. These risk factors include multiple birth, intrauterine infection, preterm or perinatal strokes, birth asphyxia, perinatal infection, placenta pathology and congenital malformation (Abd Elmagid & Magdy, 2021:2). Although preterm delivery is a well-established risk factor, post-term pregnancy at 42 weeks or later is also associated with an increased risk for CP. This was argued more than 10 years ago by Master *et al*. (2010:976) and later supported by Stavsky *et al*. (2017:3).

Shih *et al*. (2018:543) point out that the precise aetiology of CP is still not clear. Among the risk factors are preterm birth, multiple pregnancy, intraamniotic infection, perinatal inflammation, low maternal thyroid hormone levels, perinatal asphyxia, placenta abnormalities, foetal growth retardation and neonatal hyperbilirubinemia (Shih *et al*., 2018:543). Patel *et al*. (2018:125) add prematurity, low birth weight and maternal infections to the list of risk factors for CP. Furthermore, they argue that intracerebral haemorrhage and periventricular leukomalacia are the main pathologic findings found in preterm infants who develop CP (Patel *et al*., 2018:125). Gladstone (2010, as cited in Eyong *et al.,* 2018:3246) points out that severe birth asphyxia, kernicterus and neonatal infections are common risk factors for CP in Africa, whereas most studies in the United States of America and Europe show low birth weight to be a major risk factor.

CP is classified on different levels, and this is done through different systems. These classifications are discussed below.

2.2.6 Classification systems for cerebral palsy

The classification of CP was done as early as the previous century (Bax *et al*., 2005:574) and is still continuing and being refined (Ogoke, 2018:22). Bax *et al*. (2005) and Ogoke (2018) agree that among the primary factors that have an influence on the clinical classification of an individual who has CP are the age of the child, the reliability of the medical history and the extent of diagnostic investigations. The four main classification systems for CP that have recently been discussed are set out below.

2.2.6.1 Gross Motor Function Classification System

A more objective classification system for CP, namely the Gross Motor Function Classification System (GMFCS), has recently been developed (Miller *et al*., 2017:7). This new classification system has five levels, which are based on the child's ability to move, the cause or set of causes, the manner of causation of a disease or condition regarding their motor ability. This classification means that a given word in relation to CP will mean the same thing to everyone. The five levels of the GMFCS, are categorised as follows (Miller *et al*., 2017:7-8):

- GMFCS I is when a child walks without major limitations but not completely normally.
- GMFCS II is when a child walks without any device or assistance but has problems keeping up with peers or on uneven ground or stairs.
- GMFCS III refers to the stage when a child requires a walker, a cane or crutches for most attempts at walking.
- GMFCS IV is when a child is mostly in a wheelchair but can use a walker for exercise or can walk a short distance with physical assistance.
- GMFCS V refers to when a child requires a wheelchair for all transport and is dependent on or requires full support.

In this classification, children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements (Miller *et al*., 2017:8). While these levels are based on sitting and walking, the interpretation thereof could have posed a serious challenge for the parents of children with CP in this study. Firstly, the child's movement may be limited by contextual factors, or secondly, the family may prefer to keep the child indoors for fear of negative perceptions by and attitudes from local community members. Assistive walking devices may not be readily available in the rural parts of the Bojanala District due to financial constraints and, as such, movement may be limited, not by choice but by conditions.

2.2.6.2 Manual Ability Classification System

The Manual Ability Classification System (MACS) is a simple, five-point ordinal system that is analogous and complementary to the GMFCS (Paulson & Vargus-Adams, 2017:4). The five levels of this classification are as follows (Paulson & Vargus-Adams, 2017:4-5):

- An individual in MACS I can handle objects easily but may face limitations with fine motor control.
- MACS II classification indicates a decreased level of performance when handling objects.
- An individual in MACS III handles objects slowly, often with limited success, and may require assistance or setup for activities.
- In MACS IV, there is a need for continuous support and assistance.
- An individual in MACS V does not handle daily objects but is able to participate minimally with simple movements.

2.2.6.3 Communication Function Classification System

The Communication Function Classification System (CFCS) has been used for quite some time to characterise the daily communication abilities of children with CP, and is still used for this purpose (Trabacca *et al*., 2016:459). According to Paulson and Vargus-Adams (2017:6), the CFCS assesses expressive and receptive information. Westby (2020:1) concurs, stating that the purpose of the CFCS is to classify the daily communication performance of an individual with CP, which is done by placing the individual on one of five levels. The characteristics of the levels of the CFCS are based on the performance of sender and receiver roles, the pace or speed at which the individual communicates and the type of conversational partner (Westby, 2020:1). According to Westby (2020:1), the overall effectiveness of the communication performance of an individual with CP should be based on how the individual takes part in everyday situations that require communication rather than the individual's best capacity.

2.2.6.4 Eating and Drinking Ability Classification System

The Eating and Drinking Ability Classification System (EDACS) classification assesses an individual's eating and drinking safety and efficiency, as well as the level of assistance required by the child when feeding (Paulson & Vargus-Adams, 2017:6). According to McAllister *et al.* (2022:1017), several aspects of eating and swallowing may be affected. Areas that are considered are the individual's time and effort that are required to swallow liquids or food. Furthermore, McAllister *et al.* (2022:1018) posit that adults with CP may experience gradual changes in swallowing and mealtime capabilities. These challenges are reflected in an individual's increased coughing and choking, digestive or gastroesophageal symptoms and progressive loss of independence, which can lead to compounded psychosocial consequences (McAllister *et al.*, 2022:1018). In adults with CP, these changes need to be monitored, and compliance with recommendations for safety and the optimal well-being of the individual must be ensured (Balandin *et al.,* 2009, in McAllister *et al.,* 2022:1018). While the EDACS was initially used with children, research has now proved that it is a reliable and valid tool for classifying eating and drinking ability in adults with CP as well (Hyun *et al.,* 2021:351).

Ogoke (2018:22) argues that, since children with CP often differ clinically, different classifications are possible. However, it is necessary that any classification that is used with an individual that has CP should be reliable, valid, quantitative and objective and should positively assist with the management of this disability (Ogoke, 2018:22). This means that the same child may be classified differently at different times, by different people and in different regions (Ogoke, 2018:22). This may be due to changes in external manifestations, variations in maternal data recall and differences in the availability and affordability of neuroimaging and metabolic studies (Ogoke, 2018:22).

Having considered the levels referred to above, it is the contention of this investigation that with this classification of CP, which depends very much on different conditions and resources, a challenge is posed for not only researchers but also medical practitioners in the rural parts of the Bojanala District, where poverty and access to resources remain a challenge. It is suggested that the focus, therefore, should not be on classification, but rather on CP as an overall condition. It can be argued that having to comprehend the disability and its effect may be overwhelming for families and close community members in many rural parts of the Bojanala District; thus, the more basic aspects will be of more importance, rather than the specific levels and classifications.

2.2.7 Associated problems

Research indicates that CP presents with cognitive, motor and sensory problems in a range of severity that may affect the continued survival of the child. These challenges have a serious negative influence on the lives of children with CP.

2.2.7.1 Cognitive problems

Stern (2020:1) submits that about 30 to 50% of children with CP present with some level of cognitive impairment, and that children with severe CP have a greater likelihood of experiencing cognitive impairment. Cognition is the ability a person has to deliberate and reflect by using information from the brain (Stern, 2020:1). Because CP causes damage to the brain, the centre that transmits accurate information from several sources can be impaired, resulting in cognitive impairment (Stern, 2020:1). This view is supported by Fluss and Lidzba (2020:1), who say that the cognitive abilities of children with CP are frequently affected, but this may not be recognised in children with mild forms of CP. Furthermore, many ambulatory children with mild forms of CP demonstrate learning disabilities and do not achieve much in terms of education (Fluss & Lidzba, 2020:1).

2.2.7.2 Sensory problems

Regarding sensory issues, Stern (2020:3) mentions that when a child’s brain is injured, it may lead to cognitive impairments, which can cause sensory misinformation, resulting in the child not understanding external sensory inputs, for example, what he or she hears and sees. This notion is supported by researchers in the Cerebral Palsy Guide (2019:3), who argue that, depending on the severity and extent of the brain injury, sensory information that is received may be affected, causing impairment in the child in processing the information received. Children may suffer from a condition referred to as “sensory processing disorder”, which may lead to their experiencing increased or decreased sensory reactions (Cerebral Palsy Guide, 2019:3).

2.2.7.3 Physiological problems

Bajraszewski (2008:7) states that physiological problems affecting people with CP include, but are not limited to, orthopaedic problems, gastro-oesophageal reflux, saliva control problems, bone disease and a higher frequency of undescended testes in boys. They add that, as far as orthopaedic problems are concerned, muscles with spasticity or stiffness may become shortened as children grow and develop, causing muscle or joint contractures (Bajraszewski, 2008:7). These problems occur most commonly at the ankle, knee, hip, elbow and wrist. Miller *et al*. (2017:3) posit that a child with CP may have epilepsy and limitations in vision, hearing, speech, feeding, swallowing and breathing. Children with CP can also experience orthopaedic problems that affect the spine, bones, joints, muscles or parts of the skeletal system (Miller *et al*., 2017:49). They may also have problems with nutrition, which can be seen when they have difficulty in chewing, swallowing or both (Miller *et al*., 2017:49).

2.2.7.4 Mental health problems

According to the World Health Organisation (as cited by Downs *et al*., 2018:30), mental health is a state of well-being. This implies that an individual must be aware of and realise his or her own abilities, should cope adequately with normal daily stress in his or her life and should be able to work productively, making a valuable contribution to the community (World Health Organisation, 2013, as cited by Downs *et al*., 2018:30). McMorris *et al.* (2021:1) posit that many younger generations with CP have a tendency towards other psychiatric disorders. Moreover, adults with CP are more likely than the general population to have a psychiatric diagnosis (McMorris *et al.*, 2021:1). This is in line with research by Downs *et al.* (2018:33) that discovered that it appears to be common that mental health symptoms and formally diagnosed mental health disorders are observed in people with CP. Furthermore, studies show that the prevalence of mental health symptoms is high in children with CP (Downs *et al.*, 2018:8).

The ways in which CP can be managed and those who are affected by it can be supported are discussed in the section that follows.

2.2.8 Management of and support for cerebral palsy

Newman (2017) points out that there is no cure for CP, but treatment may help manage symptoms and give rise to greater independence. People living with CP need a lot of individualised support to deal with their varied conditions. Honan *et al.* (2021:51) also argue that, as “cerebral palsy” is an umbrella term with multiple aetiological pathways, one should acknowledge that a singular cure for all CP is not achievable or realistic. Instead, one should consider different cures or treatments that may be required for the various underlying afflictions and injuries that result from CP.

Cantero *et al*. (2021:276) state that a multidisciplinary team approach is preferred to address challenges associated with children with CP, as the disability is complex. The members of the team range from medical professionals to social assistance and may include all childcare professionals and teachers, as well as the parents themselves. Keforilwe and Smith (2021:98) agree that a multidisciplinary approach is important – one that includes occupational therapy, as well as input from social workers. Cultural considerations need to be taken into account, which means that it is always advisable for clinicians to respect various aspects of the life world of the child or adult with

CP. Hence, it is important that before initiating any assessment or interventions with a child with CP, a holistic picture must be obtained, which includes the family dynamics and the child-rearing practices within the family (Abdullahi & Isah, 2020:7). Furthermore, community beliefs and social norms, standards and expectations are also important to gain an understanding of all the influences to which the child with CP and his or her family are subjected (Abdullahi & Isah, 2020:7). Only then can any assessment or interventions with the child be undertaken (Abdullahi & Isah, 2020:7).

The researcher is in full support of the argument of a multidisciplinary team approach and strongly believes that a lot still has to be done for the situation of children with CP and their families in the rural parts of the Bojanala District to improve and to be comparable with those of children with CP and their families in other parts of the world. Not only do physical and human resources in the field of health need to be provided, but also other basic resources, including appropriate schooling and proper transport that these families can utilise to access places that provide for their needs. Above all, inclusive citizenship education, which ultimately will bring about changes in attitudes and perceptions, is sure to bring about positive change and go a long way in educating, promoting understanding of and supporting these families and, in particular, the children with CP themselves.

Ngubane and Chetty (2017:35) contend that the multidisciplinary rehabilitation approach in the South African public domain can manage children with CP from primary care settings through to tertiary settings. Families, friends, organisations and communities, especially those that are knowledgeable about CP, can serve as a source of support. According to Al-Dababneh and Al-Zboon (2018:733), parents' general dispositions can be improved by the presence of a conducive environment, and this can lead to their being less overwhelmed by parenting tasks. Gupta and Singhal (2004:24) believe that this improvement can give parents more time to acquire extra resources from which to gain information and support.

However, this can be a challenge in developing countries, where support organisations often are few, if not non-existent. Families and communities may not be that supportive, as observed by Groce (1999, in Bunning *et al*., 2017:15). Cultural beliefs about the cause of disability may lead to various prejudicial attitudes, discriminating behaviour and stigmatisation within the family unit, as well as in the community. These negative attitudes are still very prevalent, as noted by Menlah *et al*. (2020:9), who mention that due to these negative attitudes, caregivers end up keeping their children with CP at home for fear of exclusion. Stress can be reduced by supportive social networks, which can serve as a buffer against threatening events (Menlah *et al*., 2020:9). This will have a positive influence on the coping strategies of parents and provide emotional support (Al-Dababneh & Al-Zboon, 2018:733) but can only be achieved if the negative perceptions and attitudes of families and community members are confronted and dealt with. To initiate this change, inclusive citizenship education can be used to educate, change and promote understanding within communities and individuals for the better.

Seligman and Darling (2007), and more recently Al-Dababneh and Al-Zboon (2018:734), argue that when considering the family systems theory, which states that the family is interactive, interdependent and reactive to change, it is clear that phenomena that influence an individual family member will most likely have an influence on other members of the family system as well. Thus, it can be argued that CP does not only affect the person living with the condition but also the family as a whole, including close community members. This is the case among Africans, including in the rural parts of the Bojanala District, where it is strongly believed that “it takes a village to raise a child”. According to Gupta and Singhal (2004, in Al-Dababneh & Al-Zboon, 2018:734), positive perceptions play an important role in the coping process and help people to deal with traumatic and stressful events. They strongly believe that positive perceptions not only benefit parents and siblings in coping with the child, the disability and the problems associated with it, but the entire family in its totality is also assisted (Gupta & Singhal, 2004, in Al-Dababneh & Al-Zboon, 2018:734).

Al-Dababneh and Al-Zboon (2018:744) state that family life can be affected by CP in different ways; hence, mental health professionals should be aware of and sensitive to the diversity of attitudes among all people involved in providing care to children with CP. If mental health professionals can understand the attitudes of parents towards CP, as well as the implications of having a child with CP, they will be more dynamic and active in modifying or changing the behaviour of the parents and, thereby, promoting the facilitation of early treatment and adaptive coping for the child and engaging in support efforts for the family (Al-Dababneh & Al-Zboon, 2018:744). According to various health and educational policies, education and health-promoting programmes must be implemented so that awareness is created in rural communities about various aspects of any disability (Pretorius & Steadman, 2017:427). Furthermore, Pretorius and Steadman (2017:427) believe that health education should address not only the cause of disability but also the associated misconceptions that exist, which often surround the disability. This is based on, among other things, the argument of Cooper (2002, as cited by Keforilwe & Smith, 2021:99) that discrimination against children with CP arises because of a lack of understanding and knowledge of its causes and implications, fear of difference, fear of contamination and cultural views on disability. Rohwerder (2018:3) posits that it is important for the family of a child with a disability to advocate on the child’s behalf by actively nurturing the child’s development and making sure the child is included in the community, and also to disseminate information, which can and should counter myths and superstitions about disability. According to Rohwerder (2018:3), interpersonal interventions that involve education and are aimed at challenging inaccurate stereotypes by providing information or contact encourage positive interaction between the public and individuals with disabilities.

Rohwerder (2018:4) further points out that community-based rehabilitation and information are important; for example, holding village or community gatherings to communicate messages on disabilities is a positive start. This must be done in a way that complements and aligns with local cultural values and activities. As such gatherings can promote understanding and gain support from community leaders; they have been suggested as potential strategies to reduce the stigma associated with disability in developing countries (Rohwerder, 2018:4). Smith (2018:3) contends that besides only acquiring services for children with CP, family therapy and individual therapy can be beneficial for both parents and extended family caretakers, especially therapy that highlights and focuses on the health of the children and their families. The parents of children with CP can also be encouraged to acquire more knowledge and resources in the form of support groups, which can be provided both online and in their local community (Smith, 2018:3). Members of the extended family are a common form of social support for the caregivers of people living with CP; therefore, such support can improve overall family functioning and emotional well-being after a diagnosis of CP (Smith, 2018:4).

Caring for a child with special needs can be an isolating experience; therefore, reaching out for support, whether this is from members of the extended family or community organisations, is essential (Smith, 2018:5). Katangwe (2020:353) is of the opinion that a CP register is needed in South Africa to enable an improved evaluation of current services being provided for children with CP. This register is intended to identify gaps in the provision of services. In the South African context, resources are constrained, as is evident in the lack of equipment and interventions, the shortage of suitably trained and experienced staff and the inequitable distribution of access to healthcare (Katangwe, 2020:353). With this knowledge, a CP register can be used to identify and provide measures to improve the quality of life of children with CP and their families.

Through this study, the researcher aims to ensure that the perceptions and beliefs of families and community members regarding people living with CP will be changed positively through inclusive citizenship education, specifically so that those living with CP, who are excluded based on their disability, will be included and accepted as full members of society. Moreover, people who are marginalised due to their disability should ultimately take their rightful place in society and even contribute positively to it through the necessary education and support.

There are different views regarding CP in Africa, as well as in the rural parts of the Bojanala District in North West. These views are covered in the section below.

2.2.9 Cerebral palsy in the context of Africa

Burton (2015:876) maintains that little has been published on CP in Africa or in the African context. This lack of published research has resulted in large gaps in our knowledge of CP aetiology across the continent (Burton, 2015:876). Thus, information on the risk factors and prevalence of CP, which are vital information in the development of prevention strategies, is lacking (Burton, 2015:876). From engaged involvement, the researcher acknowledges that in the rural context of many South African communities, knowledge of the most common comorbidities of CP is also deficient. This lack of knowledge results in the most essential basic support systems needed to manage people with disabilities and support their families being severely restricted, absent or simply non-existent. This situation is pertinently evident in the rural parts of the Bojanala District in North West.

According to Donald *et al*. (2015:965), "cerebral palsy" is a general term often used in African contexts to describe all motor disability syndromes. Kirsten Donald (as cited in Burton, 2015:876) of the Red Cross War Memorial Children's Hospital of the University of Cape Town, South Africa, states that it seems that birth asphyxia, kernicterus and central nervous system neonatal infections tend to be the major risk factors for CP in resource-poor African settings. Maharaj *et al.* (2021:1235) believe that this situation has been ameliorated by medical advances in South Africa that have resulted in the increased survival of premature infants. With this positive development, the risk of developing neurological manifestations, which increases the incidence of children diagnosed with CP, can be established at an early stage (Maharaj *et al.*, 2021:1235). Unfortunately, traditional and cultural beliefs still seem to have a paramount effect on African communities' perceptions of the causes of disabilities (Pretorius & Steadman, 2017:427).

Burton (2015:876) asserts that many causes of CP in Africa can be prevented if the correct and suitable maternal resources were available. However, staffing capacity and training are still inadequate in most African countries, which negatively influences disability care that is focused on support (Burton, 2015:876). To compound this situation, multidisciplinary services and equipment are typically lacking or outdated (Burton, 2015:876), which creates challenges for many individuals who have no other choice but to use these inadequate health systems. This notion is supported by Rhoda *et al.* (2018:1), who posit that a large proportion of South African children and adults with CP is assumed to have had exposure to factors that are potentially preventable. These factors include aspects such as premature birth, intrapartum-related events and congenital and postnatal infections (Rhoda *et al.*, 2018:1). From personal observation, the researcher feels that this is the case in the rural parts of the Bojanala District, as there are limited health facilities and, where they are accessible, the majority of these children and their families do not have the necessary human or physical resources to access these services.

In addition, Wegner and Rhoda (2015:1) posit that many African communities, due to their belief that disability is caused by evil spirits, often have negative attitudes towards people with disabilities, which may lead to rejection. Singogo *et al*. (2015, as cited in Pretorius & Steadman, 2017:425) agree with this notion and add that many Africans see disability as a punishment by God or believe that it is caused by being involved in witchcraft. Likewise, Akintola (2008:360) argues that these beliefs often lead to the stigmatisation of people with disabilities and their families by members of the community. The researcher's personal experience is that many South Africans, especially those living in rural areas, are afraid of people with disabilities. Fear of the unknown is the underlying factor that motivates them to avoid people with disabilities, as well as their families. This situation leads to such families being isolated and not getting the support they need. Bond (2017:3) states that organisations working with people with disabilities in low- and middle-income countries suggest that the stigma originating from the communities is often the root cause for discrimination, exclusion and the low status of individuals with a disability. Many role players who are involved with children or adults with CP and their families, who must contend with the disability daily, experience these negative reactions (Bond, 2017:3). Inguanzo (2017:7) agrees and adds that, in conjunction with poverty and other barriers, stigma and discrimination infringe on the rights of people with disabilities and put them at risk. According to Mostert (2016:9), a lack of understanding and awareness of the causes of disabilities and the characteristics that arise from these afflictions is a key factor in the stigma that is often experienced by people with disabilities in the African context. Mostert (2016:9) adds that the stigma attached to people with disabilities often arises because of the expectations regarding these individuals. It is often believed that people with disabilities are less able to contribute to the good of the family and the community and, consequently, they are perceived to be a burden (Mostert, 2016:9). Often, these low expectations about the potential abilities of people with disabilities negatively influence the situation, resulting in, for example, children with disabilities not attending school (Inguanzo, 2017:27).

A report by the United Nations International Children's Emergency Fund (2013:3) states that it is difficult to establish the incidence of CP in most developing countries, as data on CP are not captured in any population census or other survey that could provide the relevant information. South Africa, the North West Province and the Bojanala District also face this challenge; hence, the majority of individuals with CP that are not reported or recorded may not get the opportunity of being listened to and, ultimately, receiving the support that they need. From what has been reported, it appears that the incidence of CP is higher in boys than in girls (United Nations International Children's Emergency Fund, 2013:3).

African nations may be disadvantaged by low resource levels for years to come, but Burton (2015:877) emphasises that if communities can pool their minds and hearts, a difference can be made. As the researcher agrees with this statement, she explored the attitudes and perceptions of families and close community members, as well as the relevant South African policies and the legal stance of the government regarding CP. It is worth noting that, while South Africa has a CP prevalence of 10 out of every 1 000 live births (Donald *et al*., 2014:30), Du Toit (2019:9) argues that very few studies have evaluated the survival and mortality of patients with CP in developing countries. Thus, the higher prevalence of CP in South Africa strongly suggests that a large adult CP population group could be evident (Du Toit, 2019:9).

2.3 IMPACT OF CEREBRAL PALSY ON RURAL FAMILIES

Chiluba and Moyo (2017:1) assert that CP is a major cause of disability, and most survivors are left with residual disability. This disability usually leaves individuals dependent on their parents and caregivers for essential care (Chiluba & Moyo, 2017:1). According to *The World Health Report* of the World Health Organisation (2006:1), in the caregiving of individuals with CP, the capabilities of the parents or caregivers to provide for themselves – emotionally, physically, socially and financially – are seriously compromised. If the current study is to agree with this argument, then the opinions of families and caregivers of individuals with CP, as well as those of close community members, indeed must be heard, as the researcher strongly believes that a more informed intervention strategy for the support of all affected can be developed and implemented.

Ansari *et al*. (2016:17) argue that a child living with a neuro-developmental disability affects all the family members, with the mother's health and life being affected the most. This may be because most mothers have to do the household work and assist the child with activities of daily living, which leave the primary stress of caring for a child with CP with the mother (Ansari *et al*., 2016:17). Abdikadir *et al*. (2020:401) recently echoed this statement, emphasising that the birth and upbringing of a child with a disability result in severe psychosocial stress for the parents, especially the mother.

Shih *et al*. (2018:543) point out that CP is a lifelong condition that will have a profound impact on all the family members and affect other role players who are involved in the child's life. Furthermore, the mothers of children with CP have poorer mental and physical health outcomes than those of children with typical development (Bourke-Taylor *et al*., 2012:153). This is in line with what was discovered by Madzhie *et al.* (2022:5), namely that mothers who are raising children with CP are overtly and constantly stressed by various factors, most of which are a never-ending reality, for example, the condition of the child, which is of constant paramount importance. Moreover, financial constraints and the lack of social support and treatment, which should be available from other sources and people, all add to the stress factors (Madzhie *et al.*, 2022:5).

According to Masipa (2018:1), the democratically elected government of 1994 has made considerable strides to enhance the well-being of South African society and address the socioeconomic challenges of unemployment and poverty. However, even though many changes have been made, inequality persists in South Africa, and the Bojanala District is no different. This district is mostly rural, with limited access to resources and high levels of unemployment, leaving many families dependent on social grants from the government for their survival. This situation already gives an idea that in this area, people living with CP, as well as their families, are likely to be living under very difficult conditions. This problem is exacerbated by the various challenges and financial demands that are brought about by the condition of CP. Pretorius and Steadman (2017:427) posit that caring for children with CP can be demanding and time-consuming. Accordingly, caregivers of children with CP need to be constantly supported for them to have a positive impact on the lives of those who are truly marginalised (Pretorius & Steadman, 2017:427). Saleh and Almasm (2015, as cited in Pretorius & Steadman, 2017:414) submit that a significant amount of energy for the whole family is usually required for taking care of a child with CP over a long period of time. Because of the affected person's characteristics, a great number of services, which require coordination, are needed.

It has previously been argued that neuro-developmental disability in children has a significant influence on the family, including siblings, in terms of emotional, financial, educational and social issues (Ansari *et al*., 2016:19). This view is supported by Vadivelan *et al*. (2020:2), who add that children with CP are highly dependent on their caregivers, who are mostly mothers. Furthermore, stress and a substantial burden on the parents are a reality within low- and middle-income settings in rural families; hence, when a disabled child is added to this situation, these mothers are often overburdened with the care of the family and the special care of the disabled child (Vadivelan *et al*., 2020:2). These issues and earning a livelihood all add up, increasing the stress and compounding an already difficult situation for the parents (Vadivelan *et al*., 2020:2).

In the subsections below, the economic, psychological and social impact of CP on families is explored.

2.3.1 Economic impact

According to Leonard *et al*. (1992, as cited in Kamaralzaman *et al*., 2018:156), children who experience limitations in performing daily activities require two or three times more medical services than typical children. Healthcare needs lead to a high cost of caring for children with CP compared to children who develop typically, and the total cost often exceeds the family's restricted means (Kamaralzaman *et al*., 2018:156; Wang *et al*., 2008:223). This poses a serious challenge for the parents and caregivers of children in the rural parts of the Bojanala District. Most families in these parts of the North West Province are already faced with high rates of unemployment, and the financial aids that are provided by the government are not sufficient. Moreover, the health facilities in these areas are not easily accessible and require money and modified transport, which are not readily available, to be reached.

In research by Ngubane and Chetty (2017:37), it was found that the majority of caregivers of children with CP were unemployed, and the belief is that the daily care requirements of a child with CP limit them from looking for employment. In research by Pretorius and Steadman (2017:425), another challenge that was linked with caring for a child with CP was the financial burden. This issue was raised early in research on this phenomenon (see Bourke-Taylor *et al*., 2010:127), and eight years later, Pretorius and Steadman (2017:425) found that caregivers raised the issue of financial challenges, indicating that these challenges became evident primarily when they were unable to obtain employment due to the large amount of time required daily for caring for a child with CP. Heyman and Kidman (2008, as cited by Pretorius & Steadman, 2017:425) argue that many caregivers are unable to obtain employment, as the demands associated with caring for children with CP are overwhelming. The combined negative effect of their unemployment status and the heavy financial burden often results in caregivers being unable to provide necessities for their children. This argument is supported by Madzhie *et al.* (2022:4), who posit that most parents who raise children who suffer from CP encounter financial problems.

Caregivers also have a challenge regarding transportation (Pretorius & Steadman, 2017:428). Taking into account the poor quality of roads in rural areas and the fact that public transport is expensive and not equipped to accommodate the needs of people with CP, parents are often cut off from resources that are vital for their children (Pretorius & Steadman, 2017:428). This has a negative impact on their access to a variety of essential services, such as schools and clinics. Therefore, it is argued that financial support and the improvement of the accessibility of public transport are essential; consequently, by fitting vehicles with the necessary aids for individuals who use assistive devices, support can go a long way in helping children with CP and their parents to be able to acquire the necessary assistance (Pretorius & Steadman, 2017:428). In many cases, the disability grant that is obtained from the government is the only source of income for the family of a child with CP, which results in limited finances. The fact that many of these families are solely dependent on the government grant directly arises from the fact that, in most cases, the caregiver cannot engage in any form of employment due to the caregiving requirements and responsibilities associated with children with CP, which are time-consuming and intense. Thus, these families live in a perpetuated cycle of poverty due to the needs of children with CP (Pretorius & Steadman, 2017:427) – a cycle that is difficult to break.

2.3.2 Psychological impact

Yamaguchi *et al*. (2014:125) and Al-Dababneh and Al-Zboon (2018:731) argue that CP affects the psychological development of a child, and that children living with CP, when compared to those without CP, are likely to suffer more frequently from behavioural and emotional problems. According to Schulze (2020:1), this might be due to brain damage, as pathways and networks that help to regulate emotions may be disrupted. Plant and Sanders (2007, as cited in Al-Dababneh & Al-Zboon, 2018:732) state that these behavioural and emotional problems have an increased effect on parents' ability to undertake the numerous tasks of caregiving, and so, their burden is increased. Furthermore, Al-Dababneh and Al-Zboon (2018:731) point out that a negative attitude towards disability by the child's family not only affects the child directly but also adds to the existing stress levels of the family. These arguments require the researcher to look deeper into the perceptions and attitudes of close family members and community members who reside near those affected by CP and see how best they can be educated, informed and assisted to bring about positive change.

Taking care of a child with CP can be exhausting and stressful, as many of these children suffer from compounding problems, such as spastic paralysis, cognitive impairment, speech and visual impairments, chronic pain and gastrointestinal and feeding problems (Michael *et al*., 2019:158). These limitations can result in prerequisites for long-term care that far exceed the usual needs of typical children (Michael *et al*., 2019:159). Olawale *et al*. (2013:16-18) posit that the overdependence of children with CP induces a lot of stress in their caregivers. This stress is caused by and manifested in issues such as insufficient time for other chores and responsibilities and isolation from community activities because of time spent attending to the child at home (Gona *et al*., 2011:175; Olawale *et al*., 2013:16-18). This notion is in line with Nimbalkar *et al.* (2014, as cited in Madzhie *et al.*, 2022:5), who point out that various psychological problems, such as stress, anger, tiredness and frustration, can arise in parents who raise children with CP.

To further illustrate this situation, Michael *et al*. (2019:164) state that all the parents in their study reported physical problems, such as excessive fatigue and back and bodily pains, because of carrying their children who suffered from CP. They also reported negative emotions, such as sadness, anger and feelings of embarrassment for the child (Michael *et al*., 2019:164). This is in line with the findings of previous studies (e.g. Basaran *et al*., 2013:815-822), which stated that the health of parents taking care of children with CP was affected substantially. Recent studies, such as the one by Michael *et al*. (2019:166), are in agreement that taking care of a child with CP has a negative effect on the finances, health and comfort of the family and especially the mother. Mothers have also reported experiencing social isolation due to having a child with a disability (Michael *et al*., 2019:166). Social isolation may be a result of members of the extended family and community avoiding the family for fear or anxiety of being in close contact with an individual with CP. Fear of the unknown, which can also be exacerbated by stigma and cultural beliefs, can lead to families with children who suffer from CP being isolated and avoided even further.

Smith (2018:2) suggests that families who take the time to look after the family unit through effective communication, cooperation and making time for the family are more likely to flourish. This will obviously be a positive resource for a child with CP. As caring for a child with CP can sometimes put parents or caregivers at risk of experiencing physical and mental challenges of their own, great care must be taken to support the child with CP, along with the family unit (Smith, 2018:2). Thus, when parents experience an increase in symptoms of depression and anxiety, especially those who spend many hours per day providing care to children with CP (Smith, 2018:2), careful interventions and assistance should be available to ease this burden of care and provide some improvement in these people's lives. For improvement to be recorded in the lives of those living with CP and their families, the intervention strategies that this study proposes may be regarded as a viable option to address the psychological challenges that they face, as well as many of the practical and physical restrictions that so often manifest in their daily lives.

2.3.3 Social impact

Gulati and Sondhi (2018:1015) address aspects of the social impact that parents of a child with CP experience. Chronic grief, guilt, frustration, denial, resentment and embarrassment are often apparent in parents of a child with CP, and these emotions may become even more profound when the parents are confronted with the situation, which has an impact on their social situation (Gulati & Sondhi, 2018:1015). Hence, to manage the situation, information about their child's condition should be provided with honesty and sensitivity, especially when the information is initially divulged. Furthermore, support for these parents to cope with the situation should be imparted (Gulati & Sondhi, 2018:1015). The current research proposes a further step in the support of these individuals in the form of inclusive citizenship education, whereby support is given by informing a community.

According to Ngo *et al*. (2012, as cited by Zuurmond *et al*., 2018:2), disabled children and their families face multiple barriers, such as increased caregiving duties for all family members, which may prevent participation in economic and social activities by the adults. Therefore, access to information is vital for all individuals and communities concerned with children with CP in order to minimise and limit discriminatory exclusion from services, or even better, to totally eradicate it. Such actions will mitigate the vulnerabilities that are experienced by these people and promote understanding and socialisation.

Other limiting factors are cited by Whittingham *et al*. (2011:1557). They point out that heightened necessities, such as feeding, bathing, administering medication, providing physical therapy, exercising and assisting with mobility, that are carried out by caregivers in caring for the child with CP often lead to caregivers having restricted personal time to commit to social activities (Whittingham *et al*., 2011:1557). In more recent research, Pretorius and Steadman (2017:424) have found the same challenges and add that it is often difficult for caregivers to form new social relationships or maintain those that they formed before their child's diagnosis. The reason for this is that the parents of a child with CP often find that many of their former friends are unable to relate to their present situation (Pretorius & Steadman, 2017:424). According to Madzhie *et al.* (2022:4), another factor, namely the lack of acceptance of the child's condition by the parents, often prevents them from engaging in social events and activities. Due to this overcompensation by the parents, isolation and remoteness are often experienced, as the parents believe that they must closely and constantly monitor their children (Madzhie *et al.,* 2022:4). This situation is in line with the argument in this study, namely that the support given to caregivers of children living with CP needs to be intensified, and this situation becomes more chronic in rural areas, with mothers bearing the brunt of the seclusion.

Guillamón *et al*. (2013:1579), and more recently Pretorius and Steadman (2017:427) too, reveal that due to the varying degrees and intensity of the afflictions of the conditions of the disability, children with CP often require great involvement from their caregivers. This is because a child with CP usually has care needs and requirements that extend beyond those of other children of the same age who do not have a disability. According to Pretorius and Steadman (2017:427), a further challenge that is faced, is the lack of disability-friendly services such as schools and daycare centres, which remains a huge impediment. If such facilities could be provided, they could serve as valuable resources for caregivers by providing them with an opportunity to spend some time away from their demanding caring duties that often do not allow them their own time and space to socialise or seek employment.

Support from family members is seen by caregivers as one of the crucial factors that assist family members to adjust to their caregiving duties (Davis *et al*., 2010, as cited by Pretorius & Steadman, 2017:424). This type of support prevents caregivers from feeling overwhelmed when assistance with their children is required (Davis *et al*., 2010, as cited by Pretorius & Steadman, 2017:424). Pretorius and Steadman (2017:427) add that the social isolation that caregivers experience can be reduced by support from families, friends and the community, which can also provide them with a well-deserved break. Wang *et al.* (2020:6) posit that while family support is very important for the families of children with CP, and especially for the mothers in these families, friends are also an important source of support for families with regard to emotional stability, life satisfaction and grounding the family in a reality that is often lacking in families with children with CP. On the other hand, Smith (2018:3) points out that marital strain or even instability is often the result of having a child with a developmental disability. A situation often arises where one parent ends up over-focused on and over-involved with the child, causing feelings of resentment, as one parent feels that there is a lack of involvement from his or her partner (Smith, 2018:3).

According to Ngubane and Chetty (2017:37), in African cultures, there is a belief that CP is due to witchcraft or a curse on the family. Often, these myths and beliefs are held by caregivers and community members, creating further stress for families. These misplaced beliefs of people in the community put further strain on the parents and families of children with CP, deepening the community or society challenges of the family (Ngubane & Chetty, 2017:37). This, along with the caretaking requirements, which includes medication that is usually administered by the mother, isolates the mother. Zuurmond *et al*. (2016:46) concur and add that the mothers of children with disabilities are usually isolated due to disability-related stigma, which leads to their burden of care increasing and their need to access services and humanitarian programmes escalating. To compound this issue, within rural settings in South Africa, poor roads, long distances, few services and limited transport affect access to services, which magnifies the problem for children with disabilities (Zuurmond *et al*., 2018:6). Disabled children, who often need to be physically carried for long distances or for whom complex transport arrangements need to be made (Zuurmond *et al*., 2018:6), are then left unattended, vulnerable and forgotten because of these circumstances. Zuurmond *et al.* (2018:7) further explain that stigma limits not only caregivers' access to support from extended families or communities but also their access to both government and nongovernmental organisation services and humanitarian programmes. As social support is needed to take care of a disabled child, the child is often left unattended or with poor-quality care while the mother visits agencies to seek help; this too becomes a barrier for families to attain the help they need. Smith (2018:3) believes that the siblings of a child living with CP can experience challenges that result from having a sibling with special needs, as siblings may unintentionally be jealous of the amount of attention given to their disabled brother or sister, resulting in a change of dynamics within the family and a change of behaviour by the siblings. These changes may indicate trouble within the family unit and can include changes in eating or sleeping patterns, regression to younger behaviour, acting out, a lack of interest in activities they once enjoyed or mood swings by the other children in the family (Smith, 2018:4). Moreover, Smith (2018:1) believes that communication, cooperation and seeking outside support can all improve the effective operational activities of the family unit when there is a child who has CP in a family.

As CP is a sudden event, parents or caregivers of children with CP are forced to accept unforeseen responsibilities in the absence of any preparation (Chiluba & Moyo, 2017:2). Chiluba and Moyo (2017:2) support the view of Dowswell *et al*. (2006:293), who maintain that caring for such a child has other ramifications for parents and caregivers. Once a family has a disabled child, many future plans are shattered and need to be adjusted, present income-generating activities must be revised and a decrease in leisure time is often experienced by many of the family members (especially adult caregivers); furthermore, family members can also be susceptible to deteriorating health (Dowswell *et al*., 2006:293). These challenges, according to Smith (2018:2), will likely go beyond that the childhood of the person with CP, as CP lasts a lifetime and, therefore, the family's involvement in the life of an individual with CP will automatically last for a long time.

Limited opportunities and a lack of social support in the community further isolate disabled children and their families, leading to increased levels of stress and hardship and constant adjustment to life in general (Michael *et al*., 2019:163). Nimbalkar *et al*. (2014:3) agree with Michael *et al*. (2019:163) that parents and caregivers of people with CP have limited participation in social gatherings. According to Rohwerder (2018:2), discrimination due to stereotyping, prejudice and stigma contributes to the exclusion experienced by people with disabilities and their families in all aspects of their lives across the world. She explains that attitudes towards disabilities are not the same within countries, communities or even families (Rohwerder, 2018:2). People with disabilities who can participate in their community usually are reported to experience less stigma in comparison to those with more severe disabilities who are less active within the community (Rohwerder, 2018:2). Furthermore, Rohwerder (2018:2) states that socioeconomic status can affect the attitude towards disabilities. Thus, people with disabilities in rural areas may experience more harmful practices than those in urban areas, because people in urban areas are possibly more freely exposed to the causes of disabilities and, in general, have a better understanding of these afflictions, in particular CP (Rohwerder, 2018:2).

It is the observation of the researcher that the availability and accessibility of health facilities where information can be freely sought and received play a major role in supporting children with CP and their families. These services are often better equipped and more readily available in urban areas. Furthermore, schools in urban areas are more easily accessible, have better equipment and provide proper information to affected children and their families. The unavailability and inaccessibility of health clinics and applicable and appropriate schools in rural areas remain a challenge, which is often compounded by restricted and limited physical and human resources. The rural parts of the Bojanala District are no different. While some resources may take longer to be provided, it would be of much value to ensure that the intervention strategies proposed can be easily implemented. In this selected population and against this background, Bronfenbrenner's bio-ecological systems theory was utilised to explore CP in the rural Bojanala District of North West.

2.4 THEORETICAL FRAMEWORK

The theoretical framework that grounded this study was Bronfenbrenner's bio-ecological systems theory, which is discussed in detail in this section.

2.4.1 Bronfenbrenner’s bio-ecological systems theory

As stated earlier, in Section 1.6.2, the theoretical framework that guided this study was Bronfenbrenner’s bio-ecological systems model. Bronfenbrenner (1979) contends in this theory that a child’s development is influenced by the interaction between the child’s environment, which is made up of different layers, and the child’s innate qualities. The bio-ecological systems theory explains how human development is influenced by four different types of environmental systems, namely the microsystem, mesosystem, exosystem and macrosystem (Ettekal & Mahoney, 2017:240). Eriksson *et al*. (2018:420) note that Bronfenbrenner added an outer layer, namely chronosystems, at a later stage. By adding chronosystems, Bronfenbrenner (1986) wanted to consider changes over time, not only within the person but also in the environment in which the person functions. At the heart of this system is the child, who plays an active part in his or her own development (Fiss & Jeffries, 2020:2458) (see Figure 2-2).

The microsystem is the immediate environment in which the child lives and with which he or she interacts (Gonzales, 2020:17). This system includes the child’s personal characteristics – in this case CP – as well as immediate family members, such as parents and siblings, and extended family (Gonzales, 2020:17). The interaction between the child and the individuals within the microsystem mutually influence one another’s behaviour and interaction (Fiss & Jeffries, 2020:2459). For example, if the mother, who, in most cases, assumes the caregiver status, becomes overly protective of the child with CP and does not allow the child to play freely with other children for fear of him or her being hurt, the child may become afraid of exploring, and this may extend beyond the home to the school environment. This layer plays a crucial role in the child’s development, as the way the family interacts with him or her may lead to the realisation that he or she is not like other children.

The mesosystem, which follows the microsystem, describes the relationship between the child and his or her microsystem. It looks at how the child with CP interacts with his or her siblings and schoolmates who are not living with the disability. According to Gonzales (2020:17), the third layer, that is, the exosystem, describes the connections between two or more settings that indirectly affect the child either positively or negatively. For example, a mother’s work hours and demanding job may affect the child negatively, since the child may feel neglected if the mother spends a lot of time at work. The situation of an absent father, who might have left due to the strain of having a child with CP, can also affect the child negatively.

The macrosystem describes a wider sociocultural environment that can include socioeconomic status, ethnicity, wealth and poverty (Gonzales, 2020:17). According to Fiss and Jeffries (2020:2460), this layer also includes the culture and beliefs of the community in which the child lives. A child with CP who lives among community members who are prejudiced against disability may not be accepted and may feel isolated. The fifth layer, the chronosystem, refers to environmental experiences and life transitions throughout the life of the child with CP (Gonzales, 2020:17).

In order to study CP, one must look at not only the affected person and his or her immediate environment but also the interaction with the larger environment, as one's immediate family, community environment and societal landscape drive and direct one's development (Bronfenbrenner, 1977). Changes or conflicts in any layer will cause a ripple effect throughout the other layers. The bio-ecological systems model thus helped the researcher to identify and highlight strategic points of contact and interaction between the different ecological systems involving a person with CP. Bronfenbrenner's bio-ecological systems theory used for this study is portrayed in Figure 2-2.

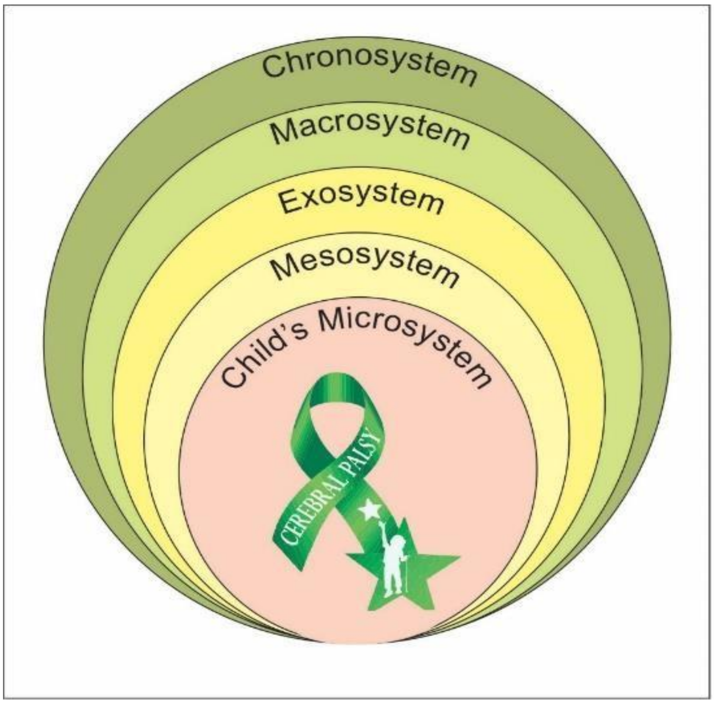


Figure 2-2: Bronfenbrenner's bio-ecological systems theory used for the study.

According to Betancourt *et al*. (2013, in Hapunda *et al*., 2017:6), research evidence shows that preventative or intervention strategies for childhood problems must be considered against the background or context in which a child lives. Furthermore, the interaction that a child has with other people and the influence of organisations, institutions and policies in the immediate and wider environment are all aspects that have either a direct or an indirect influence on the child (Betancourt *et al*., 2013, in Hapunda *et al*., 2017:6). As a result, it is useful to explore the bio-ecological systems model that can be utilised to understand the needs of people living with CP, their families and the environment. In considering this model, one can initiate support regarding these needs in the community and society in general. By using the theory as an underpinning theoretical framework (see Figure 2-2), the researcher approached the topic by looking through the lens of a systemic bioecological perspective. Thus, the researcher felt that Bronfenbrenner's theoretical framework would be a suitable theoretical base to improve knowledge of environmental and biological factors that contribute to the development and psychosocial well-being of people with CP (see Figure 2-2). However, after further consideration, the person-context-time model (Bronfenbrenner & Morris, 1998), was added as an additional guide for this study, as the process-person-context-time model includes the processes of human development over time (Bronfenbrenner & Morris, 1998) (See paragraph 1.6.2).

2.4.2 The further developments of Bronfenbrenner's bio-ecological systems theory

Eriksson *et al*. (2018:414) argue that Bronfenbrenner's theory underwent significant changes since its first inception in the late 1970s until he died in 2005. In 1994, Bronfenbrenner revised the theory and added that development was a product of four properties, namely the person, the process, context and time, as is depicted in Figure 2-3.

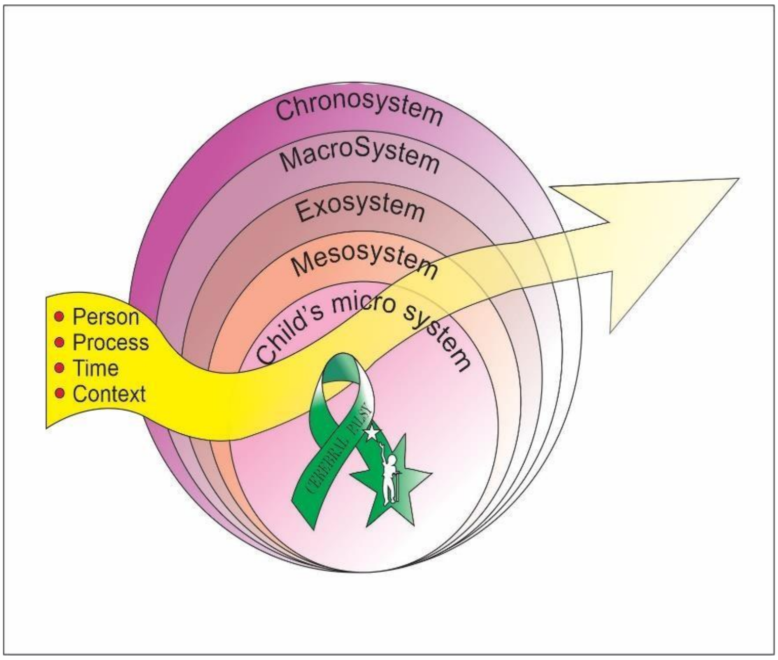


Figure 2-3: Four factors added to Bronfenbrenner's bio-ecological systems theory for the study (process-person-context-time model).

Bronfenbrenner (1994) argues that a child's development is influenced by the interaction between his or her environment and innate qualities, with added influences from these factors (see Figure 2-3). According to Ettekal and Mahoney (2017:243), the person factor refers to the characteristics of an individual, such as age, gender and competency, which interact with other settings, such as the environment, which ultimately influences development. Gonzales (2020:18) agrees with this idea and further states that this component includes other personal characteristics that the child brings into any social situation, such as intelligence, reasoning and friendliness; these are the factors that people immediately act upon when they interact with the child. In order for this study to achieve its intention, the families of people with CP, as well as close members of the community, need to be educated to understand the various characteristics that ultimately affect the development of a child. A child with CP is often judged immediately due to his or her physical appearance and challenges with speech.

The process factor includes all connections between the child and his or her immediate surroundings (Gonzales, 2020:18). These connections include influences that are responsible for the development of the child's abilities, capabilities, attitudes and general well-being (Gonzales, 2020:18). Furthermore, the process factor describes the regular mutual interaction between the child and his or her environment (Gonzales, 2020:18). For example, for an improvement to be recorded, a child with CP must continuously attend physiotherapy sessions. This may not be possible in the region where this research was conducted, as most families in the rural parts of the Bojanala District are unemployed, and the health facilities that are available are mostly found in urban areas; accessing them would be a challenge due to a lack of funds and a lack of proper transport for the child. Therefore, the process factor of this theory would be a notable challenge for the participants of this study.

Context, according to Gonzales (2020:18), refers to the five interconnected systems proposed by Bronfenbrenner, that is, the microsystem, mesosystem, exosystem, macrosystem and chronosystem. The development of a child with CP will be influenced by contextual factors. The time factor is concerned with the historic changes in society across generations (Ettekal & Mahoney, 2017:244). Addressing the negative attitudes of the families and communities in the rural parts of the Bojanala District towards people who live with CP through inclusive citizenship education can bring about an improvement over time. Neal and Neal (2013, in Thuketana, 2018:97) believe that the systems of the bio-ecological systems model are interconnected and that an important aspect to consider when using this theoretical framework is its holistic contribution to understanding the developing child at the centre of these systems.

2.4.3 Application of the theoretical framework for the study

When looking at this research, it is important to note the interactions between and within the macro-, meso-, exo- and microsystems. Bronfenbrenner (1977) developed his bio-ecological systems theory to understand human development, and this theory underwent a lot of changes in the last phase (1993 to 2006) with the process-person-context-time model being added. For the purpose of this study, Bronfenbrenner's bio-ecological systems theory was used as a macro-baseline theory, as family ecology (the eco-systemic approach) is believed to have a significant influence on child development. Thus, a child’s development is seen as resulting from the child’s genetic characteristics and interactions with his or her family and environment. Broderick (1993, as cited in Bertule & Vetra, 2020:1-2) supports this idea and regards the ecological theory of family systems and human development as affecting potential and present family needs. These needs are determined by the features and characteristics of every individual in the family and by the environment (Broderick, 1993, in Bertule & Vetra, 2020:1-2).

For the purpose of this study, individuals with CP and their parents, caregivers, siblings and friends are discussed by taking Bronfenbrenner’s bio-ecological systems theory into account and focusing on microsystems in particular. These subsystems are the primary systems within which all role players, including the child with CP, have intimate contact. According to Bronfenbrenner (1979), microsystems are the most influential systems that affect a child’s development. Furthermore, Bronfenbrenner (1994:40) sees the mesosystem as being the level that occurs between microsystems or, stated differently, in the matrix in which microsystems are evident. Therefore, in this study, the relationships between the home, school, family and friends (all microsystems) are discussed as structures within the mesosystem. It is important to note that what happens in one microsystem will influence what happens in other microsystems and in other systems on other levels.

The exosystem is seen by Bronfenbrenner (1994:40) as a system that includes a microsystem in which the individual is not directly embedded but still has an influence on the individual. For the purpose of this study, this section focuses on the community and the larger society. The macrosystem, according to Bronfenbrenner (1994:40), includes aspects of culture, belief systems, norms, values and bodies of knowledge – all of which are embedded in the broader systems. This study looks specifically at the cultural beliefs and traditions that tend to influence the acceptance or non-acceptance of children with CP in the rural parts of the Bojanala District, as well as human rights and the Constitution of the Republic of South Africa.

The fifth and final level of Bronfenbrenner’s bio-ecological systems theory is the chronosystem. This system highlights and covers all the functioning and experiences that an individual has during his or her lifetime (Bronfenbrenner, 1994:40). Thus, it includes everything from environmental events and major life transitions and changes to past events. Bronfenbrenner’s chronosystem suggests that this aspect cuts across all the systems (Neal & Neal, 2013, as cited by Thuketana, 2018:97). The chronosystem highlights that all the systems of this theory are interconnected and that an important aspect to consider when using this theoretical framework is its holistic contribution to understanding the developing child at the centre of this system. The chronosystem involves change over time; for example, regarding the child with CP, it involves his or her age and the constantly changing socioeconomic structure of the family, as well as environmental and social issues.

2.4.4 Linking the levels within the bio-ecological systems theory to the child with cerebral palsy

The microsystem within Bronfenbrenner's theory refers to the settings in which individuals interact directly (Ettekal & Mahoney, 2017:240). The mesosystem, on the other hand, involves processes that occur between the multiple microsystems in which individuals are entrenched. The exosystem includes the microsystem in which individuals are involved but not directly involved (Ettekal & Mahoney, 2017:242), and the macrosystem encompasses customs and laws, cultures, belief systems, ideologies, resources and economic and political systems in a developing child's life (Bronfenbrenner, 1979). To enhance the reader's understanding, these systems are linked to this study by placing the child with CP within this theoretical framework.

2.4.4.1 Microsystem

The microsystem is the immediate environment in which the child with CP lives, functions and interacts. Within this microcosm, the parents are usually the hardest hit by the diagnosis of CP (Liversedge, 2018:2). Having a child with CP can be met by different perceptions and attitudes (Menlah *et al*., 2020:2). The care process of children with CP is usually stressful and difficult, and in most cases, caregivers are unprepared to take care of such children (Olawale *et al*., 2013, in Menlah *et al*., 2020:2). This care process is, however, embedded in the microsystem of the child. Menlah *et al*. (2020:2) argue that constantly being exposed to the stressful daily routine of caring for a child with CP (the child's microsystem) can have adverse consequences for the caregivers' mental health. Furthermore, according to Nurullah (2013, in Menlah *et al*., 2020:3), the complexity of the disability often makes acceptance of the child very difficult, resulting in common reactions such as denial, anger, shame, guilt and other negative emotions that linger and worsen due to social stigma and misconceptions. Given these intense emotional reactions, it can be understood that in having to deal with everything within this microsystem, many challenges can occur. Therefore, caregivers and parents who are stressed and often take time to accept and embrace their children with CP are usually encapsulated in this microcosm.

In the microcosm of children with CP, they are usually totally dependent on their parents or caregivers, and if this is not embraced, it may limit them from reaching their full potential (Liversedge, 2018:2). Furthermore, challenges that may be encountered range from the hindrance of the child's development due to silent rejection by the parents to excessive physical challenges, all stemming from the immediate environment of the child. Thus, in this microsystem, CP affects not only the parents of the child but also other people, such as siblings, extended family and friends (Liversedge, 2018:2). Liversedge (2018:2) contends that a child with CP naturally will take up a lot of the parents' time, leaving the other siblings feeling as though they are missing out on a lot of attention. They may feel left out and neglected, causing some resentment of the child with CP if the situation is not handled properly (Liversedge, 2018:2).

If the parents and siblings of a child with CP can be educated and supported, they can ultimately view the child positively (Burtner *et al*., 2014:265). Hence, the sooner support is given, the sooner the child will feel warmth and acceptance and be able to open up to the environment. According to Burtner *et al*. (2014:265) and Thuketana (2018:105), participating with other children and siblings without disabilities allows children with CP an opportunity for modelled play activities. This also shows that if support can be given, positive interaction by siblings with the child with CP can yield a positive result (Thuketana, 2018:105). Therefore, it is noted that a strong support system can allow families to focus more specifically on meeting the needs of their children, and this positive support may affect the support for these children, all of which occur within the microsystem of the child with CP.

2.4.4.2 Mesosystem

Bronfenbrenner (1994:40) states that processes occur between the different microsystems of the individual, which usually are evident in the mesosystem. In this matrix, what happens at school can influence what happens at home (Thuketana, 2018:105). This implies that the teacher, as a distant role player, can upset an already unstable social circle within the child's immediate family, as these are levels that collide in the mesosystem (Thuketana, 2018:105). It is with this in mind that parents play a vital role in ensuring that the support the child gets at school facilitates the breach in the gap between home and school. A child with CP who sees a parent relating well to a teacher at school will adapt easily to this foreign environment (Thuketana, 2018:105). Also, a teacher who shows interest in the child and his or her family background will enhance the child's adjustment and development, as such a teacher provides safety and support for the child with CP (Thuketana, 2018:105). It is, therefore, in this mesosystem that relationships and interactions are perceived as good (positive) or bad (negative) in relation to children with CP, as the mesosystem provides the fluid matrix for the interaction of microsystems.

2.4.4.3 Exosystem

The third layer of the bio-ecological systems model in which the child is not an active participant but is influenced by processes in the system is the exosystem (Bronfenbrenner, 1979). This system embraces social structures such as health centres, churches and parents' workplaces. It is regrettable that a large number of people living in the rural parts of the Bojanala District must commute to nearby towns for work. Because of commuting and the type of work that the majority of these people do, they do not have time to take care of their children with CP. This is the reason why the majority of them end up leaving work in order to take care of their children. Parents' workplaces should be able to recognise the plight of people whose children have CP and offer constant support by allowing special leave days for such parents to take their children for therapy and other interventions. For the child to be accepted and supported and ultimately thrive in terms of his or her milestones, public enlightenment is needed to address these challenges.

2.4.4.4 Macrosystem

As indicated earlier, Bronfenbrenner (1994:40) contends that aspects of culture, belief systems, norms, values and bodies of knowledge are embedded in the macrosystem. To link this study to the theoretical aspects, cultural beliefs and traditions that tend to influence the acceptance or nonacceptance of children with CP in the rural parts of the Bojanala District are illuminated. As the Bojanala District is mostly rural, with the majority of people being unemployed and living below the poverty line (Statistics South Africa, 2015), it is unfortunate that the majority of children with CP are not given an opportunity to attend school. Of the 601 schools in the area, only 14 are special schools, and 70 are full-service schools. These full-service schools do not have the proper resources, and their infrastructure, in most cases, has not been adapted to cater for children with disabilities, including CP. Moreover, the majority of these schools are not located within reach of families with children with CP. While the *Constitution of the Republic of South Africa* (1996) protects the rights of all people, including those with disabilities, this study highlights the challenges faced by families with children with CP in the Bojanala District that lead to them keeping their children at home, which is an infringement on their human rights.

Thuketana (2018:114) states that cultural attitudes that establish a correlation between disabilities and witchcraft are rife in the rural areas of South Africa, with these perceptions affecting how children with disabilities are treated. The Bojanala District is no different. Furthermore, cultural beliefs are deeply rooted in the rural areas, which contribute to the exclusion of these children and have an impact on their opportunities for social participation in mainstream schools (Thuketana, 2018:115) – all of which are evident in this district. The exclusion from school will, of course, extend to other areas in which a child would have been socially active and participated, for example the sports field. This exclusion is confirmed by Madi *et al*. (2019:7), who state that mothers are commonly blamed for their children's disabilities, and secondly, mothers often speak of community attitudes that lead them to feel blamed, shamed and stigmatised or experience overt discrimination and rejection. In situations like these, the family and the child living with CP often end up being isolated.

2.4.4.5 Chronosystem

The chronosystem refers to the change of time or change in consistencies over time (Bronfenbrenner, 1994:40). This includes, but is not limited to, individual characteristics and socioeconomic structures. Brenner and Roebroeck (2018:1) note that the adults in their study, who were parents and caretakers of children with CP, indicated a deterioration in health problems, functional level and work intensity over the years, as they had to take care of their children. This deterioration often entailed the mobility aspects of the child with CP.

With age, parents or caregivers may find it difficult to carry a person with CP around because of his or her increase in weight as he or she becomes older. This progressive situation often results in parents and caretakers being forced to stay home for caregiving, as they cannot move the child, and thus experience a loss of income (Brenner & Roebroeck, 2018:1). Consequently, children with CP may end up not receiving health and educational interventions because their parents cannot afford transport to take them to these. Social isolation, exclusion, stress and depression can be experienced by all the role players, as they feel trapped, with no assistance.

2.5 SUMMARY

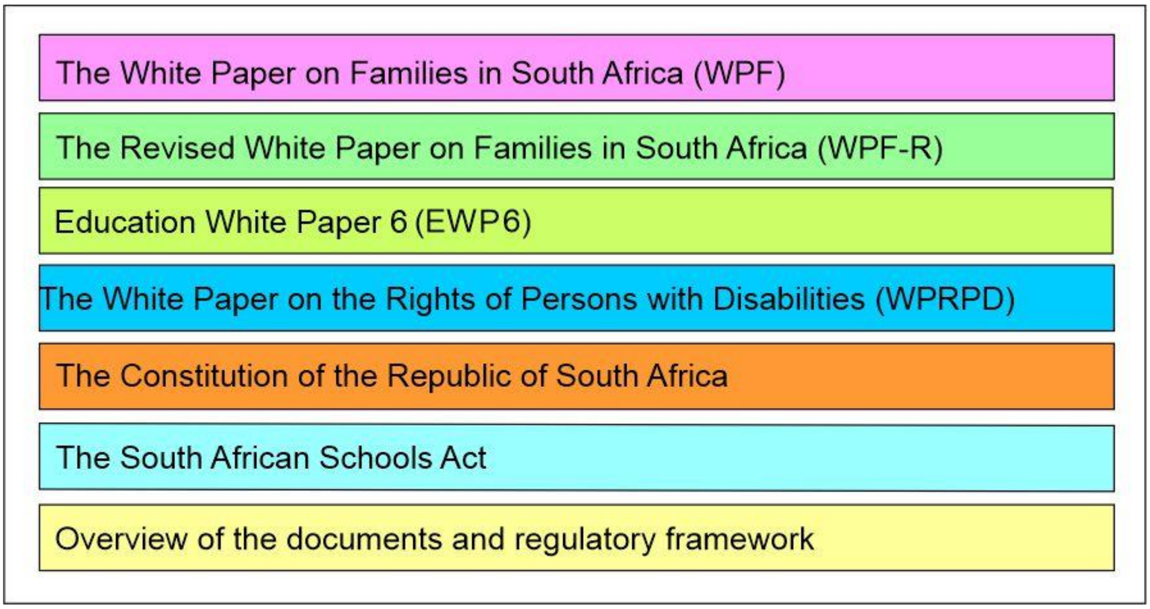
The literature regarding CP, the classification of CP and the impact the condition has on individuals, their families and close community members were reviewed in this chapter. The theoretical framework that grounded this study was also examined and linked to the situation that was evident in the Bojanala District of North West. It is evident from the literature review that CP in Africa and South Africa, and especially in the rural parts of the Bojanala District, has not been explored thoroughly and that there are still many misconceptions regarding the condition. In the next chapter, document analysis is undertaken of how CP is viewed in the South African context.

CHAPTER 3 ANALYSIS OF SOUTH AFRICAN POLICY DOCUMENTS: A LEGISLATIVE OVERVIEW

3.1 INTRODUCTION

Document analysis is a systematic procedure to review or evaluate documents in both printed and electronic form (Bowen, 2009:27). As documents provide background and context, they open avenues for researchers to ask additional questions and provide supplementary data (Bowen, 2009:27). Furthermore, document analysis is a measure through which change and development are tracked, and it can also be utilised for the endorsement of findings from other data derivations (Bowen, 2009:27). Moreover, when events can no longer be detected, documents can be the most productive measure of collecting data (Bowen, 2009:30-31). In short, document analysis is a research technique that enables researchers to revise, qualify and reproduce information. The Sage Encyclopaedia of Educational Research, Measurement and Evaluation (Sage, 2018:1) further defines document analysis as a qualitative systematic research procedure that analyses documentary evidence in order to answer specific questions. It can also be conducted as a standalone or unique study or as a component of a larger qualitative study. In light of this investigation, document analysis was utilised in conjunction with a larger qualitative research initiative, whereby interviews were conducted with people who live or are close to individuals with CP.

In this chapter, the analysis of specific documents is presented, and a regulatory framework is discussed. Figure 3-1 provides an overview of the documents that were analysed in the study.



The White Paper on Families in South Africa (WPF)
The Revised White Paper on Families in South Africa (WPF-R)
Education White Paper 6 (EWP6)
The White Paper on the Rights of Persons with Disabilities (WPRPD)
The Constitution of the Republic of South Africa
The South African Schools Act
Overview of the documents and regulatory framework

Figure 3-1: Documents and regulatory framework for Chapter 3: An overview.

3.2 WHITE PAPER ON FAMILIES IN SOUTH AFRICA

According to Macleod *et al*. (2019:1), the *White Paper on Families in South Africa*, henceforth referred to as "WPF", is the policy document that aims to facilitate family mainstreaming into all government policymaking, from the lowest municipal level, across multiple departments, to the highest national level. This White Paper was developed by the Department of Social Development in 2013. According to concerns and criticisms raised by different academics and researchers regarding the WPF (see Patel *et al*., 2018:4), the policy was revised by the Department of Social Development (2021:7). This was done through a consultative process that included stakeholders from various organisations and levels. Since these engagements were planned to take place during a period when the country was engulfed in the Covid-19 pandemic, engagements took place virtually (Department of Social Development, 2021:7). The revised WPF (WPF-R) updated its principles regarding the rights of citizenship, family divergence and resilience, community involvement, the strengthening of marriages and other partnerships, while certain aspects, such as the strengthening of responsible parenting and caregiving, as well as strategic partnerships, remain (Department of Social Development, 2021:9-10).

As was stated by the Chief Director of Families of the Department of Social Development during a round-table discussion, the vision of the WPF is that of well-functioning families that are loving, peaceful, safe, stable and economically self-sustaining (Patel *et al*., 2018:5). These families should also provide care and physical, emotional, psychological, financial, spiritual and intellectual support to their members (Patel *et al*., 2018:5). One could argue that if this vision could be realised, the situation in which people living with CP find themselves would be warm and embracing and would produce individuals who are emotionally and psychologically grounded. The following section provides the background and development process of the policy, its contents, coordination and implementation, as well as the monitoring thereof. Issues highlighted in the WPF-R will also be looked into.

3.2.1 Background of the *White Paper on Families* and the development thereof

South Africa, as a country, went through various developmental and reform stages, for example colonisation, apartheid, migrant labour and segregation based on homelands that were informed by people's languages and ethnicity (Khunou, 2009:82). Migrant labour practices led to men, who in most cases had families to take care of, leaving their families for months at a time to work far away in urban areas to try to make ends meet (Mazibuko, 2000:2). Apartheid, with its laws of separating people according to race and colour, resulted in some people living in urban areas, which were regarded as having better opportunities and others in rural areas. These developmental and reform stages led to situations in which some members of a family lived in the rural parts, while the rest of the family members were in cities and urban areas for a “better life” (Department of Social Development, 2013:7, 2021:4). The district of Bojanala is no exception. Here, while some family members resided in the bigger towns or cities in other parts of South Africa, the women and children were left behind. Harvey (1994:29) argues that, due to this segregation, South Africa ended up with a “dualistic family policy” with a disparity between families; white, Africans, coloureds and Indians, with whites getting a ‘better’ treatment as compared to other groups. (Department of Social Development, 2013:7).

The South African Cabinet approved the Green Paper on Families in September 2011; this document aimed to promote family life and strengthen families in South Africa, and the approval came after the Green Paper was evaluated during consultations with stakeholders in all nine provinces from February to March 2012 (Berry, 2012:3; Patel *et al*., 2018:6). The Green Paper gave birth to the WPF, which was approved by the Cabinet in 2013 (Department of Social Development, 2013:8). At a meeting of committee members of the Social Development Portfolio on the WPF, the then deputy minister, Bogopane-Zulu, indicated that one of the reasons the document remained a White Paper was to keep it alive; she believed that, once it became legislation, there would be challenges and delays when there was a need for it to be amended (Department of Social Development, 2013:8). Since there was no distinct policy for families, which was needed to build one nation and social cohesion in South Africa, this led to the development of a draft National Policy Framework for Families, which was developed by the Department of Social Development in 2001 (Department of Social Development, 2013:7, 2021:6). The final draft of this policy was issued in 2005, “with goals that include the protection and support of families through effective and efficient service delivery; the creation of an enabling environment geared towards the self-reliance of families; and the promotion of inter-sectoral collaboration among stakeholders in the provision of services” (Department of Social Development, 2013:7).

The rationale for the development of the WPF was multifaceted, as services to families were provided by different government departments and non-governmental organisations (Department of Social Development, 2013:7). Furthermore, the WPF was developed through a consultative process (Berry, 2012:3; Department of Social Development, 2013:7). Patel *et al*. (2018:6) note that while several social policies related to family life were evident, the focus was mainly on individual members, rather than the promotion of the family as a unit. This, they argue, resulted in a reduced effect and fewer opportunities to make positive changes to different facets of people’s lives (Patel *et al*., 2018:6).

3.2.2 Content of the *White Paper on Families* and the *White Paper on Families – Revised*

The WPF is divided into five sections. The first section describes the background and how the policy was developed; it also looks at the vision, mission and objectives of the policy. The WPF-R, on the other hand, has four sections, with the fifth being part of the annexures. The vision of this policy is to have well-functioning families that are loving, peaceful, safe, stable and economically self-sustaining and provide care and physical, emotional, psychological, financial and intellectual support for their members (Department of Social Development, 2013:9). The policy further states that its mission is to undertake activities, programmes and projects that will promote, assist, support and nourish well-functioning families. This will encourage families to be loving, peaceful, safe, stable and economically self-sustaining, which would, in turn, create an atmosphere that will provide care and physical, emotional, psychological, financial, spiritual and intellectual support for their members (Department of Social Development, 2013:9).

The objectives of the WPF (Department of Social Development, 2013:9) were, firstly, to enhance the socialising, caring, nurturing and supporting capabilities of families, in order for South African family members to contribute effectively to the development of South Africa. Secondly, families were empowered in that their members were enabled to recognise, negotiate and maximise a profitable labour market and other opportunities available to individuals in the country. The third and last aim was to improve the capacities of families by enhancing and establishing social interactions that make a meaningful contribution to a sense of community, social cohesion and national solidarity. Many of these objectives did not change in the revised version.

While the vision and mission of the revised WPF-R are like those of the WPF, they also highlight and emphasise some of the values of those that are regarded as “proper” families. According to the Department of Social Development (2021:8), the vision of this policy is “to promote safe, supportive, nurturing, and resilient families as a core unit of society”. This vision clearly emphasises supportive, nurturing and resilient families, which values were not included in the earlier vision. The mission of the revised WPF-R is “to foster a policy approach and collaborative efforts to promote family wellbeing, and strengthen and support families so that they are empowered to provide physical, emotional, psychological, financial, spiritual, and intellectual support and care for their members” (Department of Social Development, 2021:8). This is a more refined and clearly stated mission, which highlights the collaborative nature of this policy.

The second section of both versions of the WPF focuses on the family. In this section, different definitions are provided regarding types of families, as well as the different types of families found in South Africa. In general, the third section of the WPF and the WPF-R looks at the current legislative and policy framework, although this section forms part of the annexures in the WPR-R, as already mentioned. Both versions of this policy are guided by three key strategic priorities, namely the promotion of healthy family life, family strengthening and family preservation, which are referred to as “treatment and support for vulnerable families” (Department of Social Development, 2013:39-43, 2021:21). These key strategic priorities are covered in the fourth section of the WPF and in the third section of the WPF-R.

The first key priority of the WPF is the promotion of healthy family life. This priority focuses on the promotion of positive attitudes and values. Multiple requisites of families to function well are acknowledged (Department of Social Development, 2021:26). This strategy encourages collaboration with the Department of Health in ensuring accessibility to decent healthcare facilities by all families and ensuring that families with members who are at risk – in this study those with CP – know what services are for them and how to access them (Department of Social Development, 2021:26). According to the Department of Social Development (2021:26), this strategy also encourages collaboration with the Department of Education in ensuring that school-aged children can be sent to safe and secure schools. Furthermore, the policy emphasises empowering families in terms of their rights and the available services to fulfil their roles and responsibilities (Department of Social Development, 2021:27). The Department of Social Development (2021:26) and its WPF are key to ensuring that the families of people living with CP are supported and strengthened by informing them about the available support and services that can make their lives and those of people with CP easier and better.

The second key priority of the WPF is the strengthening of families, focusing on family economic success and family support systems. This involves the building of adequate systems of support, such as health care, childcare, education and other essential components of strong families (Department of Social Development, 2013:38). The second priority also looks at empowering families who are caring for vulnerable adults, such as those with disabilities, with knowledge about expectations and information on available support systems (Department of Social Development, 2021:29). Family strengthening also deals with the thriving and nurturing of communities, which emphasise the building of a nurturing and supportive environment (Department of Social Development, 2013:38).

The third key priority is family preservation, which focuses on keeping families together and developing programmes that can assist them to ensure that they are kept together. The WPF and WPF-R are both basically aimed at bringing back a sense of community. These policies emphasise the need to go back to the core family principles and the belief that a family that prays together, stays together.

The fifth section of the WPF and the fourth section of the WPF-R, as well as the last sections of these documents, consider the coordination, implementation and monitoring structures proposed by the policy documents. From the drafting of the WPF, the proposal was that its implementation required an intersectoral and interdepartmental system and mechanism for it to be realised, and that this would be managed by formalised interdepartmental mechanisms at a national, provincial and municipal level (Department of Social Development, 2013:44). This intersectoral collaboration underpins the WPF-R, which stipulates that its implementation requires coordination and intersectoral collaboration (Department of Social Development, 2021:32). The Department of Social Development, as the national department that focuses on supporting and strengthening family life in the country, was proposed to lead and coordinate all activities of the WPF and the WPF-R. The different departments and stakeholders that play a role in this process, which are led and coordinated by the Department of Social Development, have also been stipulated. In addition, the Department of Social Development will facilitate the monitoring and evaluation process that it will develop for programme supervision and control mechanisms at the national and provincial levels to assess progress made regarding both these White Papers (Department of Social Development, 2013:57).

While the WPF addresses the need for support for the entire family and recognises that sister departments, such as the Departments of Education and Health, are integral to the policy, it is not specific on the precise responsibilities. The numerous disabilities obviously are not all mentioned in detail in the policy, resulting in generalisations in the policies not adequately accommodating all the challenges and concerns regarding some disabilities. For example, the WPF, and even the WPF-R, does not provide a detailed guide for families on how to support the development of specialised schooling, even though the development thereof may be the sole responsibility of the Department of Basic Education. As CP requires specialised education, this can be seen as an attempt to address stigma and support, which may lead to acceptance when considering the education of a child with CP at a special or full-service school.

3.2.3 Analysis of the *White Paper on Families*

As the WFP-R is a revised policy that overlaps with the original WPF, a general analysis of both documents is done, and reference to specific aspects of these two policies is specifically made where applicable changes are noted. The endeavour of the South African government to develop a policy on supporting and strengthening families for them to function optimally needs to be noted, and South Africa must be appreciated for being one of a small number of developing countries that have formulated a national policy that focuses on families (Patel *et al.*, 2018:1). One of the strengths of this policy is that it acknowledges different forms of families within the South African context, for example nuclear families, single-parent families, female-headed households and cohabitation. The White Paper can also be seen as a more refined and improved Green Paper in the sense that the government started with the Green Paper, which was then consulted on in all nine provinces, as indicated earlier. The inputs and suggestions of various stakeholders were taken into consideration, and the refined paper resulted in the WPF and later the WPF-R.

A successful move on the part of the government was that the policy incorporates all government departments, as well as non-profit organisations. This holistic support encouraged the provision of a comprehensive, all-round service for the family (Department of Social Development, 2021:32). Mbecke *et al*. (2017:1) posit that this policy is one of the policies that are geared towards addressing the issue of poverty that confronts the majority of South Africans. The South African government strongly believes that if the WPF could be implemented correctly, it would address the imbalances of the past and contribute directly to the overall socioeconomic development of South Africa (Mbecke *et al*., 2017:1). Rabe (2017:1189) agrees with this notion and posits that the WPF improves on the Green Paper by admitting and recognising the resilience and adaptability of South African families, while, on the other hand, also acknowledging their poverty. However, the WPF was criticised by Hochfeld (2017, as cited by Patel *et al.*, 2018:6), for being skewed towards nuclear families, which, in his opinion, are not common in South Africa. This has, however, been addressed in the WPF-R, which states that, over time, there has been a decline in nuclear family units in South Africa, and such families are mostly found in metropolitan areas such as the Western Cape and Gauteng (Department of Social Development, 2021:12). Extended families, in which close family members stay together and, in some cases, become caregivers of children with CP, are not highlighted in the WPF, but noted in the WPF-R (Department of Social Development, 2021:12). Extended family units are common in South African provinces with sizeable rural communities, such as the Eastern Cape, Limpopo and KwaZulu-Natal (Department of Social Development, 2021:12), as well as in the rural parts of the Bojanala District, where this study was conducted. To further ameliorate this criticism, as South Africa has a high migration rate, the WPF-R states that the disposition of families in urban and rural areas differs considerably, since this migration is usually informed by age, class and ability to move or relocate (Department of Social Development, 2021:16).

Another criticism from Patel *et al*. (2018:7) is that, despite the vast engagement of stakeholders, the White Paper does not sufficiently address the social conservation of some earlier drafts of family policies, strongly believing that the family is still being viewed narrowly. According to Rabe (2017:1189), narrow ideals of family life are promoted, suggesting middle-class heterosexual values with little regard for poor families. Rabe (2017:1189) further argues that, while the WPF acknowledges family diversity, not all caregivers of children are acknowledged and supported. Also, as pointed out by Macleod *et al*. (2019:23), the practice of polygamy is criticised indirectly through reference to research that highlights its role in HIV infections and exacerbating the incidence of gender violence. Along these lines, Macleod *et al*. (2019:22) also contend that the WPF fails queer families in three ways. Firstly, little mention is made of families that do not fit into cisgender heteronomy, thereby rendering these families invisible. Secondly, where family diversity is noted, there is little engagement with the challenges and possibilities faced by queer families, except to promote tolerance by service providers who are presumed to be heterosexual cisgender allies. Thirdly, Macleod *et al*. (2019:22) believe that the policy favours family structure over family functioning. The policy is dominated by the aim of preserving a specific type of family rather than facilitating relations that support members in their diversity (Macleod *et al*., 2019:22). The same concerns have been raised previously, as Rabe (2017:1189) argues that the policy focuses on promoting stability and cohesion and, in doing so, loses sight of conflicts within intrafamilial relations such as gender inequalities in care. The researcher strongly believes that all families need support at some point in their lives and that all families should be supported in their different forms and status.

The WPF also refers to maternity and paternity leave, with the assumption that most mothers and fathers are employed. However, the South African rate of unemployment is very high, with the official rate being 32,6% in the first quarter of 2021 (Statistics South Africa, 2021:1). Moreover, the policy regards the mother as being at home more often, focusing on care, with fathers being absent, which is not necessarily the situation of many South African families. There are many families that are headed by women who provide for the family; this is supported by Patel *et al*. (2018:8), who argue that women remain invisible in this policy as the main providers of care in families. While fathers are absent in some families, mothers are absent in others, leaving fathers, in such cases, to fulfil the role of caring. The WPF-R tried to address this issue by indicating that a survey conducted in 2018 showed that 41,8% of the households in South Africa were headed by women (Department of Social Development, 2021:14).

As mentioned previously, a good point addressed by the WPF-R was to incorporate all national departments and non-profit organisations, which assisted in strengthening families, especially those with vulnerable children with CP, to perform optimally. Patel *et al*. (2018:1) raise the concern that there is no clarification of the intended outcomes in the paper. In contrast, the researcher strongly believes that the WPF-R has clarified the roles and intended outcomes. In other words, if different national departments, such as the Departments of Health, Home Affairs and Education, can be brought together to support the family of a child with CP, the services offered by these departments can indeed enhance the well-being of the child and support and strengthen the affected family. If these families can be supported and strengthened, this would extend to having a better functioning community. The execution of monitoring, evaluation and reporting systems, according to Patel *et al*. (2018:1), is not stipulated. This is supported by Macleod *et al*. (2019:22), who posit that while the policy states that there is a need for monitoring and evaluation, it does not indicate how this will be done, except that the Department of Social Development will lead and coordinate these efforts. This issue has been refined in the WPF-R, in that the structures that will lead the process are clearly stipulated; for example, the Provincial Department of Social Development, together with the office of the Premier, will lead the Provincial Family Service Forum (Department of Social Department, 2021:36). The different departments that would form part of the structure are clearly stated in the WPF-R.

As stated earlier, the WPF is inclined towards the poor and the disadvantaged. This is reiterated by the WPF-R, which states that poverty and inequality continue to put a lot of pressure on families, and most families – especially in formerly disadvantaged areas – continue to be poor and struggle in their efforts to ensure that the essential necessities of members of their families are met (Van der Berg *et al*., 2021:2). The Department of Social Development (2013:22) argues that poverty and inequality continue to discourage families from playing various roles, which often makes it difficult for the individual members of families to meet their needs. According to the WPF-R (Department of Social Development, 2013:22), people who live in urban areas are more likely to be employed compared to those living in rural areas. With this study focusing on rural areas in the Bojanala District, the possibility that the families of people with CP will be unemployed and struggling to provide for the basic needs of their family members, including those with CP, is high.

Furthermore, it is argued that women assume more household responsibilities than their male counterparts, spending a larger portion of their time on unpaid care work than men. This view is supported by Nyante and Carpenter (2019:820), who have found that caregivers are mostly mothers who must give up their work to look after their children with CP. This issue has precipitated poverty and financial hardships in these African families. These circumstances are exacerbated by the inadequate provision of childcare facilities, which causes a reduction in the amount of time women can spend on wage work. This is in line with research, including that of the WPF-R (Department of Social Development, 2021:18), which has found that mothers are usually forced to stay at home to take care of their children, some of whom are disabled, due to the unavailability or inadequate provision of childcare facilities.

If the WPF could be implemented as envisaged, as it encompasses all national departments, families who are confronted by this situation might be strengthened. The WPF still has the potential to enhance the socialisation, caring, nurturing and supporting capabilities of families in South Africa so that their members, including those with disabilities such as CP, can contribute effectively to the development of the country. However, this potential is curtailed by the challenges regarding the implementation of the policy. For example, Bukola *et al*. (2020:45) argue that minors from disadvantaged households in South Africa often have very limited or even no access to psychological or other mental health services. However, the intersectoral collaboration among stakeholders in the provision of services seems to be a challenge. Prevailing views are that national-level policies and legislation cannot be regarded as part of the solution, as these vulnerable children, many with disabilities, are often hidden at home or in institutions for both their own and their families' safety (Njelesani, 2019:58).

In conclusion, Nyante and Carpenter (2019:816) argue that caregivers need accurate and consistent information about CP to be empowered in their role and to support their children. This role can be provided by the different departments that are supposed to be coordinated by the Department of Social Development in relation to the WPF and the WPF-R. However, it remains uncertain whether people in rural areas know the WPF or the WPF-R and the services these documents advocate. A clear programme of action that is intended to advocate for these two documents, especially in rural areas, may bring hope for information, understanding, social justice and, in general, more support.

The next section looks at the policy on inclusive education, known as *Education White Paper 6* or EWP6.

3.3 *EDUCATION WHITE PAPER 6: SPECIAL NEEDS EDUCATION BUILDING AN INCLUSIVE EDUCATION AND TRAINING SYSTEM*

Education White Paper 6 (EWP6) is a policy framework document that was issued by the Department of Education in 2001. This document was released as a way of addressing two main findings: firstly, the fact that only a small percentage of learners with disabilities were receiving specialised education and support (which, unfortunately, was provided on a racial basis), and secondly, the education system had, in general, failed to provide appropriate services for diverse learner needs (Department of Basic Education, 2021b:1). Hence, EWP6 is aimed at ensuring that differently-abled learners, including those with CP, can develop and extend their potential. This policy is an attempt to address values of common citizenship, human dignity and equality, which are in line with the South African Constitution, enabling everyone to participate as equal members of society (Department of Education, 2001:11).

3.3.1 Background and development of *Education White Paper 6*

The *Constitution of the Republic of South Africa* (1996), which stipulates in Section 29(1)(a) that all children have a right to education, acknowledges that the Department of Education has a responsibility to ensure that all learners, with or without disabilities, pursue their learning potential to the fullest. Section 28(2) of the *Constitution of the Republic of South Africa* (1996:11) further stresses the importance of this fundamental right by declaring that this potential is of paramount importance in every matter that concerns the child as it is in the child's best interests.

In line with the South African Constitution, the *South African Schools Act* (84 of 1996) and the values of social cohesion and equality that South Africa promulgates, the National Committee for Education Support Services and the National Commission on Special Needs in Education and Training were appointed in 1996 by the then Minister of Education to investigate and make recommendations about education in South Africa regarding the special needs of learners and the educational support provided to such learners (Walton, 2018:33). It is stated in EWP6 (Department of Education, 2001:12) that a joint report on the findings, titled *Quality Education for All: Overcoming Barriers to Learning and Development*, was given to the then minister. Among the findings of these bodies, as stipulated in the EWP6 (Department of Education, 2001:6), was that specialised education and support had been provided for a small number of learners with disabilities on a racial basis mainly in special schools and classes. The report further mentioned that most learners with disabilities had either fallen outside of the system, leaving them without schooling, or had been mainstreamed when they should not have been (Department of Education, 2001:6). The recommendations of this committee concluded that inclusive and supportive centres of leaning must be developed in order to promote education for all. Thus, inclusivity would enable all learners to participate actively in the education process, fostering their development and extending their potential so that each individual could ultimately participate as an equal member of society (Department of Education, 2001:5). On this basis, "Consultative Paper No. 1 on Special Education: Building an Inclusive Education and Training System" was released on 30 August 1999, and it was only after inputs and submissions from the broader public, as well as social partners, had been considered, that EWP6 was released (Department of Education, 2001:6).

3.3.2 Content of *Education White Paper 6*

EWP6 (Department of Education, 2001) acknowledges the need for an education system that is inclusive and caters for the needs of all children, including the vulnerable. This policy also advocates changing the system, not the individual, and intends to build an inclusive, incorporated system for all. Adewumi and Mosito (2019:2) posit that EWP6 has paved the way for inclusive education, which was intended to facilitate access to learning for all learners by combating discriminatory attitudes. They further argue that inclusion was not only about learners being in a class physically but also about obtaining a quality education in order to succeed in being educated (Adewumi & Mosito, 2019:2). For Adewumi and Mosito (2019:1), inclusion is a universal right and, as such, the establishment of schools that are inclusive is part of the establishment of a society that is inclusive.

In the inclusive education system, EWP6 (Department of Education, 2001) posits that the provision of education will be based on the level of support that learners need to address the specific barriers to learning that they may be experiencing. Therefore, it is delineated that learners who require a low level of support would attend ordinary schools with the necessary assistance; those needing moderate support would attend a full-service school where additional assistance would be offered in the form of supplementary services; and lastly, learners who need a high or intensive level of support would then attend special schools (Department of Education, 2001:15). These special schools, as indicated earlier, would also serve as resource centres assisting ordinary and full-service schools in their proximity (Department of Education, 2001:1).

The inclusive education policy was intended to evaluate both human and physical resources already in the system and to see how to strengthen and transform them to ensure that the inclusive education system is realised (Department of Education, 2001). It also should be noted that support services play an important role in full-service schools, and these are facilitated by school-based support teams, which previously were known as “institutional support teams”. All public schools are expected to establish such teams (Department of Education, 2001:29). The primary role of these teams is to put in place properly coordinated learner and teacher support services (Department of Education, 2001:29). However, the majority of schools are still struggling to establish these teams and, where they are found, few are functional and active. The intention was for education support personnel within district support services to be trained to be able to assist and support teachers and learners (Department of Education, 2001:19).

The function of district-based support teams, as stipulated by Makhalemele and Payne-Van Staden (2018:990), is to promote classroom and organisational support by providing specialised learner and teacher support. Along with these services, the district-based support team must ensure curricular and institutional development and administrative support. District-based support teams are also expected to link up with school-based support teams to ensure that teachers in inclusive settings are supported. Moreover, district-based support teams should also assess the curriculum, with the intention to make it adaptable across all education levels and adaptable enough to cater for learners with diverse learning needs (Makhalemele & Payne-Van Staden, 2018:990).

The Department of Basic Education (2001:43) planned to designate and convert 500 of the then 20 000 primary schools into full-service schools by 2021. Thirty primary schools in 30 education districts would be converted immediately (Department of Education, 2001:42). The identification of these schools would be based on community, parent and social partner participation (Department of Education, 2001:23). The ministry intended to mobilise and recruit approximately 280 000 disabled children and young people from these schools who, at that time, were said to be outside the education system (Department of Education, 2001:22).

Through two sets of guidelines – the *National Strategy on Screening, Identification, Assessment and Support* and the *Guidelines for Responding to Learner Diversity in the Classroom through Curriculum and Assessment Policy Statement* – of the Department of Basic Education, it sets a strategy for implementing the inclusive model in the South African education system (Department of Basic Education, 2021b:9). The *National Strategy on Screening, Identification, Assessment and Support* (Department of Basic Education, 2014:14) details the process of identifying individual learner needs concerning the home and school context. This is done to establish the level and extent of additional support that is or may be needed academically or socially. Furthermore, the process is also stipulated to enable these learners to gain access to and for the teacher to provide such support at different levels. In addition, the *National Strategy on Screening, Identification, Assessment and Support* (Department of Basic Education, 2014:2) curbs the unnecessary placement of learners in special schools, identifies the best learning sites for support and provides guidelines on the central role of parents and teachers in implementing the strategy.

The CAPS document, also referred to in EWP6, provides guidelines for responding to learner diversity in the classroom through the CAPS guide for school principals and teachers. This document expounds on “how to respond to learner diversity in the classroom through curriculum differentiation” (Department of Basic Education, 2011:2).

3.3.3 Analysis of Education *White Paper 6*

EWP6 brought some positives to the education system of South Africa, where exclusion in many spheres of life, including education for all and education for people with disabilities, has perpetuated a cycle of poverty and discrimination for many years. With inclusive education, children – including those residing in the Bojanala District and living with CP – would be allowed to attend schools. EWP6 uses friendly and inclusive language, such as “barriers to learning and development” rather than the previous, unfriendly language used, such as “disability”, “learning difficulties” and “learners with special education needs” (Department of Education, 2001:12).

An issue that raises concern is inconsistencies in EWP6 and the document giving conflicting statements when basic education is defined. For example, the document endorses the definition in the *World Declaration on Education for All*, which defines basic education in terms of learning needs appropriate to the age and experience of students (Department of Education, 2001:11). However, at a later stage, EWP6 defines education in accordance with Section 29(1) of the *Constitution of the Republic of South Africa* (1996) – that it is a right in terms of the length of time that the government provides the child with education. In the South African context, this translates into seven to 15 years, or until Grade 9, whichever comes first. Section 29(1) (a) of the *Constitution of the Republic of South Africa* (1996) guarantees the fundamental right to basic education. This section, which becomes clear when it is read with Section 9, states that the state may not unfairly discriminate, either directly or indirectly, on any basis, including disability (which includes CP).

In EWP6, the Department of Education (2001:43) set out its intention to convert 500 primary schools to full-service schools by 2021. This number does not seem to be informed by anything, and it is not indicated whether it is elicited from the total number of primary schools in the country. While one full-service school per education district would initially be established, the total number per district by 2021 was not stipulated. Although these schools would be important, as inclusivity plays a very important role in building a fair and just South Africa, there is no mention of an implementation plan for turning secondary schools into full-service schools. The Department of Basic Education is responsible for schools from Grade R to Grade 12, which ranges from primary to secondary schools (Department of Basic Education, 2021a:1). Non-commitment to transforming secondary schools into full-service schools would mean losing the very learners who had been supported at the lower levels after Grade 7. Furthermore, Funda and Beere (2020:14) point out that, despite the framework guaranteeing the right to education for children with disability, there has been a continuing pattern of human rights violations at special schools and hostels. This and the lack of access to any schooling for thousands of learners with disabilities have become common (Funda & Beere, 2020:14). Moreover, there is evidence of complete failure to provide reasonable accommodation and support for learners with disabilities in ordinary mainstream schools. The failure of the government to clearly stipulate how secondary schools will be turned into full-service schools is an indication that the government has not considered all learners as equally deserving of the right to basic education (Funda & Beere, 2020:16).

In 2019, the Department of Basic Education, in collaboration with the provincial education departments, designated 848 public ordinary schools to become full-service schools (Department of Basic Education, 2019:2), that is, 348 more schools than the target of 500 that the sector had set for itself in 2001, when EWP6 was published. However, when the Auditor General of South Africa performed an audit on full-service schools in 2018 to 2019, he identified several challenges, including that, even though more primary schools were designated as full-service schools, most of them were not functioning effectively (Department of Basic Education, 2019:1). The Auditor General of South Africa also identified that there were no support programmes for these schools in line with the different services the schools were expected to provide (Department of Basic Education, 2019:1). These challenges were earlier raised by Walton (2018:33), who stated that, where it is reasonably practicable, inclusive schooling entails learners with special educational needs being accommodated in the mainstream school system with the relevant support. However, these schools are not functioning effectively because of a lack of provisioning of resources and capacitation of teachers to fulfil their roles and responsibilities.

The same situation prevails in the Bojanala District, which has 70 full-service schools. The majority of these are designated primary schools and do not have the required resources to be full-service schools. Some of them have been on a waiting list for infrastructural repairs and modifications for more than three years. Where school governing bodies were able to raise funds, some modifications were done to the infrastructure, such as building ramps. Andrews *et al*. (2020:6) point out that the lack of suitable provisioning of adequate human, technical and infrastructural resources, which could facilitate a more inclusive curriculum and environment to support learning, especially in rural areas, remains a challenge. Engelbrecht (2020:219) has found that, even though many South African teachers, in principle, support the justification for inclusive education on social grounds, there remains a lack of adequate human, technical and infrastructure resources that are needed to facilitate the implementation of inclusive education. This results in a major negative contributing factor to teachers' perceptions. On this basis, it can be anticipated that a substantial number of children with CP are still not attending school, and if they are, they remain excluded in an environment that is supposed to be inclusive. The intervention strategy that is proposed at the end of this study addresses such issues.

According to EWP6, special schools are to be transformed into resource centres, and their staff will be trained so that they can provide professional support to neighbouring schools with regard to curriculum, assessment and instruction (Department of Education, 2001:21). While a budget will be set aside for this, it is not clear whether there will be enough to convert all 378 special schools or a clear plan on the number that will be converted per year in the 20 years of intended implementation. The training of staff at special schools is also not clearly defined and planned for. Moreover, officials who are to be responsible for training have not been identified. Indeed, it is stipulated that district support teams will be coached to train and support schools. However, is the Department of Basic Education certain that all districts have such teams and, if they do, whether they will be enough to cover all schools that need to be trained? This may give rise to a delay, as the identification of such resource centres and the teams that must undergo training still has to take place.

A report by the South African Human Rights Commission (2017:48) points out that the Commission has found that many special schools in the North West Province are characterised by noteworthy infrastructural shortcomings. These inadequacies include unreliable water supply, inaccessible ablution facilities, a lack of perimeter fencing and a general and distinct lack of access to assistive devices (South African Human Rights Commission, 2017:48). The Commission also found that EWP6 was ineffectual, as this policy had failed to result in any significant improvements, which seemed to be due to the lack of budgeting and costing, as well as a lack of political will (South African Human Rights Commission, 2017:48).

According to EWP6, an estimated 280 000 children and young people with disabilities did not attend school in 2001 (Department of Education, 2001:15). EWP6 intends that all these children and youth should be mobilised to be in school; however, it does not give clear guidelines on when, how and by whom they will be mobilised. While the numbers are there, it is also not clear where all these out of school children and young people reside. The apartheid system ensured that some communities did not have schools, and with the Department of Education (2001:5) intending to convert only 30 primary schools per year at first, there is still a possibility that these children can stay out of school for years, waiting for proper and accessible schools to become available. It was also noted by the team in charge of inclusive education in the North West Department of Education, during a visit by the Human Rights Commission, that black children with disabilities faced a lot of challenges and that children with disabilities residing in a rural area were further discriminated against by inadequate resourcing and the under-provision of schooling and infrastructure in their communities (South African Human Rights Commission, 2017:48). If this conclusion is to be embraced, there is already a possibility that the families of children with CP within this study are facing a myriad of challenges, including not having schools in their communities to which their children can be admitted.

Themane and Thobejane (2019:369) state that in line with the provision of the South African Constitution for compulsory education, Statistics South Africa reported universal attendance by 14 million learners of the same age in 2018. It was also reported that close to 6 000 children with CP were attending special schools and about 350 were attending mainstream schools at that time (2018) (Luger *et al*., 2021:1475). If one compared the numbers with those estimated for children born with disabilities, one can argue that more than 15 years after the release of EWP6, a large number of children with disabilities are still being excluded from schools.

While the Bojanala District has 14 special schools, only one – Meerhof Special School – has been fully resourced to serve as a resource centre. However, it is a challenge for the majority of inclusive schools in the district, as well as other special schools, to utilise this school because of where it is located. Most schools would need transport to access this special school. The Auditor General of South Africa has also raised concerns regarding the lack of adequate business plans for what needs to be done, by whom and by when to ensure that the full-service schools in the country are functional. As a result, he recommends, among other things, the implementation of monitoring and support services to ensure that these schools function as full-service schools (Department of Basic Education, 2019:2).

The intention of EWP6 was for the inclusive education system to be fully implemented by 2021. However, Circular 54 of 2019 instructed all provincial education departments to temporarily suspend the designation of full-service schools for three years to ensure that all schools that have been designated are adequately capacitated to fulfil their roles and responsibilities (Department of Basic Education, 2019:2). Irrespective of the good intentions of EWP6 and a plethora of studies on this White Paper and the establishment of full-service schools, CP remains a challenge. Children with CP are still not attended to as they should be. The unavailability of schools that can cater for children with CP in North West and the under-resourcing of full-service schools continue to undermine the rights of children with CP. It is not clear whether this issue arises from a lack of financial or political will. South Africa has good policies in the WPF and EWP6, but children with CP seem to be left behind in the actualisation of the two policies.

Hence, the primary research question of this study, “Can inclusive citizenship education address the needs of families with members living with CP in the Bojanala District, North West Province?”, attempts to address the views of people who live with children with CP on the support that they receive and their daily struggles as they strive and wait for inclusion.

The *White Paper on the Rights of Persons with Disabilities* is discussed in the next section.

3.4 *WHITE PAPER ON THE RIGHTS OF PERSONS WITH DISABILITIES*

The *White Paper on the Rights of Persons with Disabilities*, hereafter referred to as “WPRPD”, is a policy document created by the South African Department of Social Development. This policy “acknowledges deficits in access to education, reproductive health and rights services as well as health care among people living with disabilities” (Health-e News, 2016:1). Moreover, the policy provides the framework for a consistent and coordinated approach by all government departments to assist with and support the mainstreaming of disability across all programmes of the government (Department of Social Development, 2016:38). According to the WPRPD (Department of Social Development, 2016:38), the responsibility for disability equity is seen to lie in a hierarchy; thus, the primary responsibility will be positioned nationally and followed on a provincial level and then on a local governmental level, which includes other sectors of society. Furthermore, the WPRPD allocates personal responsibility for the successful implementation of the policy to persons with disabilities and their families (Department of Social Development, 2016:38).

In the next section, the background and development of the WPRPD are discussed.

3.4.1 Background and development of the *White Paper on the Rights of Persons with Disabilities*

Disability is defined by the World Health Organisation and the World Bank in the 2011 *World Report on Disability* as “an umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (World Health Organisation, 2011:4). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2008) views disability as a revolving concept imposed by a society when a person with any impairment is denied access to full participation in all aspects of life within that society. When a society fails to uphold the rights and specific needs of individuals with impairments, it is seen as discrimination (Department of Social Development, 2016:4). According to the Department of Social Development (2016:17), disability refers to the interaction between individuals with impairments and attitudinal and environmental barriers, which can be permanent, temporary or episodic in nature. The WPRPD (Department of Social Development, 2016:18) states that disability requires a level of self-definition by individuals themselves, as it is necessary that individuals determine whether they are disabled or not based on environmental factors, context and the individuals' own perceived capabilities.

The South African Constitution prohibits discrimination based on disability and guarantees the right to equality for people with disabilities (Department of Social Development, 2016:16). In line with building a cohesive, inclusive and non-discriminatory society, the *White Paper on an Integrated National Disability Strategy* was developed and released in 1997 (Department of Social Development, 2016:19). The Office on the Status of Disabled Persons was responsible for monitoring and implementing this policy. According to the Department of Social Development (2016:19), the Integrated National Disability Strategy was designed in consultation with various independent organisations, namely the United Nations Standard Rules for the Equalisation of Opportunities for Persons with Disabilities, the Disability Rights Charter, which was developed by Disabled People South Africa, and other representative organisations of persons with disabilities. In this updating of the 1997 *White Paper on an Integrated National Disability Strategy*, the intention of the WPRPD was to initiate a freer and more just society, inclusive of all persons with disabilities, who are seen as equal citizens (Department of Social Development, 2016:18). Just like the initial White Paper, the WPRPD is based on the social model, which focuses on and stresses the abilities of people with disabilities, rather than their differences or disabilities.

Furthermore, the WPRPD appreciates the social model that "fosters respect for inability and that recognizes persons with disabilities as equal citizens with full political, social, economic and human rights" (Department of Social Development, 2016:21). This model also recognises and highlights challenges in the environment experienced by persons with disabilities, which exclude rather than include persons with disabilities in mainstream life (Department of Social Development, 2016:21). South Africa ratified the UNCRPD in 2007, followed by its protocol in 2009, which was not mandatory, as a result, binding the country to respect and implement the rights of persons with disabilities (Department of Social Development, 2016:20).

The *Baseline Country Report to the UNCRPD*, which was approved by the Cabinet in April 2013, admits that the continued vulnerability of persons with disabilities, especially children, requires more focused interventions (Department of Social Development, 2016:20). However, other vulnerable groups, such as persons with psychosocial disabilities residing in rural villages, require even more rigorous and better coordinated and targeted intervention (Department of Social Development, 2016:20). This is especially evident in the current study, which examined conditions in the rural areas of the Bojanala District. According to the Department of Social Development (2016:22), Article 8 of the UNCRPD mandates that stereotypes, prejudices and harmful practices in relation to persons with disabilities will be combated by all state parties that adopt immediate, constructive and applicable measures and thus promote respect for the rights and dignity of persons with disabilities.

3.4.2 Content of the *White Paper on the Rights of Persons with Disabilities*

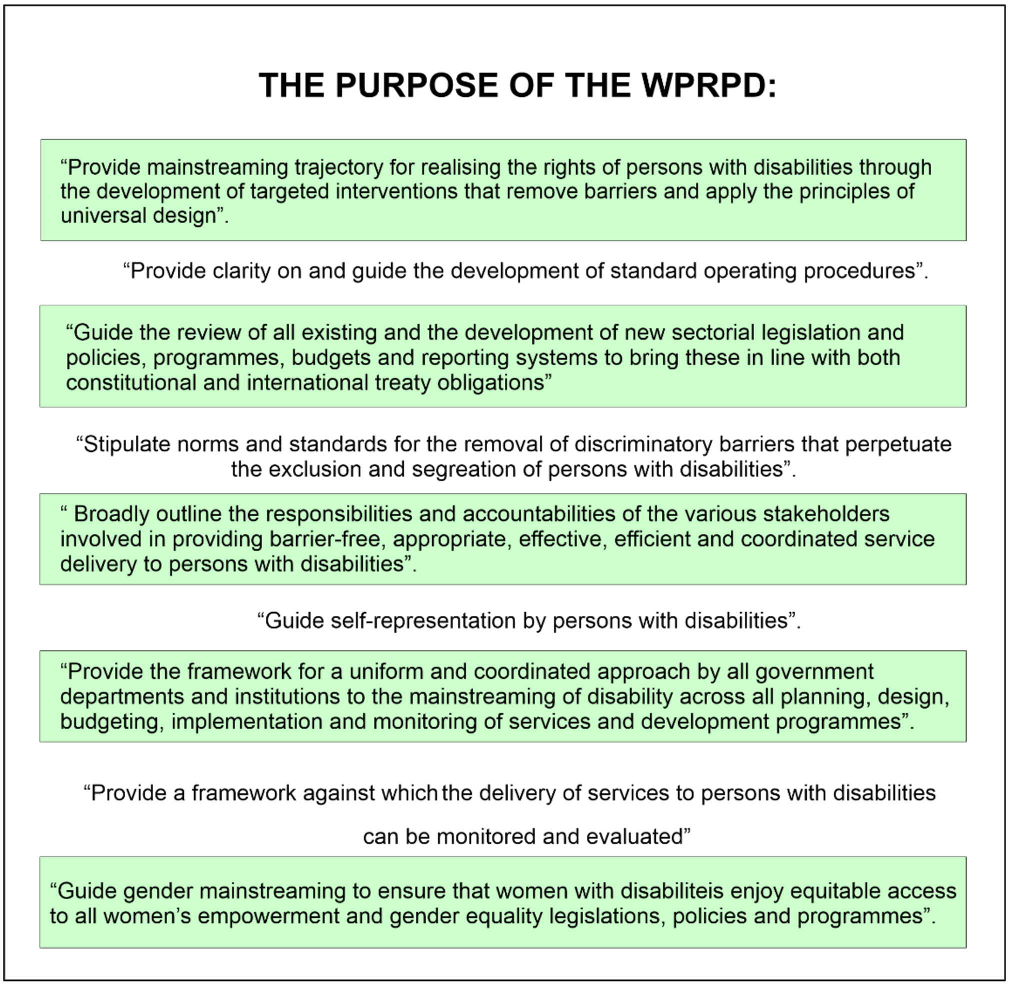
This section sets out the vision and mission of the WPRPD, its purpose, the rights and responsibilities of persons with disabilities and a strategic approach to realising these rights. The strategic pillars for realising the rights of persons with disabilities, as well as the roles and responsibilities of different stakeholders, are explored as well.

3.4.2.1 Vision and mission of the *White Paper on the Rights of Persons with Disabilities*

The vision of the WPRPD is aligned with Vision 2030 of the South African National Development Plan, the Integrated National Disability Strategy and the UNCRPD. This vision was drafted to create a free and just society that is inclusive of all persons with disabilities and sees them as equal citizens (Department of Social Development, 2016:42). The mission is aimed at inclusive and equitable socioeconomic development for all individuals within a community (Department of Social Development, 2016:42).

3.4.2.2 Purpose of the *White Paper on the Rights of Persons with Disabilities*

Figure 3-2 sums up the purpose of the WPRPD, as stipulated in *Government Gazette* No. 39792 (Department of Social Development, 2016:38).



THE PURPOSE OF THE WPRPD:

“Provide mainstreaming trajectory for realising the rights of persons with disabilities through the development of targeted interventions that remove barriers and apply the principles of universal design”.

“Provide clarity on and guide the development of standard operating procedures”.

“Guide the review of all existing and the development of new sectorial legislation and policies, programmes, budgets and reporting systems to bring these in line with both constitutional and international treaty obligations”

“Stipulate norms and standards for the removal of discriminatory barriers that perpetuate the exclusion and segreation of persons with disabilities”.

“ Broadly outline the responsibilities and accountabilities of the various stakeholders involved in providing barrier-free, appropriate, effective, efficient and coordinated service delivery to persons with disabilities”.

“Guide self-representation by persons with disabilities”.

“Provide the framework for a uniform and coordinated approach by all government departments and institutions to the mainstreaming of disability across all planning, design, budgeting, implementation and monitoring of services and development programmes”.

“Provide a framework against which the delivery of services to persons with disabilities can be monitored and evaluated”

“Guide gender mainstreaming to ensure that women with disabiliteis enjoy equitable access to all women’s empowerment and gender equality legislations, policies and programmes”.

Figure 3-2: The purpose of the WPRPD (adapted from Department of Social Development, 2016:38).

Looking at the purpose of the WPRPD in Figure 3-2, one can conclude that many of these aspects are not fully complied with, leaving the purpose of the WPRPD, as stipulated in *Government Gazette* No. 39792 (Department of Social Development, 2016:38), a good policy document with unfulfilled promises. This is even more noticeable in the rural areas of South Africa, such as the Bojanala District.

3.4.2.3 Rights and responsibilities in the *White Paper on the Rights of Persons with Disabilities*

People with disabilities have different rights and responsibilities. These rights and responsibilities are discussed below.

3.4.2.3.1 Political rights

According to the UNCRPD (2012:80), all countries, including South Africa, must guarantee people with disabilities their political rights. Furthermore, people with disabilities, just like all other citizens, have an equal responsibility to exercise their political rights (UNCRPD, 2012:80).

3.4.2.3.2 Human rights

The *Constitution of the Republic of South Africa* (1996) is based on respect for the promotion, protection and fulfilment of all human rights. The Bill of Rights of the *Constitution of the Republic of South Africa* (1996), in which socioeconomic rights are actionable is also entrenched (Department of Social Development, 2016:31). Section 9(3) of the Constitution clearly states that “the state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth” (*Constitution of the Republic of South Africa*, 1996:6).

3.4.2.3.3 Social rights

According to the Department of Social Development (2016:33), people with disabilities must be afforded social rights that are equal to those of all other citizens, since the provision of thereof will enable them to have full participation in society.

3.4.2.3.4 Economic rights

People with disabilities have the right to economic justice, and this entails, among other things, the right to own land and to have decent work (Department of Social Development, 2016:34).

3.4.2.3.5 Cultural rights

According to the WPRPD, specific obligations are placed on the government by article 30 of the UNCRPD to ensure “measures that will promote, protect and uphold the cultural rights of persons with disabilities” (Department of Social Development, 2016:35).

3.4.2.4 Strategic approach to realising the rights of persons with disabilities

The WPRPD (Department of Social Development, 2016:43) states that the social model is the only model favoured in South Africa in addressing disability. This model is established on three approaches, namely a rights-based approach, mainstreaming and a life-cycle approach (Department of Social Development, 2016:43).

3.4.2.4.1 The rights-based approach

The rights-based approach is concerned with standards that can guide and be used to assess the performance of governments in relation to human, social and economic rights (Department of Social Development, 2016:45).

3.4.2.4.2 The mainstreaming approach

Disability mainstreaming involves the individual needs of persons with disabilities being addressed by ensuring that disability is at the focus of all development initiatives and that all policies, budget plans and programmes support individual needs (Department of Social Development, 2016:45). Furthermore, this mainstreaming of disability occurs on two interrelated levels; one ensures that the disability element is inherent in a programme or project and that people with disabilities are included as one of the beneficiaries, and the other ensures that universality is achieved (Department of Social Development, 2016:45).

3.4.2.4.3 The life-cycle approach

According to the life-cycle approach, all persons ought to endeavour to amalgamate and collaborate services and the execution thereof in ensuring that all persons with disabilities in a specific geographical location or experiencing a specific handicap receive impartial services (Department of Social Development, 2016:46). Furthermore, as children with disabilities progress through different stages of their lives, including as adults, the expectation is that the provisioning of services should not be discontinued (Department of Social Development, 2016:46).

3.4.2.5 Strategic pillars for realising the rights of persons with disabilities

According to the WPRPD (Department of Social Development, 2016:50), there are nine strategic pillars upholding the rights of people with disabilities. These pillars are discussed below.

3.4.2.5.1 Pillar 1 – Removing barriers to access and participation

It is the responsibility of all people, including organisations for and of persons with disabilities, to create a barrier-free environment for people with disabilities. Six dimensions must be addressed to remove barriers to access and participation, namely changing attitudes and behaviour, access to the built environment, transport, information and communication, universal design, and access to reasonable accommodation measures (Department of Social Development, 2016:50). According to the WPRPD (Department of Social Development, 2016:53), South Africans, especially those from poor backgrounds and rural areas, need sufficient transport that is efficient, safe and easily attainable. For people with disabilities such as CP, having to access health and educational facilities without readily available transport is a challenge.

3.4.2.5.2 Pillar 2 – Protecting the rights of persons at risk of compounded marginalisation

People with disabilities experience inequality and discrimination differently, and this depends on contextual factors (Department of Social Development, 2016:60). According to the WPRPD (Department of Social Development, 2016:62), specified preventative deeds are needed through four focal points to ensure that the rights of persons with the prospect of exacerbated marginalisation are guarded and validated. These points are “the right to life, equal recognition before the law, access to justice, and freedom from torture or cruel, inhuman or degrading treatment or punishment, exploitation, violence and abuse” (Department of Social Development, 2016:62-63).

3.4.2.5.3 Pillar 3 – Supporting sustainable, integrated community life

The WPRPD (Department of Social Development, 2016:70) states that people with disabilities have choices equivalent to those of other citizens, including the right to live within the community. Furthermore, it stipulates that the government should take effective and appropriate measures to advance full gratification by persons with disabilities of this right, along with their full inclusion and participation in the community (Department of Social Development, 2016:70).

3.4.2.5.4 Pillar 4 – Promoting and supporting the empowerment of persons with disabilities

Through the support of early childhood development, lifelong education and training, social integration assistance, access to lifestyle support and the strengthening of resource mechanisms, the government aims to strengthen access to economic independence and a life of dignity for people with disabilities (Department of Social Development, 2016:81). People with disabilities and their families should be empowered to know how to access resource mechanisms if they experience discrimination or exclusion, and they should understand what their rights and entitlements are

(Department of Social Development, 2016:89). This study aimed to establish whether children with CP and their families know these rights. It is proposed that through inclusive citizenship education, these families can be enlightened and strengthened to ultimately claim what they deserve as equal citizens of the country.

3.4.2.5.5 Pillar 5 – Reducing economic vulnerability and releasing human capital

The WPRPD (Department of Social Development, 2016:90) states that barriers that prevent persons with disabilities from improving their livelihoods are related to limited access to services such as health and education. Furthermore, it is believed that a lack of or insufficient education causes poverty in people, including those with disabilities (Department of Social Development, 2016:90). There is a strong belief that improved accessibility of education by children with disabilities will lessen the prospect of them living in poverty as adults (Department of Social Development, 2016:90).

Pursuant to the lack of accessible and affordable public transport, specialised services and opportunities in rural and impoverished areas, farms and conventional settlements, persons with disabilities are likely to experience challenges in accessing employment opportunities (Department of Social Development, 2016:91). Furthermore, disability is more likely to be associated with negative traditional beliefs and practices by conventional communities (Department of Social Development, 2016:91). This issue of resource challenges and traditional beliefs pertaining to persons with disabilities living in rural areas (see Ngubane & Chetty, 2017:38; Pretorius & Steadman, 2017:2) was raised in the literature review of this study. If these issues are not addressed, the families of those with CP living in the rural parts of the Bojanala District may be disadvantaged for a long time yet.

3.4.2.5.6 Pillar 6 – Strengthening the representative voice of persons with disabilities

This pillar relates to the areas that need to be focused on for communities to intensify the representation of disabled people. Both representing oneself and representation by bodies of and for disabled people are advocated (Department of Social Development, 2016:100).

3.4.2.5.7 Pillar 7 – Building disability-equitable state machinery

According to the South African National Development Plan, which was published in 2012, a disability ought to be amalgamated into all aspects of planning as a way of recognising that there is no approach that can be uniform or apply to all life (Department of Social Development, 2016:104). According to this pillar of the WPRPD, building disability-equitable state machinery requires disability considerations to be mainstreamed in all planning processes, including budgetary and service delivery processes (Department of Social Development, 2016:106). Furthermore, it requires that monitoring and evaluation of the rights of persons with disabilities should be done within the broader context of the monitoring and evaluation process of the government (Department of Social Development, 2016:109).

3.4.2.5.8 Pillar 8 – Promoting international cooperation

According to the WPRPD (Department of Social Development, 2016:115), most of the African and international human rights policies were embraced and ratified by the South African government. Furthermore, the country is also a member of the World Health Organisation, the International Labour Organisation and the World Intellectual Property Organisation through which information is shared. As a member of these bodies, South Africa is obliged to ensure that it protects the rights of persons with disabilities who may enter the country or request residency (Department of Social Development, 2016:115).

3.4.2.5.9 Pillar 9 – Monitoring and evaluation

Monitoring, according to the WPRPD (Department of Social Development, 2016:116), refers to collecting, analysing and reporting data in a way that ensures the effective management of the implementation of the policy; also, evaluation assesses relevance, efficiency, effectiveness, impact and sustainability and, thereby, assists decision makers in its implementation. The WPRPD (Department of Social Development, 2016:117) says that monitoring should focus on three issues: first, statistical trends in the status of persons with disabilities and their related rights; second, the programmatic performance of ensuring that there is evidence that persons with disabilities are considered and integrated into programmes and policies; and third, feedback provided by stakeholders. In terms of evaluation, the policy posits that an annual report on progress made in the implementation of the WPRPD should be published in line with the targets set in the implementation matrix (Department of Social Development, 2016:119).

3.4.2.6 Roles and responsibilities

For the WPRPD to be implemented successfully, the Department of Social Development (2016:125) stipulates that different stakeholders need to play different roles. These encompass a broad spectrum of stakeholders from various government and non-government departments. These stakeholders come from different levels of operations. It is the responsibility of the accounting officers, for example, to ensure the effective implementation of the policy by putting in place proper administrative systems (Department of Social Development, 2016:125).

3.4.3 Analysis of the *White Paper on the Rights of Persons with Disabilities*

A positive point in the WPRPD is that it gives the responsibility for guaranteeing that the rights of persons with disabilities are protected to everyone, including people with disabilities themselves and their families (Department of Social Development, 2016:42). The families of people with CP are, therefore, expected to ensure that the rights of their children, including the right to education, are protected and realised. With research indicating that the majority of children with CP do not attend school, especially in rural areas, one would assume that these families are not aware that it is a right, and not a privilege, to be in school. Hence, inclusive citizenship education, as proposed by this study, is necessary to make them realise that their children are missing a right. While the vision of the WPRDP is the creation of a free and just society, inclusive of all persons with disabilities as equal citizens (Department of Social Development, 2016:42), the mission of the White Paper is not clearly outlined to ensure that it is implemented in an effective and accountable manner.

According to Tigere and Moyo (2019:58), the exclusion and marginalisation of people living with disabilities is an ongoing challenge in Africa, and this happens even though there are international conventions, such as the UNCRPD, that encourage countries to promote equal rights to the development of that segment of the population.

One of the intentions of the WPRPD is to ensure that women with disabilities enjoy equitable access to all women’s empowerment and gender equality legislation, policies and programmes (Department of Social Development, 2016:38). However, it is not stipulated how this matter is intended to be guided and facilitated; hence, the report of the United Nations Department of Economic and Social Affairs (2018:134) states that men living with a disability have an advantage over women with the same disability. The report also states that people with disabilities who reside in Africa experience higher rates of deprivation and disadvantages in accessing services such as education, health and work compared to those in developed countries (United Nations Department of Economic and Social Affairs, 2018:134).

According to Tigere and Moyo (2019:59), Statistics South Africa indicates that in 2016, out of the South African population of 57 million, at least 7,5% were regarded as living with a disability. The WPRPD (Department of Social Development, 2016:8) advocates that all policies and legislation across the public and private sectors should positively affect the lives of people living with disabilities. While responsibilities are given to different stakeholders, the WPRPD fails to indicate the measures to be taken if different sectors cannot respect and protect the rights of these people as stipulated. The education system is no different. As emphasised in research by the Human Rights Commission (2017:16), the South African education system is currently not sufficiently providing young people with disabilities with skills for the open labour market or as owners of economically viable small enterprises. This is an example of the intentions of the WPRPD not being followed simply because actions to realise them were not indicated. The inclusive citizenship education promoted by this study should be able to assist those in the Bojanala District who are living with CP, as well as their families, to realise that they have rights and that, if these rights can be realised, these people will ultimately be able to engage fully in all facets of society, including the labour market.

Despite having a good policy, the government's plan of action to implement the policy is problematic. Besides, the funding model to address disability is also not stipulated, which poses a challenge. Tigere and Moyo (2019:60) posit that the implementation of the WPRPD has been slow, with no clear-cut expectations from role players such as government departments and the private sector. According to the Department of Social Development (2016:119), as a way of ensuring that the human rights model of disability is realised, the WPRPD was extended by an implementation matrix for monitoring compliance from 2015 to 2030. Under the WPRPD, monitoring and evaluation should be based on the outcomes of the indicators which are related to the strategic pillars; this will then be followed by an annual report on progress made which will be published by the chosen national disability rights coordination mechanism (Department of Social Development, 2016:119). Unfortunately, it is not possible to find annual reports on the implementation of the WPRPD as promised in the White Paper.

The next section looks at the legal framework within which this study took place.

3.5 REGULATORY FRAMEWORK

Several pieces of legislation find application in this chapter. The *Constitution of the Republic of South Africa* and the *South African Schools Act* are discussed below.

3.5.1 The *Constitution of the Republic of South Africa*

South Africa previously had policies and laws that segregated groups according to race, but with the advent of democracy, the country adopted a constitution that became the point of referral for and a tool against which all policies, legislation, acts and omissions are measured. The South African Constitution is regarded as the supreme law of the Republic of South Africa (Botha & Bekink, 2018:10) and it "provides the legal foundation for the existence of the republic, it sets out the rights and duties of its citizens, and defines the structure of the Government" (Department of Education, 2021:1). According to Roux (2019:90), the Constitution has been amended by 17 acts since 1996.

3.5.1.1 Background to and development of the *Constitution of the Republic of South Africa*

After all liberation movements were unbanned by the then president of the Republic of South Africa, President FW de Klerk, and political prisoners were released, it was important to bring all interested parties to the negotiating table to find common ground. An agreement on the drawing up of a constitution was reached and, according to Bilchitz *et al*. (2016:34), its purpose was to lay a foundation for a society "in which government is based on the will of the people". This clearly affirms that the Constitution was created by the people and for the people. Van Berkel (2014:35) sees the purpose of the Constitution as being a peace treaty between the contending parties to avoid a bloody civil war and as a document that can be utilised to heal the rifts of the past and establish a society founded on fundamental human rights, social justice and democratic values. Furthermore, Van Berkel (2014:38) states that the Constitution was seeking to create the basic institutions and processes necessary for a democratic system and the rule of law to operate.

Formal negotiations began in December 1991 at the Convention for a Democratic South Africa, but they broke down after the second plenary session in May 1992 (Bilchitz *et al*., 2016:33; Wikipedia, 2021:2). It was only in April 1993 that the parties returned to the table, which was then referred to as the "Multi-Party Negotiating Process" (Wikipedia, 2021:2). An interim Constitution was drafted and completed in 1993. It was formally introduced in parliament and came into force on 27 April 1994 (Bilchitz *et al*., 2016:34). The Constitutional Assembly was responsible for the drafting of the final Constitution, and a Constitutional Court was established with the mandate to test the final Constitution against 34 constitutional principles to which it had to conform (Wikipedia, 2021:2). The Constitutional Assembly engaged in a public participation programme for input from the public, and the final Constitution was completed on 8 May 1996 and signed by the then president of South Africa, President Nelson Mandela, on 10 December 1996. The *Constitution of the Republic of South Africa* (1996) was officially published on 4 February 1997.

3.5.1.2 Contents of the *Constitution of the Republic of South Africa*

The Constitution covers a preamble and 14 chapters, containing 244 sections. This study focuses only on two chapters, namely Chapter 1, which covers the provisions under which the Constitution was founded, and Chapter 2, which covers the basic rights of all citizens of the country, including those with disabilities, as well as the institutions that can be approached in relation to human rights issues (*Constitution of the Republic of South Africa,* 1996). These chapters are highlighted in this paper because the researcher strongly believes that they are directly related to the issue of disability and how those affected by a disability should be treated and embraced as full citizens. All these aspects are covered in this section.

3.5.1.2.1 Preamble

As already stated in the discussion on the development of the Constitution, the preamble covers the purpose of the Constitution.

3.5.1.2.2 Chapter 1 – Founding provisions

Chapter 1 of the Constitution deals with the founding principles upon which the Republic of South Africa is based. It states that the Republic of South Africa is one sovereign democratic state that is guided by the values of human dignity, the achievement of equality and the advancement of human rights and freedom, non-racialism and non-sexism (*Constitution of the Republic of South Africa*, 1996:3). It is in this section that the supremacy of the Constitution is explained – that no law, policy or act is or can be above the *Constitution of the Republic of South Africa* (1996:3).

3.5.1.2.3 Chapter 2 – Bill of Rights

Chapter 2 of the Constitution deals with the Bill of Rights. The majority of these rights apply to everyone in the country, except for the right to vote, the right to work and the right to enter the country, which apply only to citizens (Wikipedia, 2021:4). Of paramount importance is the fact that Section 7 sets apart the rights in the Bill of Rights as the cornerstone of the South African democracy. Furthermore, it enshrines the rights of all people in the country and affirms the democratic values of human dignity, equality and freedom (*Constitution of the Republic of South Africa*, 1996:4).

The right to equality is guaranteed in Section 9 of the Bill of Rights. It states that everyone is equal before the law and has the right to equal protection and benefit of the law (*Constitution of the Republic of South Africa*, 1996:5). As stated earlier in Section 3.4.2.3.2 of this study, "the state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth" (*Constitution of the Republic of South Africa*, 1996:6). It is further stipulated that discrimination on one or more of the grounds listed above is unfair, unless it is established that the discrimination is fair (*Constitution of the Republic of South Africa*, 1996:5). Section 10 of the Bill of Rights stresses the human dignity of all South African citizens, including those with CP. It declares that everyone has inherent dignity and the right to have their dignity respected and protected, and that no citizen may be deprived of citizenship (*Constitution of the Republic of South Africa,* 1996:7*).*

In recognition of the role of children in the future and sustainability of South Africa as a country and its development, the parliament enacted Section 28 (*Constitution of the Republic of South Africa*, 1996:9), which deals with the rights of children. It proclaims that every child has the right, among other things, to family or parental care or to appropriate alternative care when removed from the family environment, as well as to basic nutrition, shelter, basic healthcare services and social services. Section 29 provides all learners of school-going age with the right to basic education (*Constitution of the Republic of South Africa*, 1996:10).

The rights guaranteed in the Bill of Rights are subject to limitations as set out in Section 36 (*Constitution of the Republic of South Africa*, 1996:12-13), which provide that:

> … the rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, except as provided in subsection (1) or any other provision of the Constitution, no law may limit any right entrenched in the Bill of Rights. (Constitution of the Republic of South Africa, 1996:16)

The rights set out above have been a subject of interpretation and consideration by various courts as part of enhancing democracy in South Africa.

3.5.1.2.4 Institutions for human rights

The *Constitution of the Republic of South Africa* has six state institutions that support it, namely the Public Protector, the South African Human Rights Commission, the Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities, the Commission for Gender Equality, the Auditor General and the Electoral Commission (*Constitution of the Republic of South Africa*, 1996:62-63). These institutions are independent and subject themselves only to the *Constitution of the Republic of South Africa* (1996:63).

3.5.1.3 Analysis of the *Constitution of the Republic of South Africa*

The *Constitution of the Republic of South Africa* (1996) is hailed by many, including other countries, as one of the best in the world. According to the preamble, the form of human excellence that is envisioned and pursued includes living in a community that supports democratic values, social justice and essential human rights, as well as improves the quality of life of all citizens and emancipates the potential of all. However, it is not determined how all this will be achieved and what action will be taken to guarantee that it is achieved (*Constitution of the Republic of South Africa*, 1996:3).

The Constitution is there to protect, among other things, the rights of all citizens of South Africa, including those living with a disability such as CP. As human rights apply to everyone, all people within the country are entitled to human rights by simply being human. In terms of Section 9 of the *Constitution of the Republic of South Africa* (1996:5), “everyone is equal before the law and has the right to equal protection and benefit of the law”. No one, including state or non-governmental institutions, may unfairly discriminate, either directly or indirectly, against any person on the grounds of race, gender, colour, age or disability (*Constitution of the Republic of South Africa*, 1996:5). However, from the literature reviewed in Chapter 2, it is seen that several challenges in access to rights are experienced by persons with disabilities, including social barriers such as a lack of consideration of the different types of disabilities in the community. This leads to a lack of acceptance of people with disabilities by communities, as well as misunderstanding and prejudice that prevent society from appreciating and experiencing the full possibilities that individuals with disabilities can achieve, further negative attitudes due to ignorance and psychological barriers based primarily on fear for their safety (Bunning *et al.,* 2017:15; Menlah *et al.,* 2020:9; Wegner & Rhoda, 2015:1). Structural barriers include a lack of access to facilities and infrastructure, a lack of support services or technology, a lack of information in accessible formats and a lack of reasonable accommodation in schools and workplaces (Engelbrecht, 2020:219).

According to the South African Human Rights Commission (2021:4), Section 10 of the Constitution further provides that everyone has the right to have their dignity respected and protected. This is a clear acknowledgement that people with disabilities are equal and valuable members of society and should be acknowledged in all aspects of life. These disabilities also include CP. However, while the Constitution protects these rights, what happens on the ground differs from what is on paper. Pursuant to interrelated challenges experienced by children with disabilities, they are often inclined not to complete their education (World Report on Disability, 2015:10), are comparatively more inclined to be unemployed and are prone to earn less than their counterparts without disabilities. This situation worsens according to the severity of the impairment (World Report on Disability, 2015:10). Furthermore, due to the inaccessibility of health care, persons with disabilities oftentimes do not receive proper health care (Mont, 2021:23).

The *Constitution of the Republic of South Africa* (1996:4) implores the state to “respect, protect, promote and fulfil the rights in the Bill of Rights”. These include the rights of people with disabilities, and it does so through a legal framework that creates primary responsibilities for key government departments to promote and protect the rights of persons with disabilities. The *Promotion of Equality and Prevention of Unfair Discrimination Act* 4 of 2000 aims to promote equality and “provide for measures to facilitate the eradication of unfair discrimination, hate speech and harassment, particularly on the grounds of race, gender and disability”, among other things. With specific reference to disability, “no person may unfairly discriminate against any person on the ground of disability, including denying or removing from any person who has a disability, any supporting or enabling facility necessary for their functioning in society" (*Promotion of Equality and Prevention of Unfair Discrimination Act*, 2000:9). Moreover, "failing to eliminate obstacles that unfairly limit or restrict persons with disabilities from enjoying equal opportunities or failing to take steps to reasonably accommodate the needs of such persons" (*Promotion of Equality and Prevention of Unfair Discrimination Act*, 2000:9) is also prohibited.

The *Constitution of the Republic of South Africa* (1996:9-10) provides that every child has the right to, among other things, basic healthcare services and social services, as well as the right to basic education for all children of school-going age. However, five years after EWP6 was completed, it was reported that an estimated 280 000 disabled children and youth were not attending school in 2001 (Department of Education, 2001:15). The Constitution does not stipulate how it is going to ensure that the citizens of the country respect and ensure that what is captured in the Constitution is appreciated, respected and carried out. If all citizens were to respect the Constitution, then the families of children with CP would not struggle to ensure that they enjoy equal opportunities as those without disabilities. A very notable issue is the lack of a clear indication of how all citizens will be informed and taught about the Constitution. The Constitution is a good document that is well known by some but often not known by those who are already disadvantaged by poverty and a lack of education. In an attempt to improve the lives of those who contend with CP, the intended inclusive citizenship education proposed in this study will assist people in knowing the *Constitution of the Republic of South Africa* (1996) and the benefits and rights that are encapsulated in it.

The following section deals with the *South African Schools Act*, which is clearly linked with Section 29 of Chapter 2 of the *Constitution of the Republic of South Africa* (1996:12), which deals with the right to education.

3.5.2 The *South African Schools Act*

The *South African Schools Act*, which was promulgated in 1996, puts in place the critical elements required for the building of an education system framed by the ideas of the South African Constitution (Soudien, 2019:147). After the Constitution, it is the responsibility of the government to ensure that it puts in place systems in education that will ensure that there is uniformity in governance and in funding.

Soudien (2019:148) posits that the previously separate and racially bound education subsystem that served the country was brought together in a single administration by the *South African Schools Act* of 1996. This act attempted to standardise management through the curricula and funding platforms from which individual schools move to achieve specific and comparable outcomes in what all learners learn and how they learn (Soudien, 2019:148).

3.5.2.1 Background to and development of the *South African Schools Act*

In order to put into practice the rights guaranteed in Section 29 of Chapter 2 of the *Constitution of the Republic of South Africa* (1996), the South African parliament passed the *South African Schools Act* in 1996. The preamble of this act states clearly that South Africa needed a new national system for schools that would redress past injustices in the provision of education and provide an education of progressively high quality for all learners (*South African Schools Act*, 1996).

3.5.2.1 Contents of the *South African Schools Act*

The *South African Schools Act* (1996) has seven chapters that cover, among other things, the learner, public and independent schools and the funding of public schools. The chapter on the learner describes what is expected of learners and what age parents are expected to ensure that there is compulsory schooling (*South African Schools Act*, 1996). The chapter on public schools describes the public school in all its dimensions, its governance provisions and who has responsibility for specific aspects of the management and governance of the school. The norms and standards for funding public schools are stipulated in the *South African Schools Act* (1996), and the establishment of private schools and their provision of education are covered as well.

3.5.2.2 Analysis of the *South African Schools Act*

The *South African Schools Act* (1996) sees learners as people who are passively involved in schooling in that the responsibility of schooling is bestowed upon the parents. Parents are expected to ensure that learners attend school from the year in which they turn seven to the one in which they turn 15. The rights of these children, as stipulated in Section 29 of the *Constitution of the Republic of South Africa* (1996), are not emphasised. The parent is specified concerning the learning of the child as someone who has the obligation of ensuring that the child is in school, and where the child falters, it is the parent who will face investigation and punishment (*South African Schools Act*, 1996).

The Act emphasises that a “public school must admit learners and serve their educational requirements without unfairly discriminating in any way” (*South African Schools Act*, 1996:6). However, learners with disabilities, including CP, are still confronted with the challenge of not being admitted in schools of their choice. An example is the case of *Phadi v Meerhof and Others* (2017), in which the parents took the matter to court because they believed that the right to education of their child who had CP was tampered with in that the school was only prepared to admit the child as a day scholar and not to the hostel. The school argued that the child needed high care that the school could not afford and provide.

The *South African Schools Act* (1996:8) requires that a school adopts a Code of Conduct that must be dedicated to correcting and maintaining the quality of learning and the aim to establish a disciplined and steadfast school environment. While schools are aware of this requirement, Codes of Conduct that are developed, especially by formerly disadvantaged schools, are found to be wanting. It is unfortunate that these schools still have a majority of members of their school governing bodies not being conversant with the laws and acts of this country. Some are not educated or enlightened enough to be able to draw up a Code of Conduct that is in line with the policies of the government.

Furthermore, the *South African Schools Act* (1996) stipulates that corporal punishment may not be administered to learners. This provision has caused a great deal of discontent in schools and among parents with children of school-going age (Ogbe, 2015:23). Teachers and parents have complained about the state taking away their authority, with a lot of blame being placed on the state when it comes to ill-discipline at schools and some parents and teachers recommending that corporal punishment be restored (Ogbe, 2015:23). Recently, a study undertaken by *TimesLIVE* (2021:1) revealed that more than 20 years after corporal punishment was abolished, it is still practised in South African schools.

According to Section 3(5) of the *South African Schools Act* (1996), the admission policy of a school is determined by the school governing body. The policy may not exclude learners on the basis of language, disability, race, culture or religion. This matter has created a lot of problems, with some criticism indicating that these factors are used as tools not to admit learners of other racial groups or languages. Although school admissions have been contested in various court cases, for example the case between the School Governing Body and Rivonia Primary School and the MEC for the Education, Gauteng Province (Mestry, 2017:6), some schools in the country are perceived as using languages of learning and instruction that are said to be exclusive. The negligence of many schools to correctly interpret or consistently apply legislation and regulations relating to learner admission hampers the mandate of the government to correct past injustices and focus on social justice and equity in public education (Mestry, 2017:1).

The *South African Schools Act* (1996) stipulates that no one can establish and run an independent school unless it is approved and registered by the head of the Department of Basic Education. *Media24* (2020:1) reported the closure of two illegal schools in Johannesburg, and an illegal private school was shut down in Mpumalanga in May 2021 (*Media24*, 2021:1). It seems like the country is battling with illegal independent schools that have mushroomed in the large cities. When parents struggle to secure space for their children with disabilities in proper schools, these illegal schools are alternatives for them.

3.6 SUMMARY

Various policies and legal prescripts that govern the way in which disability and CP are handled in South Africa were interrogated in this chapter. The background of how these policies came into being, as well as their impact on society and those who are directly affected, was explored. A discussion of the research paradigm, research design, methodology and ethical considerations will unfold in the following chapter.

CHAPTER 4 METHODOLOGY, PARADIGM, DESIGN AND ETHICAL ASPECTS.

4.1 INTRODUCTION

This chapter provides a description and discussion of the research methodology that was used to collect the empirical data to address the research questions. Lucas *et al.* (2018:215) describe a methodology as a frame of reference on which the method of inquiry is based. Subsequently, the research methods, data collection and analysis, and trustworthiness will be discussed, followed by the research paradigm, research design, and ethical considerations that were at play in this research are discussed. To begin with, the research questions will be revised.

4.2 RESEARCH QUESTIONS

According to Jansen (2019:3), a research question is a beacon that guides a researcher in an effort to find answers. Jansen (2019:4) posits that it provides researchers with a focus for data collection and prevents them from drifting away from the original purpose. This is in line with Maree (2007:3) and Agee (2009:446), who say that research questions not only extract answers from the collected data but also act as a beacon for systemic progress towards the answering of the research questions. Moreover, research questions guide a researcher to the relevant literature to be engaged with for the purpose of the study. According to Maree (2019:27), the primary research question is a reframing of the statement of purpose in order to form a question. Secondary questions should be linked to the primary question and the statement of purpose (Maree, 2019:27). Furthermore, all secondary or sub questions should be researchable in their own right (Maree, 2019:27-28).

The primary research question of this study is:

Can inclusive citizenship education address the needs of families with members living with CP in the Bojanala District, North West Province?

The secondary questions that this study aimed to answer are as follows:

- What are the current practices and policies regarding inclusive education in the Bojanala District, North West Province?
- How does CP affect the families of people living with CP?
- What perceptions are evident in communities within which there are people living with CP?
- How can communities be assisted to transform their attitudes towards the families of people living with CP?
- What are the various role players' experiences of the support that is given to the families of people living with CP in order to accommodate them inclusively?

- What guidelines can be developed for a framework to support all role players?

4.3 RESEARCH METHODS

Research methods are the various techniques a researcher uses to generate data in order to respond to the research question (Hammarberg *et al*., 2016:499). According to Johnson and Christensen (2012, in Hammarberg *et al*., 2016), the research method also explains how the researcher will select the study population and how data will be collected. Creswell and Creswell (2018:53) use the term “research methods” to refer to techniques such as questionnaires, interviews, observation, document analysis, and artifact analysis. It is important to choose appropriate research methods in any study for the collected data to answer the research question. This study is about addressing CP through inclusive citizenship education in the Bojanala District, North West. The choice of research method had to be appropriate to suit the data collection, answer the research questions and reach the research aims. The tools selected to enable the researcher to gather data about this social reality for this study were interviews, the collection of textual information from policies, and general observations of the participants during the interviews. Furthermore, the researcher’s own experiences were considered, as these laid the foundation for this study as she found there was a general lack of assistance and education of individuals regarding children with CP.

4.3.1 Sample selection

Naderifar *et al*. (2017:1) define “sampling” as a process of choosing a part of the population to represent the whole. Showkat and Parveen (2017:1) agree with this definition and further describe sampling as a technique for selecting participants from a population. Sampling can generally be performed in two ways, namely probability and non-probability sampling (Naderifar *et al*., 2017:1). In the non-probability sampling method, the rules of probability are applied, and each sample has an equal chance of being selected (Naderifar *et al*., 2017:1). McCombes (2021) posits that nonprobability sampling involves non-random selection based on convenience or other criteria that allow the researcher to collect data easily. Consequently, non-probability methods of sampling involve samples that are available to the researcher or are selected by the researcher (Naderifar *et al*., 2017:2), resulting in not everyone having an equal chance of being selected.

The different methods of non-probability sampling are convenience, purposeful and quota sampling. With the purposive sampling technique, participants are selected based on their knowledge of, relationship with and expertise in a research subject (Grey, 2014:217; Merriam & Tisdell, 2016:108). Gray (2014:174) explains that within qualitative research, purposeful non-probability sampling is utilised as a result of insights gained from a particular phenomenon within a specific context and time. McCombes (2021) states that purposive sampling involves the researcher using his or her expertise to select a sample; this sample is usually the most useful and reliable for the purposes of the research. Qualitative research is where the researcher wants to gain detailed knowledge about a specific phenomenon rather than draw statistical inferences.

Purposive non-probability sampling was used in this study. Participants were selected purposefully, as they possessed rich information about the phenomenon of CP and inclusive citizenship education. Nieuwenhuis (2019:93) submits that "members of a sample are chosen with a 'purpose' to represent a phenomenon, group, incident, location or type in relation to a key criterion". Although the findings cannot be generalised with confidence to the entire population based on the size of the sample, the purpose of qualitative research is to gain a deeper understanding of a phenomenon rather than to generalise the findings (Naderifar, 2017:2).

According to Kyngäs *et al*. (2020:8), an adequate sample size is not defined in qualitative research, as data collection stops once saturation occurs, that is, when the participants' information becomes repetitive, with nothing new being reported. Qualitative researchers should ensure that the chosen informants have the best possible knowledge of the research subject; hence, researchers will often use a convenience sample comprising people who are related to the research topic (Kyngäs *et al*., 2020:8). There are no rules for sample size in qualitative research, as the sample size depends on what a researcher wants to know and what can be done with the available time and resources (Nieuwenhuis, 2019:92; Patton, 1990:184). According to Merriam and Tisdell (2016:18), qualitative research usually makes use of non-random purposeful selection, which entails a small sample.

In this study, the sample consisted of 17 participants – nine biological parents of children with CP and two members of extended families living with and taking care of the child (caregivers), along with six community members who resided in the locality of the six families and had some affiliation with the families of the children with CP. All the participants resided in the rural parts of the Bojanala District in the North West Province of South Africa.

4.3.2 Inclusion criteria

The sample that was selected met the following inclusion criteria, as provided by Diseko (2017:19) in her study of the experiences of caregivers caring for children with CP in Mahalapye, Botswana. The participants had to be the biological parents of a child living with CP or members of the extended family who took care of a child with CP (caregivers). The names of the children were obtained from the registry of the Department of Health (see permission letters – Annexures D and E). In addition, close community members who resided in the same locality and had some affiliation with the family or the child with CP were included. Another important criterion that guided the inclusion of participants was that they had to reside in the rural parts of the Bojanala District.

4.3.3 Exclusion criteria

Exclusion criteria are factors that disqualify participants from participating in a study (Hornberger & Rangu, 2020:4). In this study, the following people were excluded as participants: biological parents or caregivers of children with CP who were not on the Department of Health registry and were unknown to the Department, as well as people who did not live in the rural parts of the Bojanala District. People who were under the age of 18 years or mentally incapacitated were also excluded, as they represent a vulnerable population that would need extra care.

4.3.4 Data collection

Data were collected for this study by engaging in three different methods, namely a literature review, document analysis and in-depth interviews. The study used triangulation to validate and ensure the reliability of the collected data, as indicated below.

4.3.4.1 Literature study and policy document analysis

The first phase of the study was a detailed and thorough study of the available and relevant literature on the phenomenon, which was done to contextualise the study, grounding it in the most recent and relevant research that is pertinent to CP. Along with this, a document analysis of the relevant South African policies and legal acts was undertaken to ascertain the stance of the government on disabilities, support and related topics. Reference was made to various sources to minimise bias, as it ensured that the data collected were enriched, refuted, confirmed and explained (see Carvalho & White, 1997).

4.3.4.2 Semi-structured interviews

A semi-structured, in-depth interview is a personal and unstructured formal or informal conversation to identify and explore a participant’s emotions, feelings and opinions on a particular research subject (Langkos, 2014:38). DeJonckheere and Vaughn (2019:2) add that semi-structured interviews are used to gather information from key participants who have personal experience, attitudes, perceptions and beliefs related to the topic of interest. Nieuwenhuis (2019:108) contends that an unstructured interview often takes the form of a conversation. Thus, these conversations are often used by the researcher to explore the participants’ views, ideas, beliefs and attitudes about specific events or phenomena (Nieuwenhuis, 2019:108).

The advantages of using semi-structured interviews are that there is direct contact between the researcher and the participant during these personal interviews, providing the researcher with an opportunity to become involved with the participant and facilitating responses by the participant (Langkos, 2014:38). DeJonckheere and Vaughn (2019:1) explain that to obtain quality data, interviews should not be conducted with a transactional question-and-answer approach. An interview should rather be an unfolding conversation of interactive interactions that occur between the interviewer and the interviewee (DeJonckheere & Vaughn, 2019:1).

Semi-structured interviews are usually based on questions the researcher prepared before the interview (Nieuwenhuis, 2019:93). These are usually followed by other questions to obtain further clarity. Merriam and Tisdell (2016:110) posit that semi-structured interviews permit more flexibility and responsiveness to themes by both the researcher and the participants, hence their popularity. As indicated earlier, in order to obtain comprehensive information from family and community members, the researcher conducted semi-structured individual interviews with 17 participants (see Annexures A and B). The majority of these interviews were conducted in Setswana, which was the local language and mother tongue of the participants. A few participants preferred using English during the interviews to share their personal experiences and views. This was in accordance with the notion that qualitative research is exploratory and new knowledge can be extracted from the data that are collected (Johnson & Christensen, 2012, in Hammarberg *et al*., 2016:499).

Merriam and Tisdell (2016:131) contend that digitally recording interview data is common in research. According to them, this method guarantees the security of information for analysis and also provides the researcher with a chance to listen for ways of improving the interview (Merriam & Tisdell, 2016:131). Furthermore, they believe that audio recordings are the most rooted practice of ensuring that everything that was said is preserved for analysis (Merriam & Tisdell, 2016:131). Grey (2014:397), on the other hand, prefers a dual method of recording interviews. He proposes that both written notes and audio recordings should be utilised so that key words can be noted to describe the researcher’s observations (Grey, 2014:397).

For this study, the researcher chose the dual method and, accordingly, collected the data. Before the researcher started with the interviews, she obtained the approval of the participants to use a small recording device and to take notes on her writing pad. She operated the recording device and took notes as the interviews unfolded. It is important to note that the researcher was personally involved in transcribing the data, and this helped her to become acquainted with the data that had been obtained. This is in line with what is proposed by Merriam and Tisdell (2016:131), namely that it is beneficial to transcribe the interview oneself because one becomes increasingly familiar with the data and has the chance to write analytic memos during the transcription process. The notes that had been made during the interviews were compared to the recorded and transcribed data for themes that unfolded (see Section 4.7 below and Chapter 5). The researcher was also involved in the transcription and translation of the interviews from Setswana to English, turning them into text while quoting the participants verbatim.

In this study, the process of interviewing the families of people living with CP, as well as members of the communities within which they lived, gave the researcher an opportunity to obtain their views and uncover new aspects regarding this topic.

4.3.5 Data Analysis and Interpretation

Creswell and Creswell (2018:218) and Ngulube (2015:1) comment that qualitative data analysis is about transforming raw data. This transformation is usually done through various techniques, such as searching, evaluating, recognising, coding, mapping, exploring and describing patterns, trends, themes and categories (Creswell & Creswell, 2018:218; Ngulube, 2015:1). These techniques are used in order to interpret the raw data and provide their underlying meanings. Creswell and Creswell (2018:152), Merriam and Tisdell (2016:195) and Thomas (2017) all agree that qualitative data analysis has general aims that describe a phenomenon by comparing several cases and highlighting the commonalities or differences and that a theory of the phenomenon under study can be postulated from the empirical material.

Flick (2014:3) believes that data analysis represents a central step in qualitative research, having a great influence on the outcome of any research conducted. This idea is supported by Graue (2016:8), who argues that qualitative data analysis is a process of describing, classifying and interconnecting phenomena on the basis of the researcher’s concepts. McMillan and Schumacher (2014:364) state that the data in qualitative research are analysed as they are collected because data collection and analysis are interactive and occur in overlapping cycles. This explanation is supported by Ngulube (2015:2), who states that it is not always possible to separate data analysis from data collection in qualitative research, as analysis sometimes occurs during data collection. In line with this, data analysis in this study started as soon as the data were collected to avoid forgetting and overlooking emerging patterns.

4.3.5.1 Thematic Analysis of data

The data were analysed through thematic analysis. According to Maguire and Delahunt (2017:2-3), thematic analysis is a method by which themes are systematically identified and analysed. It further is the process in which the data are organised and described in detail in order to respond to the research question (Maguire & Delahunt, 2017:5). Clarke and Braun (2013:78) and Merriam and Tisdell (2016:202) state that thematic analysis offers a clear and usable framework for analysing data (see Figure 4-1). After performing these steps, the researcher was able to establish themes (patterns in the data that are significant) that could "tell the story" of the phenomenon being researched as perceived by the participants. This was in line with what Maguire and Delahunt (2017:5) assert, namely that a good thematic analysis makes sense of the data collected and highlights the themes and interesting or important aspects.

The six stages of qualitative data analysis as proposed by Braun and Clarke (2006:87) and Scharp and Sanders (2018:2) were used in this research. These six stages are set out in Figure 4-1.

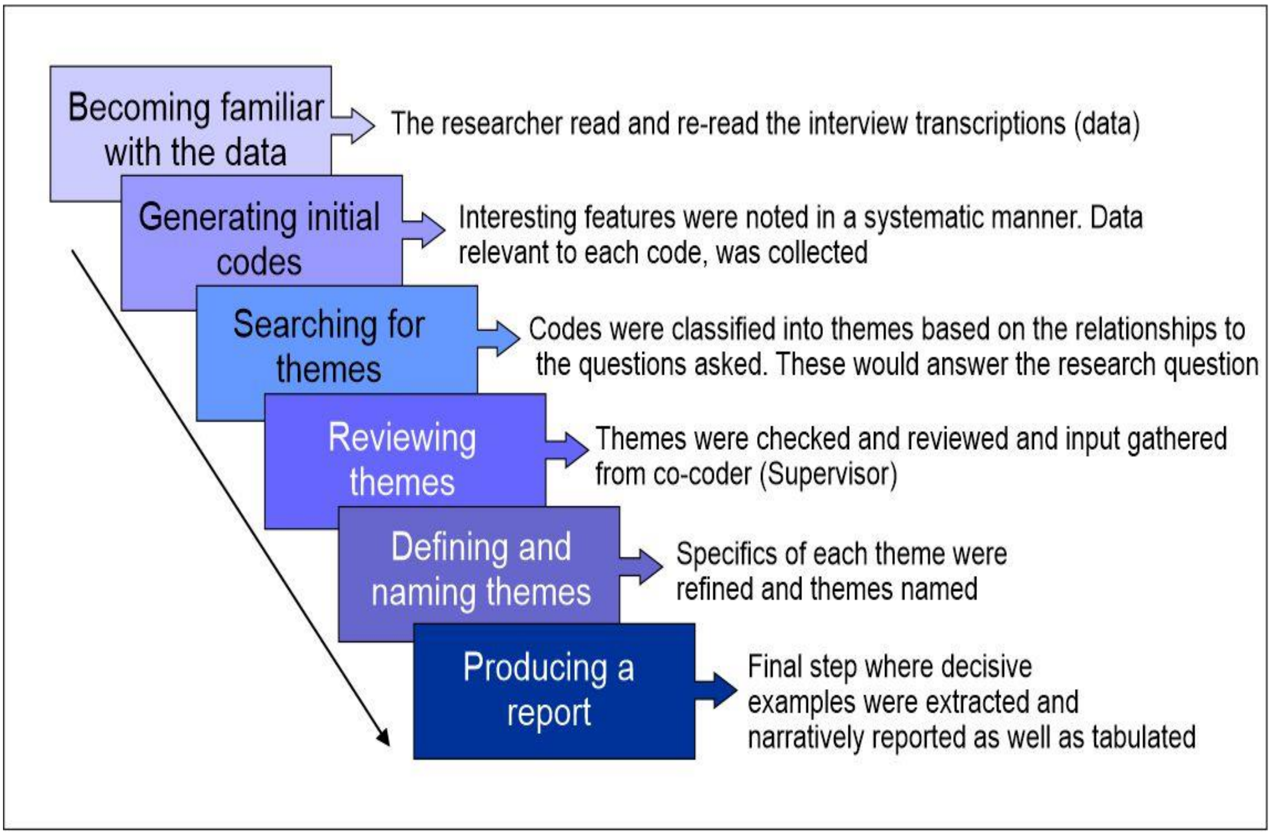


Figure 4-1: Steps in thematic analysis (adapted from Braun & Clarke, 2006) with the researcher's input at every stage.

As indicated in figure 4-1, the researcher used coding guidelines to generate the codes, after which the researcher identified themes based on the codes. In figure 4-2 the researcher included a text excerpt of how she identified the codes and themes

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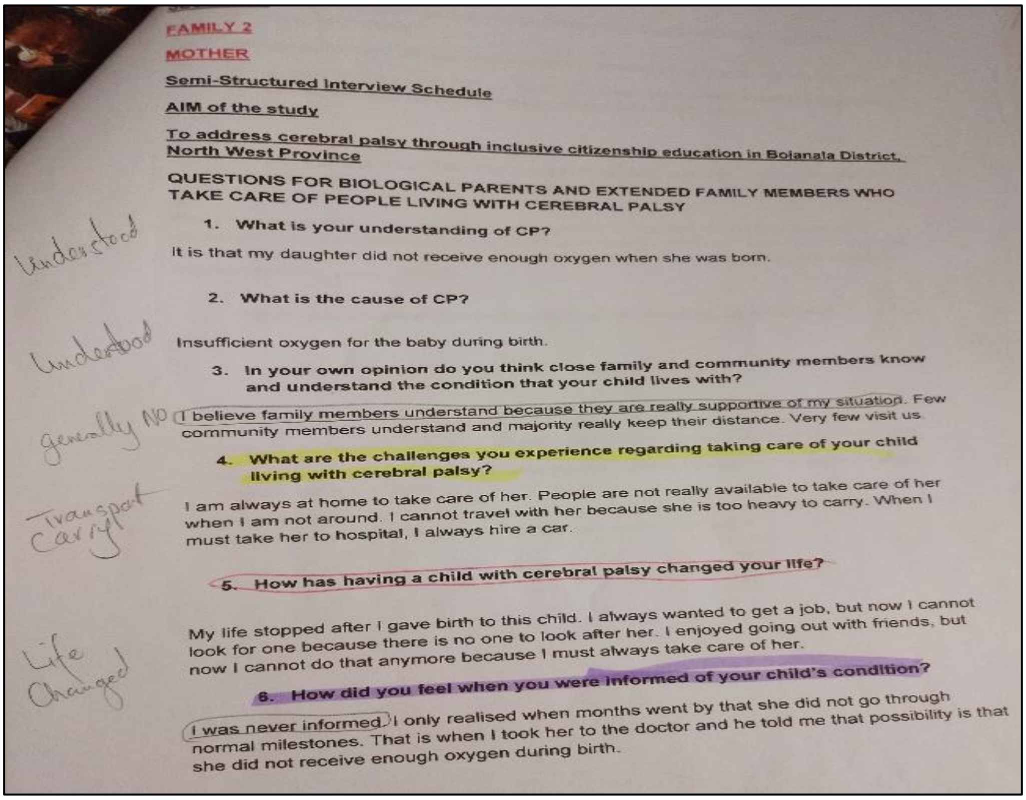


FAMILY 2

MOTHER

Semi-Structured Interview Schedule

AIM of the study

To address cerebral palsy through inclusive citizenship education in Bojanala District, North West Province

QUESTIONS FOR BIOLOGICAL PARENTS AND EXTENDED FAMILY MEMBERS WHO TAKE CARE OF PEOPLE LIVING WITH CEREBRAL PALSY

1. **What is your understanding of CP?**

Understood

It is that my daughter did not receive enough oxygen when she was born.

2. **What is the cause of CP?**

Understood

Insufficient oxygen for the baby during birth.

3. **In your own opinion do you think close family and community members know and understand the condition that your child lives with?**

generally No

I believe family members understand because they are really supportive of my situation. Few community members understand and majority really keep their distance. Very few visit us.

4. **What are the challenges you experience regarding taking care of your child living with cerebral palsy?**

Transport
Carry

I am always at home to take care of her. People are not really available to take care of her when I am not around. I cannot travel with her because she is too heavy to carry. When I must take her to hospital, I always hire a car.

5. **How has having a child with cerebral palsy changed your life?**

Life
Changed

My life stopped after I gave birth to this child. I always wanted to get a job, but now I cannot look for one because there is no one to look after her. I enjoyed going out with friends, but now I cannot do that anymore because I must always take care of her.

6. **How did you feel when you were informed of your child's condition?**

I was never informed. I only realised when months went by that she did not go through normal milestones. That is when I took her to the doctor and he told me that possibility is that she did not receive enough oxygen during birth.

Figure 4-2: Text excerpt of the identified themes which was obtained from the coding

4.3.5.2 Trustworthiness of the data

The trustworthiness of qualitative research is an important aspect that makes a study credible and reliable. Researchers must ensure that credibility, transferability, dependability, and confirmability are taken care of to ensure trustworthiness (Korstjens & Moser, 2018:2). All these aspects were considered in the study and are communicated under each heading below.

4.3.5.3 Credibility

According to DeJonckheere and Vaughn (2019:7), credibility refers to whether the findings of a study accurately and fairly represent the data. Kyngäs *et al*. (2020:42), on the other hand, argue that credibility involves two aspects, namely carrying out the study in a way that ensures that readers will believe the presented findings and taking steps to demonstrate credibility in the research report. Ngozwana (2018:25) describes reflexivity as a form of continuous self-scrutiny by the researcher, which assists in the preservation of credibility. Reflexibility portrays the views and opinions of the researcher against those of the participants (Ngozwana, 2018:25). In this study, credibility was ensured through prolonged engagement and reflexivity. While collecting data from various family members of the person living with CP and other close community members, the researcher did self-scrutiny on a continuous basis and then compared this with other collateral information to be able to make sense, derive meaning and draw conclusions from the data.

4.3.5.4 Transferability

Transferability denotes whether the findings of a study can be applied to other situations and circumstances (DeJonckheere & Vaughn, 2019:7). In this study, transferability was implemented by retaining all records of the research from beginning to end (see Korstjens & Moser, 2018:2) to ensure that the study could be replicated if necessary. The study provides a database that will allow readers and other researchers to relate the information in the study to their own experiences.

4.3.5.5 Dependability

Dependability refers to whether the findings of a study are consistent and sustainable over time (DeJonckheere & Vaughn, 2019:7). Lincoln and Guba (1985, in Kyngäs *et al*., 2020:44) define dependability as an assessment of the quality of the entire process of data collection, data analysis and theory generation, while Kyngäs *et al*. (2020:44) see it as referring to the stability of data over time and under different conditions. Furthermore, dependability is concerned with consistency across the research, from the starting point to the data collection and analysis (Kyngäs *et al*., 2020:44). The dependability of this study was ensured by recording all responses both manually and by using a recording device. This was done after obtaining permission from all the participants to do so. All records, notes, minutes of meetings, interview transcripts and any other information relating to the research process are kept in order to ensure the dependability of the study (see Korstjens & Moser, 2018:2). Furthermore, an external audit of the study by supervisors and external examiners will be used to determine the dependability of the study.

4.3.5.6 Confirmability

Confirmability is about the ability of the results of a study to be neutral (Korstjens & Moser, 2018:3). Emmanuel and Wendler (2008:123) argue that confirmability is a measure of how well the study findings are supported by the data collected by focusing on the connection between the data and the results (Kyngäs *et al*., 2020:46). In this study, the researcher ensured confirmability by documenting every procedure (literature review, document analysis and interviews) to ensure that the outcome is based on the true experiences of the participants, and not on the researcher’s personal biases or perceptions.

4.4 RESEARCH PARADIGM

“Research paradigm” is defined by Schwartz and Ogilvy (1979:1) as an enabler to tell a coherent story by depicting a world that is meaningful and functional but culturally subjective. This notion is supported by Lincoln and Guba (1985:15), who see a paradigm as a representation of what one thinks about the world but cannot prove. More recently, a research paradigm was defined by Nieuwenhuis (2019:58) as a set of assumptions or beliefs about fundamental aspects of reality. These beliefs reflect a particular worldview. The research paradigm addresses basic assumptions taken on faith, such as beliefs about the nature of reality and the relationship between the knower and what is known, as well as assumptions about methodologies (Nieuwenhuis, 2019:58).

Terre Blanche and Durrheim (2006:36) state that paradigms are comprehensive systems of interrelated practice and thinking. Paradigms usually define the nature of the researcher’s enquiry for him or her along three dimensions. These three dimensions reflect the manner in which one uniquely views and critically transforms the world (ontology), the way in which one creates knowledge (methodology) and where the transformation of one’s knowledge takes place (epistemology). In interpreting these definitions, Nieuwenhuis (2019:58) argues that a paradigm serves as the lens through or organising principle by which reality is interpreted.

There are different types of paradigms, such as interpretivism and positivism (Nieuwenhuis, 2019:67). Bonache and Festing (2020:104) describe positivism as a research paradigm that seeks to explain and predict what happens in the social world, which is accomplished by searching for regularities and causal relationships between its constituent elements. According to Kumatongo and Muzata (2021:17), positivism assumes that reality is objectively given and can be measured by using independent properties by the researcher and his or her instruments.

Interpretivism was strongly influenced by phenomenology and is an approach that advocates the need to consider the subjective interpretations of human beings and their perceptions of the world (Nieuwenhuis, 2019:67). This subjective view can then be used as a starting point to understand social phenomena (Nieuwenhuis, 2019:67). Furthermore, interpretivists believe that reality is not objectively determined but socially constructed. Because of this, Hussey and Hussey (1997, as cited by Nieuwenhuis, 2019:67) state that the assumption is that by studying people in their social context or natural environment, there is a greater opportunity to understand the perceptions they have of their own activities. According to Kumatongo and Muzata (2021:18), interpretivist researchers believe in reality based on people’s subjective experiences of the external world. Furthermore, they assume that knowledge and meaning are acts of interpretation; thus, they refute an objective view of knowledge (Kumatongo & Muzata, 2021:18). Nieuwenhuis (2019:67) posits that in order to understand how people construct meaning within their situation, their world should be entered into and observed from within through the direct experience of the person. This is the essence of interpretivism, as interpretivism focuses on people's subjective experiences, how they construct the social world by sharing meanings and how they interact with and relate to one another.

According to Bonache and Festing (2020:104), the objective of interpretivism is to make meaning of the subjective intentions of individuals. It must be remembered that each subjective intention must be seen in context, without imposing a previous analytic category or idea. Thus, in this attempt to understand the world from the participant's perspective, an interpretative effort by the researcher is required (Bonache & Festing, 2020:104). Whereas Merriam and Tisdell (2016:9) believe that interpretive research is the most common type of qualitative research, Bonache and Festing (2020:104) disagree, saying that it is rarely used when compared to positivism.

Based on the arguments above, this study was undertaken from an interpretivist perspective. This perspective was used because the researcher believed that in order to answer the research question on the use of inclusive citizenship education to address the needs of families with members living with CP in the rural parts of the Bojanala District, the participants' own construction of knowledge would be needed. In obtaining this information, an understanding of the phenomenon would enable the researcher to draw logical conclusions regarding the perspectives the family and community members have of CP. Understanding these perspectives would then assist in the use of inclusive citizenship education to inform families and communities that must contend with CP.

4.5 RESEARCH DESIGN

A research design comprises a plan and a structure. Merriam and Tisdell (2016:17) state that a research design serves to plan, structure and execute the research to maximise the validity of its findings. It also gives directions from the underlying philosophical assumptions for the research design and data collection (Merriam & Tisdell, 2016:17). A research design can also be seen as the manner, path or strategy that one employs to move from an underlying philosophical assumption or paradigm to a research-level on which meaning can be made from the data collected (Kivunja & Kuyini, 2017:26). Therefore, the research design specifies the selection of the participants, the data gathering techniques to be used and the data analysis to be done to produce a comprehensive research study (Maree, 2019:95). According to Asenahabi (2019:77), a research design reflects the researcher's ideas and assists him or her to put together a structured plan that shows how all the sections of the research work together to address the research questions. Asenahabi (2019:78) further posits that a research design is a process adopted by a researcher before data collection and the analysis process commence in order to achieve research objectivity in a valid manner. Furthermore, a research design usually determines the analysis done and indicates what data are required, what methods will be used and how the data are going to answer the research questions

(Asenahabi, 2019:78). This explanation is supported by Nieuwenhuis (2019:80), who states that a research design is a process that is grounded in the underlying philosophical assumptions, progressing to specifying the selection of participants and indicating the data-gathering methods to finally underpinning the data analysis done. Furthermore, the choice of research design is usually based on the researcher's ontological and epistemological perspective, research skills and research practices, all of which influence the way in which data are collected and analysed (Nieuwenhuis, 2019:80).

Generally, research designs are divided into three groups, namely qualitative, quantitative and mixed-methods research (Asenahabi, 2019:78). A qualitative approach was used in this research in order to gain information on and knowledge of the experiences, engagements, perceptions and attitudes of the families of people with CP, as well as community members who must contend with the challenges CP presents. Qualitative research is aimed at studying phenomena, ideas or events in their natural settings. In this study, participants reported on their experiences, engagements, perceptions and attitudes regarding CP, from which the researcher attempted to make sense of or interpret the phenomenon in terms of obtaining answers to the unique meanings people attach to their experiences (see Denzin & Lincoln, 2011, in Creswell & Poth, 2018:7). Furthermore, as this research used a qualitative research design, it involved an interpretive, naturalistic approach (see Creswell & Poth, 2018:7). This is in line with Hammarberg *et al*. (2016:499), who argue that qualitative research methods are usually used to answer questions about a participant's experience, meaning and perspective, and these experiences are most often interpreted from the standpoint of the participant.

4.6 ETHICAL CONSIDERATIONS

Ethical considerations, or ethics, are a widely accepted set of moral principles (Thomas, 2017). These principles define the rules, correct conduct and behavioural expectations of the researcher towards participants and respondents. Thus, research procedures should always be ethical and legal and reflect the integrity of the researcher (Tetzner, 2021:1). Ethical issues emerge during different phases of the research process, namely prior to conducting the study, at the beginning of the study, during data collection and analysis, in reporting the data and in publishing the study (Creswell & Poth, 2018:53). According to DeJonckheere and Vaughn (2019:4), ethical attitudes that should be present at the beginning include that the researcher should show respect, sensitivity and tact towards the participants throughout the research process. To observe the ethics prescripts, the researcher took various steps, as set out below.

4.6.1 Ethics committee

Before this research was conducted, the researcher applied for and received ethical clearance from the EMTEL Ethics Committee of the North-West University (NWU-01117-20-A2), dated 13 October 2020 (see Annexure C). The researcher also requested permission from the North West Department of Health to conduct the research, as the participants were sought from the register of the Department; this permission was granted (see Annexures D and E). Furthermore, the Department of Social Development was approached to assist with a social worker to act as a mediator between the researcher and the participants. Two social workers agreed to be part of the study (see Annexure F).

4.6.2 Protection from harm

Harm can range from physical harm, to resource loss such as time, emotional harm and reputational harm (Flemming & Zegwaard, 2018:211). To ameliorate this situation, the participants have to be fully informed of what the risks are (Flemming & Zegwaard, 2018:211). In this study, the participants were protected from potential harm by using social workers to act as mediators. These social workers, who signed indemnity forms (see Annexure J), explained all the processes of the research to the participants. The first contact was made when the mediators used flyers that were easy to read to explain what the research entailed (see Annexure G). The potential participants were then given letters of consent that clearly stipulated that participation in the study was voluntary and that they were free to withdraw from the study at any time they wanted (see Annexure H). This is in line with what Flemming and Zegwaard (2018:211) and Thomas (2017) indicate as aspects of consent, which should include information on the right of participants to withdraw from the study at any time and without providing a reason and the participants' right of access to their data.

People who showed an interest in participating in the study were given a week to consider their participation. After a week, the mediators went back to collect their signed letters of consent and returned these to the researcher in sealed envelopes. This was done in line with the guidelines of Merriam and Tisdell (2016:261). All interviews were held in the privacy of the participants' homes. As the study was undertaken during the Covid-19 pandemic, all protocols were observed (see Annexure I). Furthermore, a social worker was readily available during the interviews in case some questions evoked intense emotions in the participants.

4.6.3 Voluntary participation

All the participants were informed by the mediator that their participation was voluntary. This is in line with Sim and Waterfield's (2019:3004) assertion that coercion to participate in research cannot be entertained. As indicated earlier, the letters of consent that were signed by the participants highlighted that their participation was voluntary and that they could withdraw at any time. The participants were continuously assured of their right to withdraw during the process (see Annexure H).

4.6.4 Confidentiality and anonymity

Confidentiality and anonymity mean that the setting and participants should not be identifiable in any reporting on the study (Ngozwana, 2018:26). Furthermore, Flemming and Zegwaard (2018:211) argue that participants' confidentiality means that although their identities are known to the researcher, the data have been de-identified and their identities are kept confidential. Sim and Waterfield (2019:3008), on the other hand, state that confidentiality relates to what is done with the information once it is in the researcher's possession, and specifically the extent to which it is disclosed to others. To safeguard confidentiality in this study, the researcher ensured that identifying details were made anonymous by allocating numbers and letters to the participants and their responses. This ensured that no individual's responses could be linked to any specific participant. Researchers should always focus on active care of and respect for participants (Tetzner, 2021:1) and ensure confidentiality, which entails not discussing any aspect of the participants who are involved in the research without their written consent.

In addition, confidentiality was ensured by requiring that the official from the Department of Health who identified potential participants from the register of the Department, as well as the mediators (the social workers from the Department of Social Development who administered the consent form), signed confidentiality forms (see Annexure K). The reports on the findings are anonymous, which makes it impossible to trace any information to any of the participants. Thus, all personal information regarding the participants is known only by the researcher and the Department of Health official and the mediators who all signed confidentiality forms. The recorded interviews were transcribed, and the voice recordings are stored on a password-protected device. These records will be deleted after five years. All recorded interviews and consent forms containing the biographical information of the participants were kept in a locked filing cabinet in the researcher's home office and were shredded upon completion of the research.

4.7 SUMMARY

In this chapter, the research methodology, paradigm, design and ethical aspects, were discussed. The researcher also explained why the qualitative research method was followed. Before data could be collected, the social workers who were used as mediators contacted the identified families to inform them of and prepare them for the research. This was done because they were identified through the registry of the Department of Health and to ensure that the participants' fear was allayed. While the mediators were readily available during the interviews, their services were not needed.

Chapter 5 provides a discussion of the analysis of the data and the interpretation thereof. During this process, the main question, sub-questions and research aims and objectives will be examined to ascertain whether they have been responded to. The theoretical framework employed in this research will also be used to check whether the research aims have been achieved.

CHAPTER 5 DATA ANALYSIS AND INTERPRETATION

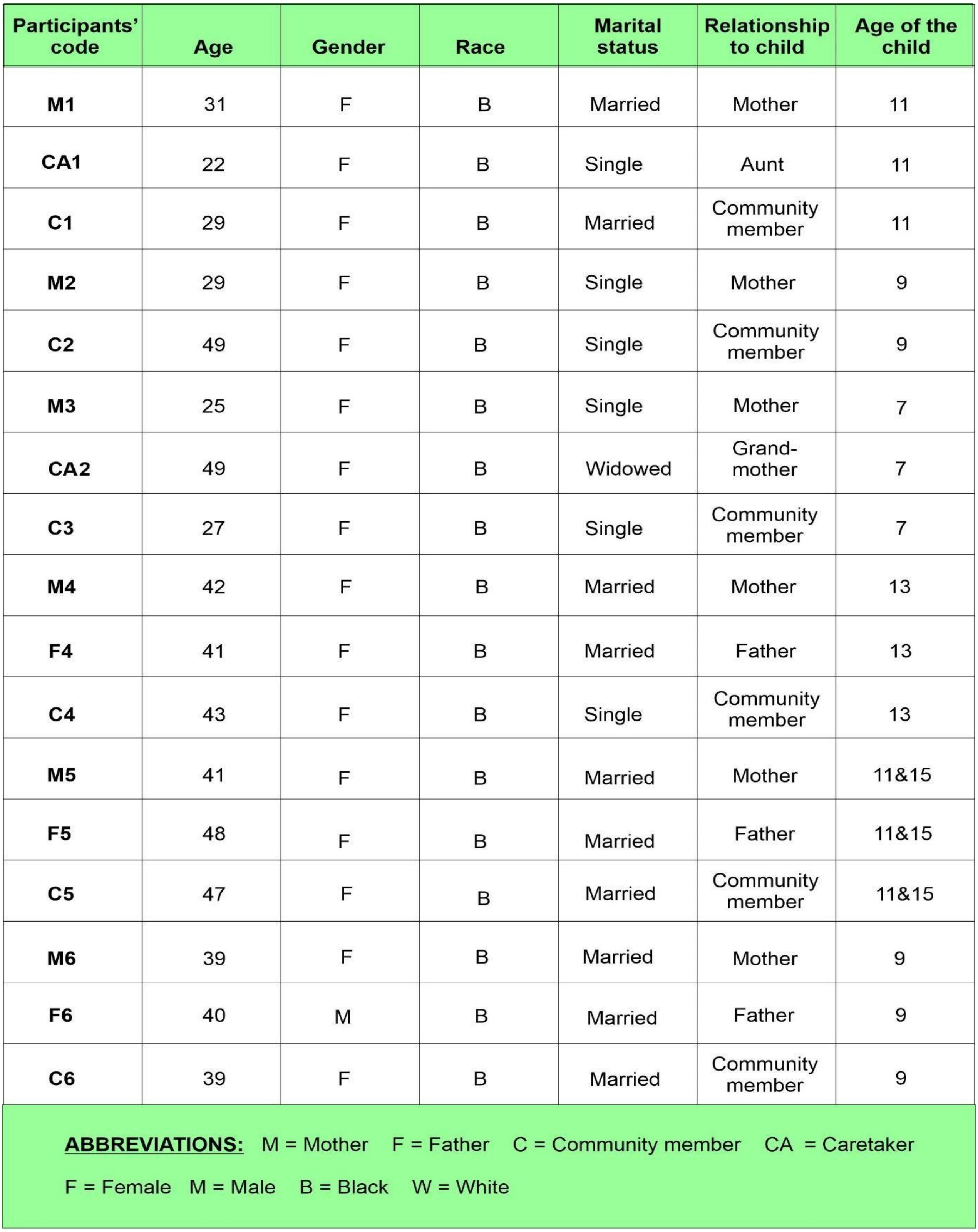
5.1 INTRODUCTION

The research design and methods used in this research, as well as the rationale for using them, were presented in the previous chapter. In this chapter, the empirical data collected are analysed and interpreted. Padgett (2016:68) describes data analysis as a process of bringing order, structure and meaning to a mass of collected data. The aim of the study, as was previously indicated, was to explore the impact of CP on the families of children who must contend with it and to establish how inclusive citizenship education might assist in the plight of these families, children with CP and their communities.

5.2 BIOGRAPHICAL INFORMATION OF PARTICIPANTS

A qualitative research approach was used, and as has been indicated earlier in the study, semi-structured interviews were conducted with nine biological parents and two caregivers who were members of the extended families of children with CP, as well as six community members who had some affiliation with the families of the children with CP. The initial plan was to have two parents or caregivers per household, but one family had only one participant instead of the anticipated two. However, this did not pose a challenge since, by the tenth interview, data saturation, which is the conceptual yardstick for estimating and assessing qualitative sample sizes (see Lincoln & Guba, 1985; Guest *et al.,* 2020:1), had already been reached. In other words, various themes had already been repeatedly mentioned and no new information was emerging. As was indicated earlier, 10 of the 17 participants were interviewed in their mother tongue, which was Setswana. The researcher then translated these interviews into English. The other seven participants preferred English.

Three participants were male, and 14 were female. The participants ranged from 22 to 49 years of age (mean = 37,7). The participants consisted of 14 black and three white members. The age of the children with CP ranged from three to 15 years (mean = 9,4). One family had two children with CP. Twelve of the participants were unemployed (70,5%), while the other five (29,5 %) were employed. The marital status and relationship of the participants with regard to their children are indicated in Table 5-1.



Participants' code	Age	Gender	Race	Marital status	Relationship to child	Age of the child
M1	31	F	B	Married	Mother	11
CA1	22	F	B	Single	Aunt	11
C1	29	F	B	Married	Community member	11
M2	29	F	B	Single	Mother	9
C2	49	F	B	Single	Community member	9
M3	25	F	B	Single	Mother	7
CA2	49	F	B	Widowed	Grand-mother	7
C3	27	F	B	Single	Community member	7
M4	42	F	B	Married	Mother	13
F4	41	F	B	Married	Father	13
C4	43	F	B	Single	Community member	13
M5	41	F	B	Married	Mother	11&15
F5	48	F	B	Married	Father	11&15
C5	47	F	B	Married	Community member	11&15
M6	39	F	B	Married	Mother	9
F6	40	M	B	Married	Father	9
C6	39	F	B	Married	Community member	9

ABBREVIATIONS: M = Mother F = Father C = Community member CA = Caretaker

F = Female M = Male B = Black W = White

Table 5-1: Biographical information of participants.

5.3 METHOD OF DATA ANALYSIS: THEMATIC ANALYSIS

As indicated earlier, thematic analysis was done in this study. Maguire and Delahunt (2017:2-3) describe thematic analysis as a method in which themes are identified and analysed, with data being organised and described in detail. Thus, thematic analysis is done in order to answer the research question (Maguire & Delahunt, 2017:5). Furthermore, thematic analysis is a method for analysing qualitative data that entail searching across a data set to identify, analyse and report repeated patterns (Braun & Clarke, 2006:87; Kiger & Varpio, 2020:2). Both Kiger and Varpio (2020:2) and Braun and Clarke (2006:82) stipulate that thematic analysis is a method for describing data and involves interpretation in the processes of selecting codes and constructing themes. Kiger and Varpio (2020:2) describe themes as patterned responses or meanings derived from the data that informs the research question.

The most widely accepted framework for conducting thematic analysis, which involves a six-step process, was followed by the researcher (see Braun & Clarke, 2006:87; Clarke & Braun, 2013:78; Scharp & Sanders, 2018:2; Kiger & Varpio, 2020:2). The six steps of this process are familiarising oneself with the data, generating initial codes, searching for themes, defining the themes, naming the themes and producing the report.

5.4 RESULTS OF THE STUDY

Five themes and 17 sub-themes were identified in this study. These are presented in Table 5-2.

THEMES AND SUB-THEMES OF THE RESEARCH STUDY	
THEMES	**SUB-THEMES**
THEME 1: Knowledge about CP	Lack of knowledge
	Cultural beliefs (witchcraft)
THEME 2: Impact of CP	Isolation
	Lack of employment
	Burden of care
	Stress and frustration
THEME 3: Resources for families with members living with CP	Financial burden
	Lack of schools
	Assistive devices
	Lack of or insufficient information from professionals
THEME 4: Psycho-social experiences and support	Isolation
	Stigmatisation
	Lack of support
	Feelings of devastation and denial
THEME 5: Possible interventions	Schools and care centres (educational aspects)
	Financial and physical resources
	Professional support

Table 5-2: Themes and sub-themes of the research study

5.5 THE NARRATIVE DISCUSSION OF THE THEMES AND SUB-THEMES

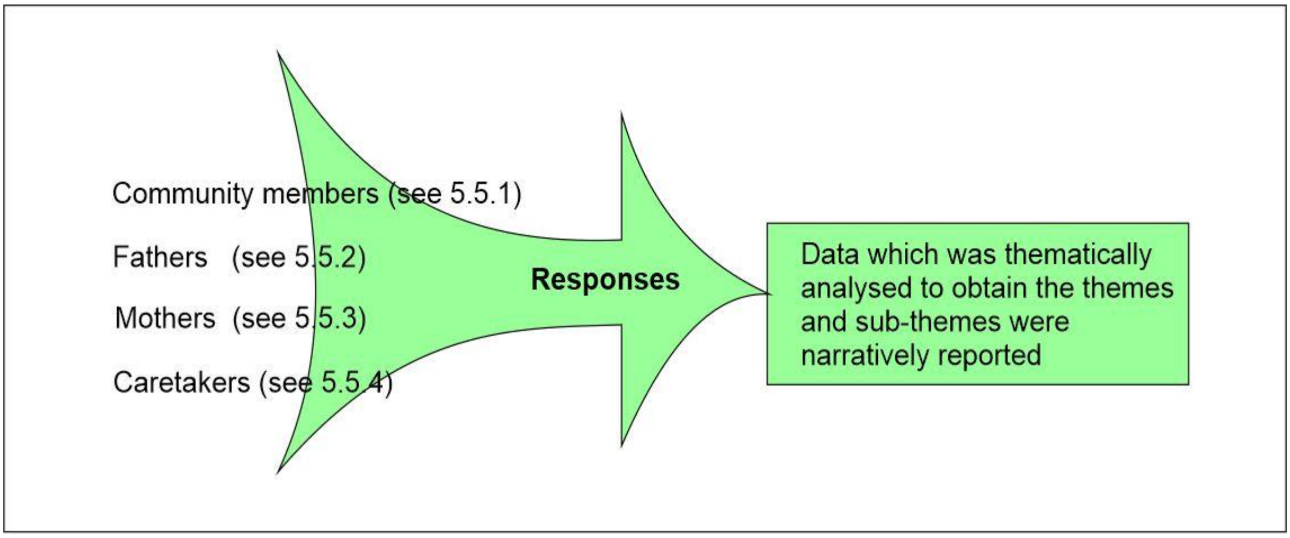


Figure 5-1 Responses from the participant's interviews, which formed the theme and sub-themes

A narrative discussion of how the five themes and sub-themes were identified follows in the next section. The data were collected through face-to-face audio interviews that were transcribed. Specific groups of people were interviewed, namely members of the community and family members of children with CP. Some researchers (e.g. Monk & Wee, 2008:104; Tigere & Makhubele, 2019:2) posit that compared to other social institutions, such as the school and community, family is the most pronounced and universally considered as applying the most influence on children's development because of its provision of care, love, support, protection, guidance and direction to children. It must be noted that all the families that were interviewed in this study were part of communities within the Bojanala District. Therefore, occurrences in the community influenced these families, and vice versa; thus, these families did not function in isolation. As such, this enabled community members to honestly provide detail regarding children with CP within their communities, and the families truly reflected the opinions, perceptions and beliefs within the communities.

5.5.1 Responses from community members

The analysis of the data began by exploring the views of the communities, as the community member participants reflected the larger environment in which the families of CP children must function and live daily.

5.5.1.1 Responses to Question 1

At the very beginning of the interviews, a profound question was asked to orientate the researcher and the participants on the general concept of CP. The initial question that was posed to the community members was *“What is CP?”* This question provided the researcher with a definite response of the participants not really knowing or only getting the concept half right. All the community participants stated that they did not really know what it was. The variations on this answer also reflected communities that were not informed: *“I only know they are different*” (CM1); “*they suffer from it and cannot do things like other children”* (CM6); and “*I only know that the child is not like other children*” (CM2).

5.5.1.2 Responses to Question 2

With the second question, “*What is the cause of CP?*”, a further lack of insight and knowledge was evident among most of the participants. Their answers ranged from “*I think it is genetic because the child’s paternal aunt is also disabled*” (CM3) to “*all I know is that it is a defect before birth*”. Other responses indicated that the participants saw the mother as the cause of the condition, as the *“mother [was] not doing well during pregnancy”* (CM6).

5.5.1.3 Responses to Question 3

Question 3 was aimed at establishing the knowledge of CP within the community: “*Do you think community members understand and are appreciative of families and people living with CP?*” The community members provided varied responses that ranged from understanding to not understanding at all. It should be noted that the community members who were nearer to the family of the child living with CP had the propensity to advance more of an understanding, while the opposite was equally true. The following similar responses were provided:

> *Not everyone understands, but there are those like me who understand and support such families.* (CM1)
>
> *The majority of the community members do not understand CP, but there are those like me who understand.* (CM2)
>
> *The majority of the community members do not understand. But very few, those who are close to the family, I think understand*. (CM4)

5.5.1.4 Responses to Questions 4 and 5

The next two questions explored the community members’ views on what they thought the challenges of the families and their needs were. Once again, these two questions reflected an underlying element of ignorance regarding the full implication of having a child with CP. In responding to the challenges faced by these families, the main idea that was evident to the community members was that these children had to be carried and that this factor presented a major challenge for families.

Of the six participants, four pertinently mentioned this challenge –

> *He can't walk on his own; so, family members must always carry him. When there is no car, it is a problem. He cannot talk; so, they must think for him. They must always wonder whether he is hungry or thirsty.* (CM1)
>
> *The 11-year-old cannot walk. They must carry her around. Bath time is really hectic.* (CM5)
>
> *The boy cannot walk on his own at times. He must be carried, and he is heavy. When the car is not around, it is a challenge.* (CM4)
>
> *They must always carry the child around. They must do everything for the child. I really feel for them. I can tell it is difficult.* (CM6)

It can be suggested that in the community, children with CP are seen as people who cannot do anything for themselves, and only the worst cases are noted by community members. These responses reminded the researcher of Mostert's (2016:9) statement that a lack of understanding and awareness regarding the causes and characteristics of the disability is a key factor in the stigma experienced by people with disabilities in Africa.

The focus of most community members was on the external challenges that they saw, namely the inability of the child to move. By considering this, it can be deduced that many of the internal psychological and private challenges that are faced by these families are not really noticed by members of the community. This aspect is discussed in more detail in the section where the responses of the families are provided. The researcher believes that a difference can be made to this situation, and it can be remedied through inclusive citizenship education, which would bring knowledge to these communities. Other responses by community members included the aspects of financial needs –

> *The child is too expensive, and the family is struggling.* (CM3)

Furthermore, issues of the isolation of the mother and the protection of the child were mentioned –

> The *mother cannot leave the child alone. She is even scared to leave her with other people. Being a girl child, she is always afraid of the possibility of sexual harassment. She has not started menstruating, but we are already worried of how the child is going to cope.* (CM2)

These two final comments reflect community members who are looking further than the child's immediate disability, as consideration is given to other challenges such as finances and isolation (especially of the mother), and evidence of more future-orientated thinking is provided, namely the protection of the child and the child’s welfare. From these responses, one can see that some community members are more involved with families, as CM2 stated:

> *The majority of the community members do not understand CP, but there are those like me who understand.*

It can thus be suggested that the closer a community member is to the family, the more empathetic, understanding and supportive he or she is towards the family. From this, it is strongly suggested that if inclusive citizenship education is introduced to the majority of community members, acceptance, understanding and inclusion of families with children with CP, as well as the child with CP, will be facilitated and more support will be provided to them.

With this in mind, it brings this discussion to the following questions posed to the community members. These questions were posed to elicit a feeling from the participants of their being in the shoes of these family members and offering their views on the needs of the people. They were asked: *“What community support could be given, and how could a community encourage these families?”*

Numerous views on the needs of these families were provided by the community members, as transport, education, schools and physical and financial resources were reported as problems.
Aspects regarding transport were frequently mentioned –

> *Transport to take the child to the hospital is always a challenge. The mother must always hire a car because taxis are not adjusted to accommodate these kinds of children. The safety of these kinds of children, especially girls, is also a concern.* (CM2)
>
> *They need a car to take the child around. Sometimes he is very aggressive when he tries to communicate and you do not understand. The family needs to be taught how to deal with aggressive behaviour.* (CM4)

These two community members were the ones who seemed to be the closest to families of children with CP, as they both declared that they understood the situation. The aspect of transport also emerged at the end of many of these interviews, when the participants commented that because of transport problems, children with CP could not go to their follow-up appointments and were not able to attend physiotherapy appointments.

The second major aspect entailed education and schools. CM1 commented on the situation regarding community needs by stating that the first major need was *“education to understand why the child is the way he is”.* The participant added:

> *The family cannot even take the child with CP to school because there are no schools for such children in the area. They once took him to a school a little way from here. Unfortunately, they did not treat him well, so the family took him out.* (CM1)

Therefore, as CM3 stated*, "they need a school to be able to take the child to*". The final general comment was that the main need of these people was resources. This general remark again reflected transport issues as a resource *"to make their lives easier"* (CM5).

5.5.1.5 Responses to Questions 6 and 7

The next two questions required the community members to give their opinions on whether their communities were supportive of these families and how their communities could encourage them. CM1 took this question personally and responded:

> *Yes. I do assist the mother with the child when she is needed somewhere. If I am not available, other family members look after the child.*

One can assume that this participant, even though a community member, is involved with the family and takes supporting this family quite personally. Another participant offered the following response: *Very few community members are supportive. I sometimes look after the children when the parents are not around.* (CM5)

However, many of the participants were rather uncommitted regarding the needs of these people. For instance, the following responses were provided:

> *Very few are supportive. They usually just offer words of comfort.* (CM4)
>
> *No. Very few are concerned.* (CM3)

This apathy regarding the situation is a factor that one can change by introducing inclusive citizenship education in an effort to build up community unity, understanding, empathy and, eventually, community support. There is one concern that does, however, come to the fore, and that entails the attitudes that were displayed by some of the participants, revealing a disposition of total disinterest when it comes to these families. For example:

> *I really do not know. People here mind their own business*. (CM3 and CM4)

However, on the encouragement of communities to support families and people living with CP, many participants offered positive and meaningful suggestions, such as the following:

> *Social workers can have a programme of teaching those who do not know anything about these children about the support that they can give to those affected.* (CM1)
>
> *They must establish support groups to share challenges regarding CP.* (CM2)
>
> *I really do not know. I think they can be encouraged to look after the children for at least a day so that parents can take a break. I think it is just too much for the parents.* (CM5)
>
> *They can be made aware of the challenges that these families face. Maybe they are not aware.* (CM6)

Questions 6 and 7 return to the aspect of education and inclusion being achieved through inclusive citizenship education. The researcher found it concerning that some community members were not willing to open themselves up to these educational experiences. This poses a challenge as to what other avenues can be followed to support and educate communities regarding CP.

5.5.1.6 Responses to Questions 8, 9 and 10

The final three questions that were posed to the community members concerned the services that were available within the communities, what community members thought the government did to support families with CP and, lastly, supportive interventions they could suggest in assisting these families and children.

To begin with, the responses about the services within the community that could be employed to assist these families and children were unproductive. Answers such as the following were provided:

> *Nothing. The child is only taken to the hospital when he is not well.* (CM1)
>
> *None. Even when the child is not taken for follow-up treatment at hospital, they never make follow-ups.* (CM2)
>
> *Nothing really.* (CM3)
>
> *None.* (CM4)

The comments reflect the lack of community services and support, which also reflects the lack of government involvement. The only supportive intervention that was mentioned was the disability grant. Participants commenting on the child's disability grants – "*only a disability grant*" (CM5 and C6) – highlighted the only source of income that some families had. Considering these responses, it can thus be said that services for families of children with CP in the rural area where this study took place range from very limited to non-existent. On further consideration of these comments, one wonders whether the nonchalant nature of these responses could be a result of the lack of knowledge and lack of insight regarding the matter with respect to community members. Maybe it is only when a community member comes into contact with a family that has a member who has CP and the problems and challenges that they experience, that he or she starts to think about the situation and starts to comprehend the immense nature of the challenges experienced by these families.

Regarding government interventions and support, most of the participants stated that the government was not doing enough to assist and support these families. Five of the six participants simply answered "*not really*". When probed about suggestions regarding support strategies for these families and their children with CP, many of the suggestions were very simple and humble. The suggestions provided were as follows:

> *Yes. They can be provided with walking assistive devices, regular physiotherapy to assist with walking, as well as disability grants. This family has been requesting a grant, but so far, they have not been assisted.* (CM1)
>
> *Yes. The government to build facilities where these children can be safe and protected from sexual harassment. Social workers to support families with CP children.* (CM2)
>
> *Yes. The government must provide assistive devices for CP children. They must also provide physiotherapy to assist with walking. Disability grants must be provided for all children with CP.* (CM4)
>
> *Yes. The government must build a school for these children so they can be taught basic skills.* (CM3)
>
> *Yes. Government must provide assistive devices for CP children. A wheelchair can come in handy for an 11-year-old.* (CM5)
>
> *The government must build schools for CP children. They must have hostel facilities. At least parents can then put children in such during the week and only look after them during weekends. These can assist parents to be able to do other things during the week. The mother can even get a job.* (CM6)

All the suggestions given by the participants were realistic and feasible regarding assistance that the government could provide. Moreover, all the suggestions could easily be realised to facilitate the lives of children with CP and those who take care of them. These suggestions must also be considered in conjunction with the Constitution, which states that everyone is equal before the law and everyone has the right to equal protection and benefit of the law (*Constitution of the Republic of*

South Africa, 1996:5). In light of this, many of these suggestions can be regarded as a right of these children and their families. The *Constitution of the Republic of South Africa* (1996:5) states that no individual should be unfairly discriminated against, directly or indirectly, 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. When contemplating these simple suggestions, one can see that children with CP and their families have been unfairly discriminated against.

Another contentious issue, namely inclusive education, represented in EWP6 and introduced in South Africa in 2001, aims to ensure that the provision of education is based on the level of support that a learner needs to address the specific learning barriers he or she experiences (Department of Education, 2001:15). As previously mentioned, EWP6 clearly states that learners who require a low level of support should be able to attend ordinary schools. Learners who need moderate support should be referred to full-service schools for their educational needs, and learners who need a high or intensive level of support should be referred to a higher level of educational support, that is, they should attend special schools (Department of Education, 2001:15). Unfortunately, most of the children with CP in this study did not seem to have benefited from this policy; for example, four of the children that were noted in this study were still not in school. The literature also reflects this situation, as Funda and Beere (2020:14) state that despite the regulatory framework declaring and guaranteeing the right to education for children with disability, it has been seen that a persistent human rights violation at special schools and hostels is evident. This matter and the lack of access to any schooling for thousands of learners with disabilities reflect a complete failure to provide reasonable education, accommodation and support for learners with disabilities in ordinary schools. This failure was evident in this study, with many of the participants' children either not attending school at all or attending a school that did not adequately cater for their needs.

Consequently, it came to the fore that the community members presented as participants who did not have the necessary knowledge saw CP in a negative light and experienced the care of a child with CP as a burden of care. On the theme of possible intervention, the community members proposed, among other things, the building of schools and the provision of transport and assistive devices to support these families.

Table 5.3 below indicates the responses of community members and the link between the community responses with the identified themes (see Table 5.2)

Theme	Sub-Theme	Community members' responses that relate to the theme/sub-theme
Knowledge about CP	Lack of knowledge	CM1, CM2
	Cultural Beliefs (witchcraft)	CM4, CM6
Impact of CP	Isolation	CM2, CM4
	Lack of employment	
	Burden of care	CM1, CM4, CM5, CM6
	Stress and frustration	CM1, CM4, CM5, CM6
Resources for families with members living with CP	Financial burden	CM3
	Lack of schools	CM1
	Assistive devices	CM1, CM2, CM4, CM5
	Lack of sufficient information from professionals	CM1, CM4
Psycho-social experiences and support	Isolation	CM2, CM4
	Stigmatisation	CM3, CM4
	Lack of support	
	Feelings of devastation and denial	
Possible interventions	Schools and care centre's (educational aspects)	CM1, CM2, CM3, CM6
	Financial and physical resources	CM2, CM4, CM5
	Professional support	CM1, CM2, CM4

Table 5-3: Tabulated responses of community members linking their responses to the identified themes

5.5.2 Responses from fathers

The second set of data that were analysed was collected from the fathers. This group is deemed important, because in the African culture, these family members are viewed as providers and protectors of their wives and children. The only participating fathers who were available for this study were in Families 4, 5 and 6. The father of Family 1 was not available because of work commitments, but he was very much involved in the life of his child. The mother of Family 3 indicated that the father of the child disappeared immediately when the child started to be ill. Although he did not live far from the family, the mother indicated that he never even greeted them when he met them on the street. According to Thuketana (2018:114), cultural attitudes that establish a correlation between disabilities and witchcraft are rife in South African rural areas, with these perceptions having a significant impact on how children with disabilities are treated. The grandmother (CA2) of this child of Family 3 strongly believed that the child was bewitched. This could also have played a role in the father turning his back on the child and the family. There was no mention of the father in Family 3; it was clear that he had never been involved in the child's life. Tigere and Makhubele (2019:1) state that fathers are not available in some families with disabled children, as the majority of men do not want to be linked with a disability. This gives rise to the researcher wondering whether this was the case with the father of Family 3 abandoning his family.

5.5.2.1 Responses to Questions 1 and 2

The interviews for this subgroup of participants also took the form of semi-structured questions. As with the community members, the first two questions focused on the fathers' knowledge and understanding of CP. The first question required information regarding the understanding they had about CP. Most of the participants were fairly on track with their answers –

> *… a person whose brain is damaged, especially when still a child.* (F4 and F5)
>
> *There is a problem with the brain.* (F6)

When exploring the causes of CP further in Question 2, one father gave a personal rendition of the situation regarding his child:

> *The umbilical cord was around the neck of our child during delivery. He did not get enough oxygen.* (F4)

The second participating father responded as follows:

> *It is caused by a problem with the brain. That is what they said at Baragwanath Hospital.* (F5)

The third father (F6) plainly stated that he did not know. From these responses, it was evident that even though two fathers were on track with their understanding of the causes of CP, extensive knowledge gaps about the situation of parents and families of children living with disabilities remain, as confirmed by Tigere and Makhubele (2019:2).

5.5.2.2 Responses to Question 3

The third question required reflection by the fathers to review the knowledge of close family and community members about the circumstances surrounding a family that must deal with a child with CP. Their responses reflected varied opinions of family members and communities as seen through the eyes of the fathers. The responses ranged from ignorance and neutral to negative –

One participant said:

> *No, they do not know.* (F6)

The following neutral response was provided:

> *Family members understand because we have another relative who has CP. I also did not understand what CP is all about until I had this child. Very close community members understand, but I really do not think that others do.* (F4)

Another father gave a negative response –

> *I do not really think that they understand. Family members never really want to assist. Community members never visit us. Everyone minds his or her business.* (F5)

Consequently, one can see that from a father's perspective, this group of participants had a vague idea about CP but did not fully understand the condition until they experienced it first-hand. Furthermore, the comments reflected that immediate family members and close community members understood better, as these individuals had already experienced people with CP, giving them personal insight into the challenges that these individuals faced.

However, a general lack of understanding was experienced by the fathers regarding family members and communities, resulting in the isolation and stigmatisation of a family with a child with CP. For example, two participants noted that their families did not talk about these children or did not want to help them – *"No, they do not know*" (F6) and "*Family members never really want to assist"* (F5). Also, community members had cut them off – *"Community members never visit us"* (F5). The last comment of F5 is the most concerning – *"Everyone minds his or her business".* This can be seen as a lack of empathy within the community to get involved and assist when there is a need. The question that arises is what would be needed to change this situation. The researcher submits that inclusive citizenship education would go a long way in remedying this situation.

5.5.2.3 Responses to Questions 4, 5 and 6

Questions 4, 5 and 6 were aimed at eliciting a personal or emotional response to the situation, with questions regarding challenges experienced, how their lives changed and how they felt when they first heard about the diagnosis. The challenges that the fathers experienced regarding their children with CP ranged from simple communication complications to physical difficulties, as one participant said:

> *He cannot talk so it is difficult to know what he wants. We must always guess.* (F6)

The same participant commented as follows on the physical challenges:

> *We must always carry him around because he cannot walk, and now he is heavy.* (F6)

This physical challenge was also reflected in the responses of the community members, as they only focused on outward and specifically noticed physical problems. However, the intensity of maintaining and rearing such a child was verbalised as follows by one of the fathers –

> *He needs assistance with everything that he does. So, I must always be readily available to assist. The school has at least assisted to make him a little independent.* (F4)

On the other end of the spectrum, one participant was rather critical of his child and stated:

> *I strongly believe that these children are manipulative. They always say that they have pains in the body when they do not want to exercise.* (F5)

This comment illustrates the lack of empathy and understanding that is often present in families and communities.

Questions 5 and 6 explored the area of how having a child with CP changed the lives of their parents and caregivers and the emotional responses that were experienced when they were informed that their child had CP. For these questions, the responses were unusually accepting and, at times, even positive, when considering some of the frustrations that were evident in the previous responses. One participant stated:

> *It really has not changed my life that much. Like any other parent, I was hoping and looking forward to a healthy child, but I got this one. I have since adjusted to the situation.* (F4)

Even though this response revealed the father's disappointment, there was a glimmer of hope with the acceptance of the situation. Another participant explained his feelings as follows:

> *We were still young when we got our first child. We had dreams of travelling the world. Now we cannot even visit because of the children we have. We must always carry the 11-year-old.* (F5)

Again, the father's disappointment is clear, but as the child is 11 years old, acceptance and understanding are evident even though there was an initial level of frustration.

F6 seems to be the most realistic father of the group, as it appears as if he has accepted the situation; however, he is also realistic enough to focus on all the family members and not just on his child with special needs. The challenge of giving equal attention to all family members is often experienced in families where there is a child in need of special care (Tigere & Makhubele, 2019:7).

> *We wanted four kids. But after we had this one as our second, we stopped trying for fear of having another one like him. At times, I feel we are neglecting our firstborn and just focusing on this one because of his challenges.* (F6)

Tigere and Makhubele (2019:7) reveal that the challenges associated with rearing a child with a disability result in many parents being afraid of having more children. F6 confirmed this fear of having another child with CP and that some parents feel it is better to avoid it than to deal with compounded challenges. The responses of the fathers, especially F5, were in line with several researchers (e.g. Chiluba & Moyo, 2017:2; Dowswell *et al*., 2006:293) purporting that caring for a child with CP has other implications for parents and caregivers, including feeling as if the future was shattered and causing frustration for fathers. Tigere and Makhubele (2019:1) also support the argument that the experience of parenthood is affected when a child is diagnosed with a disability, and parents' expectations about the child and the future may have to be adapted.

Further exploration of the emotional responses of the fathers reveals a wide range of emotions. On the one hand, there is acceptance because of a lack of knowledge and insight, as indicated by one participant –

> *I was just fine. They did not explain much, so I am seeing other things now.* (F6)

Another participant revealed numbness due to even more inexperience and unawareness –

> *I did not feel much pain because the doctors did not explain much.* (F4)

On the other hand, a deep-seated emotional pain was revealed in the same participant's expectations being shattered and the realisation that it would not be easy for him to move forward – I *felt really bad. I really never expected this to happen to me. It was really not easy.* (F4)

Questions 4, 5 and 6 reflected the fathers' very personal and emotional reaction to the news that their newborn children were not perfect. Even at a later stage when the news was given to the fathers, they tended to have a deeply emotional grieving and emotional response to the news.

5.5.2.4 Responses to Questions 7 and 8

The seventh and eighth questions requested information regarding support from family members and the community with respect to the challenges the participants experienced. The participants' responses reflected a range of emotional reactions, sometimes blatant and sometimes underlying – *We do not get support from community members, and regarding family support, there is no support.* (F6)

> *We really do not get much support from family members. We also prefer not to leave them with other people because they might not understand them and not take care of them the way we do. … There is totally no support from community members.* (F5)

These responses reflected the bluntness of the reaction by the community and family, as reported by F6 and F4. F5 responded in a much calmer manner, considering the children and showing great concern for their welfare. Some participants indicated that even though there was hardly support, there still was some support –

> *Yes, friends and colleagues give us all the necessary support.* (F4)

In evaluating this situation, it can be seen that support for these families is scarce. This is in line with Groce's (1999, in Burning *et al.,* 2017:15) observation that families and communities may not be that supportive, as cultural beliefs about the causes of disability may attract prejudicial attitudes and discriminatory behaviour within the family unit and beyond, in the community.

5.5.2.5 Responses to Questions 9, 10 and 11

In the final stage of the interview, Questions 9, 10 and 11 aimed to obtain information regarding services and support from the government. The care and support services that were received from the government proved to be little to none, as evident in the distinct declaration by F9 that there was *"none*". The general indication obtained from the participants was that there was a lack of support from the government. Furthermore, most of the participants' responses indicated that they felt that the government could do more. Many responses acknowledged that while there were disability grants for minors with disabilities, these did not come without challenges. The participants explained: *The 11-year-old gets a disability grant, and at work they, at times, provide us with nappies. It is just that with Covid 19 having made things difficult, they are no longer giving us as many nappies as they used to. But we survive on what we have.* (F5)

> *The child also gets a disability grant from SASSA … regular check-ups at the hospital and physiotherapy.* (F6)

Although the fathers knew and acknowledged the services, they were realistic enough to acknowledge that there were problems obtaining these funds. On further enquiring into the adequacy of these services, more problems were revealed –

> *No. We do not always have a referral letter to the doctors. When we can't access the local hospital, doctors demand such. At times it is not possible, especially when she has an epileptic attack. We then struggle to get help.* (F5)

This response suggests that the necessary medical emergency services are not always available and there seems to be a lot of "red tape" to get the assistance that is vitally needed. With regard to education, F4 offered a definite "*no*" and added:

> *There are not enough schools in the area for children with CP. He is presently attending a school that is predominantly Afrikaans. He struggled with the language at the beginning, but now he is fine. He is happy.* (F4)

The response of F4 evokes feelings of frustration at the lack of schools. This raises a concern, especially because, as was indicated earlier in the document analysis chapter, South Africa issued a policy on inclusive education (EWP6) as early as 2001. EWP6 was introduced as a way of addressing two main negative challenges, namely that only a small percentage of learners with disabilities were receiving specialised education and support, and secondly, that the education system had generally failed to provide services appropriate to the needs of learners (Department of Basic Education, 2021b:1). The frustration that was indicated by the participants in the study highlights that as a country, we still have not reached all people who are directly affected by the lack of services, whether medical or educational.

On the other hand, some participants indicated that they were satisfied with the services provided. For example, F6 responded with a definite "*yes*" and declared that he was completely happy with the services that were provided (medical and educational). This may be ascribed to his having accepted the situation, especially as he did not know what services were available and what was needed by the child and what support was available for the families. Once again, the researcher would like to remind the reader that inclusive citizenship education will be exceptionally helpful to these individuals by providing them with knowledge that would inform them of appropriate and applicable information to assist them and their families.

The final question posed was to gauge the opinions of the fathers regarding the support provided by the government for people living with CP and the general support that was given to their families. Many of the responses came as suggestions, for example:

> *Doctors and nurses can be open and explain to parents what exactly the child is suffering from.* (F6)

Thus, it can be inferred that the medical personnel do not fully engage the parents and take time to explain aspects concerning the child. Another participant said:

> *The government must build more schools for children with CP. These schools must be accessible to all, and these schools must have sufficient human resources like assistants.* (F5)

Furthermore, F4 stated that schools that cater for children with different languages must be established. Thus, in general, these participants indicated that they needed the government to build more facilities with sufficient resources.

Themes that were identified in the analysis of the fathers' responses included insufficient knowledge about CP disability and the burden of care, as the fathers indicated that they had to carry their children with CP around and do almost everything for them. A lack of support from family and community members, which results in these families being isolated, was also raised by the fathers. Another theme noted in this section was that of healthcare professionals not providing the fathers with full information regarding their children's disabilities. Insufficient support from the government, including the support provided by schools, was also evident. On the theme of possible interventions, the fathers agreed that the government must build more schools that could cater for children with CP. They also agreed on the issue of professionals being available for information and support.

Table 5.4 below indicates the responses of fathers and the link between the fathers' responses with the identified themes (see Table 5.2).

Theme	**Sub-Theme**	**Fathers' responses that relate to the theme/sub-theme**
Knowledge about CP	Lack of knowledge	F6
	Cultural Beliefs (witchcraft)	
Impact of CP	Isolation	F2, F5
	Lack of employment	
	Burden of care	F4, F6
	Stress and frustration	F5, F6
Resources for families with members living with CP	Financial burden	F5
	Lack of schools	F4
	Assistive devices	F6
	Lack of sufficient information from professionals	F6
Psycho-social experiences and support	Isolation	F2, F5
	Stigmatisation	
	Lack of support	F5, F6
	Feelings of devastation and denial	F4
Possible interventions	Schools and care centres (educational aspects)	F4, F5
	Financial and physical resources	
	Professional support	F6

Table 5-4: Tabulated responses of fathers linking their responses to the identified themes

5.5.3 Responses from mothers

The mothers of this study were important as they form a crucial part of the microsystem of the child. They are the closest family members with whom children associate; consequently, they are great influencers in their children's lives. Mothers know the needs of their children with CP. In the sample group, each family had a mother present. Five of the mothers were not employed, and only one had a full-time job. This is in line with what was raised in the literature review. In the research done by Ngubane and Chetty (2017:37), it was found that the majority of caregivers of children with CP were unemployed, and the belief was that the daily care requirements of a child with CP limited them from looking for employment. In the current study, one of the five mothers that were unemployed previously had a full-time job; however, because of the challenges that go hand in hand with taking care of a child with CP, this mother had to give up her job almost immediately to look after her disabled child.

Again, 11-question interviews were conducted with the mothers of children with CP. This interview schedule was the same as that of the fathers.

5.5.3.1 Responses to Questions 1 and 2

At the beginning of the interview, Questions 1 and 2 were aimed at gathering information on the mothers' understanding of CP and the cause of CP. Regarding their understanding of CP, many of the mothers demonstrated more insight into the medical condition than the other groups of participants. M1 honestly related that her understanding was limited but concedes that these children were different –

> *I do not really understand much about it. Only knows that these kinds of children are just different and that their brain and spinal cord are damaged.* (M1)

The other participants commented on the specific medical reasons; however, a lack of medical facts showed their lack of comprehensive medical knowledge and revealed limited insight. The following responses were given:

> *It is an ailment that happens when there is a problem with the brain.* (M6)
>
> *… my daughter did not receive enough oxygen when she was born.* (M2)
>
> *CP is an ailment that destroys your brain. It reduces the functioning of everything.* (M4)
>
> *It is an ailment that causes fits.* (M3 and M5)

From these responses, it is evident that the mothers, as compared to the other groups, generally had a better understanding of CP. This can be ascribed to their being the primary caregivers who are more involved with and concerned about their children with CP, especially in the absence of the fathers (see Phumudzo *et al*., 2021:3). This might have pushed them to seek further information regarding the ailment. It must also be noted that even though the mothers had a range of responses, they were better informed in general.

When it comes to the cause of CP, two of the mothers started by indicating that they did not know what it was; however, as they continued to explain, it was evident that they had an idea of the cause of CP. They said:

> *I do not really know. I was told by a nurse that the umbilical cord was around my son's neck and that he did not get oxygen for some time.* (M1)
>
> *I do not really know. The doctor said that it is something to do with the brain.* (M5)

The other two participants responded with confidence, and while they did not give comprehensive responses about the cause, they showed some understanding of the cause –

> *Insufficient oxygen for the baby during birth.* (M2)
>
> *CP is caused by a lack of oxygen during birth – that is what the doctor told me. The umbilical cord was around the neck of the child during delivery.* (M4)

Both M3 and M6 simply stated that they did not know. However, while one associated it with witchcraft, the other one associated it with being in labour for a long time –

> *I really do not know. I was in labour for more than 24 hours. Then after the delivery, they only said that the child was tired.* (M6)
>
> *I really do not know. My child was fine after birth. Everything changed when she was three months old and my family threw a party for her. After this party, she started having fits. My family thought that she was bewitched. They took her to lots of traditional doctors, but it did not assist.* (M3)

While the responses by the mothers were varied, many of their comments showed vague knowledge of the causes and medical reasons for their children having CP. Once again, the researcher strongly feels that by empowering these mothers with correct and timeous information, their lives would be improved, and with this knowledge, they could begin to plan and actively look for support and information for their children and themselves. Furthermore, they can also endeavour to dispel the myths of witchcraft and, from the beginning, have enough knowledge to feel empowered and brave enough to face their communities.

5.5.3.2 Responses to Question 3

When the mothers were asked whether their families and community members knew and understood CP, various responses indicated that there was overall inadequate understanding and support for children with CP. One of the participants said:

> *I believe family members do not understand. Some family members thought that I was bewitched, and we had to explain to them. Community members do not really understand. When I walk with my son on the street, they usually stare at us and at times even ask why he is the way he is. I always explain to them.* (M4)

This participant's response reflects a lack of understanding among family members, which even goes as far as a misguided belief in witchcraft. Furthermore, this mother indicated that the community was isolating them by staring at them and asking them questions. Other mothers also voiced their misgivings about the community's understanding of the situation. Inclusive citizenship education will be a starting point to spread correct and applicable information on CP within these communities, which must always be seen as empowering inclusive knowledge, and not an effort to change the culture. The other mothers' responses to this question were as follows:

> *Few community members understand, and the majority really keep their distance. Very few visit us.* (M2)
>
> *No, they do not know. We do not get support from anyone. It is only us and the kids.* (M5)
>
> *No, they do not know. The little ones used to laugh at him, but now they are used to him.* (M6)

These responses all have in common the underlying theme of community members not knowing or understanding CP. This lack of information about the condition in the community tends to isolate these children and their families. Moreover, it leads to individuals who are uninformed, ask questions and even laugh at children with CP, thereby eventually creating a scenario where stigmatisation is rife.

From the above responses, one can deduce that the majority of community members within the area where the study took place, namely the Bojanala District, tended to stay away or keep their distance from these families. As a result, these families are isolated due to the prevailing ignorance about this unfamiliar situation or condition and the lack of understanding and empathy within the community.

As stated earlier, Mostert (2016:9) argues that a lack of understanding and awareness of the causes and characteristics of disabilities creates an environment that perpetrates stigma, which is often experienced by people with disabilities in Africa. It is possible that many community members stay away from families with a child with CP because of the negative perceptions of and stigma that is attached to CP. This may be compounded by African beliefs such as witchcraft. With community members picking up on a child's disability and asking questions and even mocking the child, the family is pushed away from the community into an isolated world of stigmatised disability. Furthermore, the avoidance of these situations by community members once again leads to a lack of communication and integration, resulting in less and less support. Inclusive citizenship education is, therefore, the suggested solution to assist these individuals. Once mothers are empowered by understanding and knowledge, they will be able to drive for better conditions, improve the support given to the affected child and socially realise their place and stand strong within their communities.

People's lack of understanding regarding CP was clear from the responses of the mothers. Some of the mothers indicated that family members totally misconstrued the situation –

> *I believe family members do not really understand because they used to tell the child that she must try to do something and not just sit.* (M3)
>
> *Some family members thought that I was bewitched, and we had to explain to them.* (M4)

On the other hand, once there has been some contact with a person with CP, there tends to be a glimmer of light as understanding and empathy are present in the personal experiences that other people have had with children with this condition. Out of all the participating mothers, only two of them (M1 and M2) believed that their families understood the condition and were supportive of the situation, even though only a few community members supported them and the majority kept their distance. They commented as follows on the situation:

> *I believe the family members understand because they are really supportive of my situation.* (M2)
>
> *The family understands because there is someone in our family who has the same challenge. Even I did not understand before I had this kind of child.* (M1)

From these responses, one can deduce a sense of loneliness and frustration among the mothers because of being isolated. Moreover, various comments suggested that there was a lack of understanding from the community and family members. However, the general feeling the mothers indicated was that their families were isolated and that they kept to themselves, either by choice or because of being ignored by the community. The following remarks were made:

> *The majority [community] just keep their distance.* (M1)

> *It's only us and the kids.* (M5)
>
> *Few community members understand, and the majority really keep their distance; very few visits.* (M2)

5.5.3.3 Responses to Questions 4, 5 and 6

As with the participating fathers, Questions 4, 5 and 6 were aimed at eliciting more of a personal or emotional response from the mothers. These questions covered the challenges they experienced and how their lives had changed and what their feelings were when they first received the diagnosis.

All the mothers indicated that their lives had changed after giving birth to their children with CP, as the majority of these children could not do anything for themselves and had to be continuously supported and assisted. Chiluba and Moyo (2017:1), as stated earlier in the literature review, also highlight that CP is a major cause of disabilities and most people with CP are left with residual disability aspects, which often leave them dependent on parents and caregivers for essential care. This notion was reflected in the responses of the participants too, as the mothers repeatedly stated that they must always be home to take care of their children. They explained as follows: *I must do everything for him, including feeding [him]. He can't talk; so, we must think for him – what he wants, whether [he is] thirsty or hungry.* (M1)

> *I am always home to take care of her. I cannot travel with her because she is too heavy to carry.* (M2)
>
> *He is nine years old. He cannot walk; so, I must carry him around. I must feed him and even take him to the toilet.* (M6)

Only one mother said that she had a job.

Two mothers raised their frustration regarding the temperament that their children displayed. It was evident that these children were emotionally intense and needed constant supervision and additional emotional support. One family had two children with CP, which presented a difficult situation to handle. The mothers described a range of difficult situations, such as their children being hyperactive and having serious emotional outbursts. Children with CP who are growing up present even more challenges, such as personal hygiene and care. The following descriptions of these problems were provided:

> *The two children are a handful. The 11-year-old cannot walk but crawls the whole day. I must use medication at night to make her sleep. At least the 15-year-old can walk. But her temper is very short. She sometimes becomes so angry that she breaks*

> *things in the house. They are both on ADHD medication. The 11-year-old has epilepsy. The first time, the attack lasted for five hours. It was really scary. … I cannot work but must look after the kids. I must carry the 11-year-old around at times. It is really difficult to bathe her. She has already fallen five times when I tried to put her in the bath. She is too heavy to get in and out of the bath.* (M5)

> *Sometimes he is very aggressive when he wants to do something and he is unable to due to his limitations. We must always try to calm him down.* (M4)

It can, therefore, be deduced that many of these children need intense extra physical care, which places a lot of stress on their mothers. The additional emotional support that children with CP tend to require to cope with their daily routines compounds the situation, adding stress to the mothers' lives and to the family in general. According to Abdikadir *et al.* (2020:401), the birth and upbringing of a disabled child are severe psychosocial stress factors for the parents, especially for the mother. Mothers are also reported to experience social isolation on account of their having children with a disability (Michael *et al.,* 2019:166).

Question 5 required that the mothers provide their opinions of how having a child with CP had changed their lives. Their responses were often emotional, with despondency, guilt and sadness emerging as these mothers explained the change in their lives. One participant gave the following account:

> *Life is now very difficult. I do not feel safe when I leave him with other people. I am very protective of this one; as a result, I spend most days at home. Sometimes I feel like the young ones are not mine, because I spend a lot of time doing things for this one.* (M1)

Moreover, many of these mothers indicated that they felt that they neglected their other children, as the disabled child took up a lot of their time. This is in line with the point made by Tigere and Makhubele (2019:7) that as more attention is given to the child with special needs and the other children within the household are neglected, family disruptions often occur. Furthermore, many of the participating mothers in the current study indicated that they had given up and saw their lives as limited and inhibited. Some of them displayed emotions such as sadness, dejectedness, disconsolation, a feeling of not fully accepting the situation, resulting in a negative outlook, and a feeling of having lost their freedom and even themselves, as seen in the following responses:

> *My life stopped after I gave birth to this child. I always wanted to get a job, but now I cannot look for one because there is no one to look after her. I enjoyed going out with friends, but now I cannot do that anymore because I must always take care of her.* (M2)

> *I worked before I had this child. Now I do not work anymore because I must look after her. The father left me immediately when the child started to be ill. He works but does not do anything for the child.* (M3)

However, some of the participants displayed more positive emotions and were grateful for what they had. They said:

> *Having children with CP has taught me to appreciate life. I have so much to be grateful for. At least I can talk, walk around and do almost everything I want to do.* (M5)

> *It has humbled me. It is an honour to have a child like this one. It has really taught me to be appreciative of what I have. I believe God prepared me for this when I was 16 years old. Our neighbour had a CP child. I always had to carry her on my back when going to school. I would drop her off at the local crèche that was not far from my school. For this, her family used to give me money for my lunchbox.* (M4)

Mothers like these are inspirational and are an excellent resource that can be used as a positive source of support for others who feel the loss and frustration of having children with CP. This is in line with Pretorius and Steadman's (2017:15) suggestion that the social isolation experienced by caregivers of people with CP can be mitigated by support from families, friends and the community.

The final question in this section, Question 6, enquired about the feelings and emotions that the mothers experienced when they were informed of their children's condition. In general, the mothers were emotional and devastated. Feelings of devastation, disbelief and utter shock were voiced –

> *I was devastated. It has never happened in our family.* (M3)

> *At first, I did not understand. But I was heartbroken. I am still heartbroken.* (M6)

> *I was devastated, but I thought he was going to recover.* (M4)

> *I wonder, why me, when other people's children are normal?* (M3)

> *With the second one, I was so shocked. I could not cry, I just kept quiet. The doctor told us when I was five months pregnant.* (M1)

> *At four months, he could not do anything. That is when we took him back to the hospital.* (M4)

To further complicate the situation regarding the shock of the news that their children had CP, some of the mothers only realised the implications of the situation after a few months or even years. They explained as follows:

> *I was never informed. I only realised when months went by that she did not go through normal milestones. That is when I took her to the doctor, and he told me that the possibility is that she did not receive enough oxygen during birth.* (M2)
>
> *It was really hard. With the first one, I only knew when she was six years old. She was not developing like other children. When the doctor informed us, I cried. I could not stop crying for more than a month.* (M5)
>
> *I was told that it would be fine, that he would improve with time; so, I was not very worried.* (M1)

The emotional responses of the participating mothers suggested that receiving the news of their children having CP was an exceptionally painful, stressful and devastating experience for them, which was accompanied by feelings of denial and guilt. This situation is also reflected in the literature where Gulati and Sondhi (2018:1015) contend that the parents of a child with CP may experience chronic grief, guilt, frustration, denial, resentment and embarrassment when confronted with the situation of having a child with CP. To manage the situation well, information about their child's condition should be provided with honesty and sensitivity (Gulati & Sondhi, 2018:1015). The responses of the mothers provided above lead one to wonder whether the South African healthcare system is responsive to the needs of mothers who give birth to children with CP. Furthermore, are those who are tasked to provide answers and information to these individuals and their families challenged themselves in conveying the appropriate and applicable information, or are they just inconsiderate, in not taking the time to be really present for these mothers? Whatever the reality of this situation is on the ground, inclusive citizenship education can most definitely assist in empowering those in the healthcare system and the Department of Health, as well as the individuals at the grassroots level who are the first line of information and are expected to inform and support mothers and families who are affected by a child with CP in their family.

5.5.3.4 Responses to Questions 7, 8 and 9

Questions 7, 8 and 9 were aimed at eliciting responses regarding the support and services that the mothers felt they received from their close family, community members and in general. Question 7 was directed towards support from family members. Responses to this question ranged from good support to no support at all. Initially, two of the mothers acknowledged such support they received, but unfortunately, these support systems were not located near their families. They said:

> *Yes, we do get support. It is just that the majority live far away.* (M1)
>
> *Yes, I get support from my siblings, even though it is minimal, since they do not live nearby.* (M2)

Other mothers also acknowledged the support they received from family members, but they indicated that they saw it only as words of comfort or recent support after the family had finally realised and understood the situation. In general, support for these children and families is very scarce. The participants responded as follows:

> *… words of comfort.* (M4)
>
> *Yes. But they have only started recently to support me. Previously, it was like the child is lazy to do certain things. At times I even thought that they are afraid of her. They avoided her. It is only recently that it seems they have accepted that she cannot walk or talk.* (M3)

Question 8 focused on support provided by the community members. Again, the general response was that the families received none to very little community support. This limited support seems to create a situation where it affects the household and the family members feel alone and isolated. One participant declared:

> *We do not get support from anyone. It is only my husband and me. Sometimes it becomes overwhelming. We, at times, end up fighting with each other*. (M5)

Only two participants acknowledged that they got community support, which was encouraging to the researcher, as this acknowledgement gave her a framework in which inclusive citizenship education, if conducted properly, could be used as an educational tool in the community. The two participants who responded positively said:

> *Yes, they are even able to look after the child when I am not around.* (M1)
>
> *Yes. Friends and colleagues at least now understand this condition. They encourage me when I am a little discouraged.* (M4)

The comments from these mothers indicate that these families experienced isolation, seclusion and avoidance when it came to community engagement. It seemed that these mothers were really crying out for help and social support but remained isolated. With this evident in both the sample and the literature, the researcher assumes that a lack of knowledge of CP and the demands that children with CP put on their mothers create a situation that leads to mothers spending more time taking care of their children with CP and less time in the community and, as a result, becoming more isolated. As indicated earlier, Menlah *et al.* (2020:9) believe that due to negative and discriminatory attitudes towards children with disabilities, caregivers end up keeping their children with CP at home for fear of exclusion. Unfortunately, this affects these families negatively. Once again, the researcher believes that inclusive citizenship education can empower these family members and the communities in which they reside to understand the causes of CP and provide them with skills on how to support those affected. This can ultimately improve the attitudes of all role players and heighten awareness of CP and the support they should give to families of children with CP.

The final question in this section entailed the general services that were available to support children with CP. Again, a generally negative response was given by most of the participants. These responses ranged from comments regarding hospital services to the services provided by social workers, all of which were thought to be inadequate. The following responses were given:

> *No. We were never informed of any services that the government provides for children with CP or their families. When the child is not well, we go to the local hospital.* (M4)
>
> *Nothing. We only go to hospital when the child is sick. They sometimes refer him to the physiotherapy section within the hospital, but we must always pay.* (M1)
>
> *Only regular check-ups at the hospital and physiotherapy. The child also gets a disability grant from SASSA.* (M6)

This minimal support from the local government incurs extra challenges for children with CP and their families. For example, the lack of information services within municipality creates challenges as parents with children with CP do not know where to seek assistance for their children in a form of hospitals or/and clinics, physiotherapy and disability grants.

> *He does not get a disability grant. We are still trying to sort out the papers for it.* (M1)

Two of the participants had positive comments about the general services provided. They said:

> *Yes. I take her to physiotherapy at the local hospital on a monthly basis. She received a wheelchair from the hospital. All these were free of charge. She also gets a monthly disability grant of R1 890.* (M3)
>
> *When she experienced epileptic seizures, she was treated without any charge by doctors at the local hospital. She also gets a monthly disability grant of R1 890.* (M2)

One can see from the responses that the mothers are cognisant of the various services provided to people with disabilities. However, these services are not rendered in all communities, suggesting that services that should be available nationwide are limited and restricted in some areas. Furthermore, those families who have their disability grants sorted out seem to be better off than those who do not, and they also have a better knowledge of the various services provided. This suggests that if inclusive citizenship education was introduced into areas where there is a lack of knowledge, it could make a difference.

5.5.3.5 Responses to Questions 10 and 11

Questions 10 and 11 were the final two questions of the interviews. These questions focused on the mothers' evaluation of the services that were provided to them and their views on whether the government could do more to support people with CP and their families. Question 10 aimed to explore the mothers' views on whether the various services provided were sufficient. As this question did not prescribe specific services, it opened a wealth of information that was pertinent to each participant. Many participants directed their comments towards the government, clearly stating that they thought the government was not doing enough for these families or children with CP. One participant (M2) simply said "*no*" without any elaboration on this reply. Others elaborated or added some suggestions, such as the following:

> *No. I wish they can give us some grant so we can afford diapers.* (M1)
>
> *No. The government can augment the grant with food parcels, since no one in our family works. My mother works only for two days a week; so, it is difficult.* (M3)

The Department of Education also came under scrutiny, as some of the mothers questioned the ethics and capabilities of the schools. This matter and the fact that there are not enough schools to accommodate children with CP were mentioned by most of the participants. One participant said: *No. Some special schools are not welcoming. We took our child to one private special school, and one teacher asked us who was going to change his diapers. We then went to a public one and our child is very happy there. We are also happy with the school.* (M3)

The other governmental aspect that was a point of discussion entailed social workers – *No.*

> *I wish social workers can sometimes visit us for support. I also wish that I can take him to a nearby school that is suitable for him, but there is no such school.* (M6)
>
> *No. I wish social workers can visit us for support. At times, my husband and I end up fighting because of frustration.* (M5)
>
> *Social Development must visit the families of CP children for support. We are all by ourselves. We need people to talk to. We also need resources, like a small lift that can be used to get the child in and out of the bath*. (M5)

In evaluating these responses, one can assume that these participants are not really satisfied with the services provided by the Departments of Social Development, Education and Health. This is in line with Pretorius and Steadman's (2017:427) statement that while there is progress with regard to financial support for children with disabilities by means of disability grants, the government needs to do more. One can deduce that there is a level of dependency among these mothers on the various government departments. In the rural area in which the participants reside, due to their financial situation, they are completely dependent on government grants and services for support and care for their children and to improve their overall situation.

The final question, Question 11, pertinently focused on what the participants thought the government could do to support them and their children. The main themes that emerged from this question were educational aspects, social development aspects and financial matters. The educational theme was the most prominent, as most of the participants mentioned the need for schools, hostels, care centres and educational facilities. The following responses were given:

> *They can increase the grant that they are giving us. They can build a school with boarding facilities so we can leave the child there during the week and collect him on Fridays for weekends.* (M6)
>
> *The government must build facilities where children with CP can be kept so their parents are able to have a life and work. I do not trust the self-established facilities. These government facilities must have educational facilities so these children can be taught.* (M5)
>
> *The government must give parents or caregivers a monthly allowance to survive on, since they are not able to work.* (M2)
>
> *The government must build a school not far from our residential area where the child can attend but still stay at home, and the government must assist to force the father of the child to support the child financially.* (M3)

The main ideas that the mothers reflected on are the need for more local schools and hostel facilities for the children with informed and well-trained teachers –

> *Educators and employees at school must be continuously workshopped to be receptive and supportive.* (M4)

According to Pretorius and Steadman (2017:427), the lack of disability-friendly services such as schools and daycare centres remains a challenge. As was indicated earlier, the introduction of the policy on inclusion (EWP6) in 2001 does not seem to have yielded satisfactory results. This was also noted by the inclusive education team in the North West Department of Education during the Human

Rights Commission investigation. The team noted that African children with disabilities faced a lot of challenges, with rural children with disabilities being discriminated against even more as a result of the inadequate resourcing and under-provisioning of schools and infrastructure in their communities (South African Human Rights Commission, 2017:48).

In conclusion, one can clearly detect frustration and desperation from the mothers who participated. This led the researcher to ask the following questions: While South Africa has good policies on paper, do these policies translate into the best protection and support at ground level for these vulnerable children and their mothers? Are these policies indeed in the best interest of the child? According to Njelesani (2019:58), as cited in the document analysis, the dominant view is that policies and laws at the national level are not always regarded as part of the solution, and they are not always in line with reality. As many children with disabilities are hidden at home or in institutions for both their own and their families' safety, it is clear that these policies and laws are not implemented at the grassroots level. The researcher believes that it is possible that inclusive citizenship education can address and overcome some of these challenges, since those directly affected by disabilities will be engaged and empowered by knowledge of their rights and the rights of their children.

Table 5.5 below indicates the responses of mothers and the link between the mothers' responses with the identified themes (see Table 5.2)

Theme	**Sub-Theme**	**Mothers' responses that relate to the theme/sub-theme**
Knowledge about CP	Lack of knowledge	M1, M3, M5, M6
	Cultural Beliefs (witchcraft)	M3, M4
Impact of CP	Isolation	M1, M2, M5
	Lack of employment	M1, M2, M3, M5. M6
	Burden of care	M1, M2, M5, M6
	Stress and frustration	M4, M5
Resources for families with members living with CP	Financial burden	M1, M3
	Lack of schools	M3, M6
	Assistive devices	M5
	Lack of sufficient information from professionals	M1, M2, M4, M5
Psycho-social experiences and support	Isolation	M1, M2, M5
	Stigmatisation	M3, M4, M5, M6
	Lack of support	M3, M5, M6
	Feelings of devastation and denial	M1, M2, M3, M6
Possible interventions	Schools and care centre's (educational aspects)	M3, M5, M6
	Financial and physical resources	M2, M6
	Professional support	M4

Table 5-5: Tabulated responses of mothers linking their responses to the identified themes

5.5.4 Responses from caretakers

This section was a bonus, as two families, where there were no fathers present, had additional family members as caretakers. This is a common occurrence in the African culture where members of an extended family share the same household. It is particularly common when mothers are not married. As stated in the WPF-R, many families in South Africa include multiple generations and extended kinship networks (Department of Social Development, 2021:7). CA1 resided with Family 1 and was related to the child as an aunt; CA2 was connected with Family 3 and the child's maternal grandmother. As stated before, Smith (2018:5) believes that caring for a child with special needs can be a lonely and isolating experience; therefore, reaching out for support from extended family, the community and society in general is essential. These two members were interviewed in the same manner as the other three participants in the sample that was selected.

5.5.4.1 Responses to Questions 1, 2 and 3

With regard to the participants' understanding of CP and the causes thereof, the following responses were provided:

> *I do not really understand it. I only know that he cannot do anything for himself.* (CA1)
> *It is an ailment that causes fits.* (CA2).

The responses revealed that these family members did not really understand the concept of CP. Therefore, the second question that was posed, focused on their knowledge of the causes of CP. Their responses varied from a definite *"I do not really know*" (CA1) to an elaborate explanation given by the grandmother –

> *I do not really know. But I think this child is bewitched. She was fine until we had a ceremony of exposing her to the public. She stayed indoors for three months after birth in line with our culture. Then, on the day she was to be taken out, we had this party. I think she was bewitched on that day.* (CA2)

Witchcraft is a belief that is still common in African culture, including the rural parts of the Bojanala District. This grandmother believed that the baby (like any baby) was regarded as a bundle of joy for the family. However, due to many African views and beliefs, some people are viewed as evil, as they do not want any good to come of anything and nothing good for other people. These "evil-doers" are considered to be capable of bewitching a person or object. Thus, in the interview with the grandmother, she openly expressed her beliefs and commented that "*they"* (the evil-doers*)* bewitched her granddaughter so that she could not progress and develop like other children.

The final question in the first section was Question 3. Here the focus was on the participants' knowledge of the understanding of the condition among close family and community members. Again, the grandmother gave a simple and almost naive comment –

> *Yes, they know she suffers from fits.* (CA2)

However, the aunt provided a more comprehensive answer –

> *Family members understand this kind of illness because there is someone in our family who has the same challenge. Very few community members know about the child because he is always indoors; so, they never really see him.* (CA1)

The aunt resided with this family, but it seemed that she did not really bother or was afraid to enquire about the true condition of the child. Also, she is related to another person who has "*the same challenge*". Her comment that few people knew about the ailment, as the child was always indoors, was an indication of how isolated this family was and that the child might be kept indoors because the family wanted to protect him or was embarrassed about his disability. However, she indicated that she believed that the family and some of the community members understood the ailment.

5.5.4.2 Responses to Questions 4, 5 and 6

The questions in this section focused on the challenges these caretakers experienced regarding taking care of the child with CP, as well as their feelings about the situation and how it had changed their lives. The challenges highlighted were that everything must be done for these children and that it was not easy to take care of them –

> *I must always think for him. Sometimes I am not sure whether he is hungry or not.* (CA1)
>
> *We must do everything for the child. She is heavy, and when she must be bathed, it is not easy.* (CA2)

Both these participants agreed that everything must be done for these children. They indicated that because the children were dependent on them, it was a challenging situation, even though it had not really changed their lives. They said:

> *It really has not changed my life.* (CA2)
>
> *It really did not change my life that much. Only that I cannot do all things I want to do when I want to do them, because, at times when my sister is not around, I must look after the child.* (CA2)

In reality, the comment of CA2 can be construed as a complete change in one's life, while CA1 saw the care of the child as a family duty. The noted lack of change in these participants' lives can be because they are not as directly affected as the biological parents of the children with CP. While they are related to these children, they still have a choice in assisting with care and support or not.

Question 6 was aimed at exploring the participants' emotions and feelings when they first heard that the children had CP. Both caregivers indicated that it was painful when they were informed that the children were not well, which evoked various emotional feelings. The aunt said: *It was really painful (crying).* (CA1)

The grandmother gave a more detailed response and, as indicated earlier, believed that her granddaughter was bewitched –

> *It was really hard to understand why she was ill. We went to many traditional healers, but nothing changed. It was only when she was five years old that we decided to stop taking her to all these healers.* (CA2)

A sense of desperation and failure was evident in the grandmother's response.

5.5.4.3 Responses to Questions 7, 8 and 9

Once again, this section aimed at exploring the participants' views regarding the services and support mechanisms that were available for the family and the child with CP. Both participants acknowledged that there was support, but one added that the biggest problem was the distance –

> *Yes, we get support.* (CA2)
>
> *It is just that the majority stay far.* (CA1)

Regarding support from the community, one participant stated that they did not really expect any support

> *We actually do not expect anything from the community. We do everything ourselves.* (CA1)

In contrast, the other participant stated:

> *Yes. Some are even able to look after the child when we are not around.* (CA2)

In reflecting on this situation, it is again suggested by the researcher, as was proposed earlier, that inclusive citizenship education can be used to remedy the situation by providing knowledge and understanding and reducing stigmatisation and unfounded beliefs about CP.

Question 9 required the participants to consider any service available to the family and child that they were aware of. The grandmother stated:

> *She attends monthly physiotherapy sessions at a local hospital. Recently, they gave her a wheelchair. She gets some money from the government every month.* (CA2)

However, in contrast, the aunt said:

> *Nothing. We only go to the hospital when the child is sick. They sometimes refer him to the physiotherapy section within the hospital. My sister must always pay for this. If she does not have money, they, at times, attend to the child, but she must always go back to pay.* (CA1)

With this stark contrast, one can see the disadvantages and unfairness that are experienced in the South African context, especially in rural areas.

5.5.4.4 Responses to Questions 10 and 11

These final questions were posed to gauge the opinions of the caretakers regarding the quality of the services that they received and the support provided by the government to people living with CP.

In response to Question 10, pertinent grievances concerning the services that were available, services that were unavailable and the need for more services were verbalised – *No. I wish they can increase the disability grant because they become more expensive as they grow. They can also provide us with diapers for the child. She also needs a chair to sit on when she is fed.* (CA2)

> *I wish they can approve a grant so we can afford diapers and soft food for him. He only eats soft food*. (CA1)

In general, these two caregivers indicated that the government could do more to support their families and the children regarding their different unique needs. In response to Question 11, they indicated that services were available and present but not adequate. One participant explained: *Social Development must support families of children with CP, especially because we are poor. The government must provide us with an RDP [Reconstruction and Development Programme] house because this two-roomed house that we stay in belongs to the farmer who employs me. I started working for him for five days a week; now he reduced it to two days. I am worried that one day he might say that there is no longer work for me and that we must vacate the house.* (CA2)

Historically, low wages have been a reality on South African farms, and farmers provide free housing and services to their employees (Devereux, 2019:2; Hartwig & Marais, 2005:932). As this caregiver was a farm worker, the situation for her was challenging. She stated that she wished the government would provide her with a Reconstruction and Development Programme house. These houses, which are provided free of charge by the South African government, emanate from the policy that was introduced after 1994 as a way of assisting low-income communities (Department of Housing, 2009). Being provided with a house of their own would greatly assist her and her family.

The other participant also commented on services that should already be available to the child who was in her care –

> *They must provide physiotherapy free of charge, at least on a monthly basis. They must give him a wheelchair because he is too heavy to carry around.* (CA1)

These aspects highlight the fact that there is a lack of support services, information, networking and communication among caregivers who care for children with CP from government departments who are there to specifically support the most vulnerable in the country.

Table 5.6 below indicates the responses of caregivers and the link between the caregivers' responses with the identified themes (see Table 5.2)

Theme	**Sub-Theme**	**Caregivers' responses that relate to the theme/sub-themes**
Knowledge about CP	Lack of knowledge	CA1, CA2
	Cultural Beliefs (witchcraft)	CA2
Impact of CP	Isolation	CA1
	Lack of employment	
	Burden of care	CA1
	Stress and frustration	CA2
Resources for families with members living with CP	Financial burden	CA1, CA2
	Lack of schools	
	Assistive devices	CA1, CA2
	Lack of sufficient information from professionals	
Psycho-social experiences and support	Isolation	CA1
	Stigmatisation	
	Lack of support	CA1
	Feelings of devastation and denial	CA1, CA2
Possible interventions	Schools and care centre's (educational aspects)	
	Financial and physical resources	CA1, CA2
	Professional support	

Table 5-6: Tabulated responses of caregivers linking their responses to the identified themes

As indicated earlier, red tape often causes problems for those in need. This is in line with what is stated by Phumudzo *et al.* (2021:2) and the National Information Centre for Children and Youth with Disabilities, as far back as 2003. When a mother learns that her child has a disability, the information initially comes as a shock to her, resulting in feelings of loneliness and isolation. These mothers, confused and bewildered, often do not know where to search for help, information or support, and thus their cycle of isolation and loneliness begins. Therefore, as a mother with a child with disabilities, the suggestion of addressing CP through inclusive citizenship education in the Bojanala District, North West, is proposed as a way in which these families can be supported and given hope to begin to live an inclusive life.

5.6 SUMMARY

Chapter 5 reported on the thematic analysis of the data collected through individual interviews. The participants shared their personal experiences with children with CP. The attitudes of community members towards children with CP and their families were also looked at. Themes and sub-themes that emerged were ascertained and thematically analysed. In the next chapter, the researcher will present the findings, reflect on the research questions and discuss the contribution of the study, the limitations, recommendations and the conclusion of the study.

CHAPTER 6 FINDINGS, RECOMMENDATIONS AND CONCLUSION

6.1 INTRODUCTION

> *Having a disability is not really a problem; the problem is the social and non-inclusive environment that so many of us are living in, which dismantles self-esteem and discourages achievement.* (Njeri, 2018:3)

In the previous chapter, the data that had been obtained through the various research methods were analysed and interpreted, and the results of the research were delineated. The results obtained were based on the data collected through the literature review, the document analysis and in-depth interviews, which were thematically analysed to derive meaning and provide insight into answering the research question. In this chapter, these research findings are discussed in detail, leading to the researcher being able to draw conclusions and add to the body of academic knowledge by suggesting some solutions to the challenges that are evident.

After giving a synopsis of the study, the findings that were first linked to the theoretical and conceptual framework are highlighted. This is followed by a discussion of the findings linked to the literature study. The reflection on the research questions is then discussed, and recommendations are made that contain suggestions on improving knowledge and support for people living with CP and those who must contend with it, namely their families and caregivers. Thereafter, the limitations of the study are discussed. The chapter concludes with suggestions and proposals for further research in this area.

6.2 SYNOPTIC OVERVIEW OF THE STUDY

Chapter 1 presented the study and gave an overview of what to expect throughout the study. A background on the research was provided, and the reader was presented with the problem statement posed in the research study. The main intent of the study was to explore the impact of CP on families and individuals who have to contend with people living with CP, namely caregivers, parents and members of the extended family. The research aims and the objectives of the study were provided. Bronfenbrenner's bioecological theory guided this study; therefore, this theory was discussed and applied to provide a theoretical framework for the study. Furthermore, the main concepts of the paradigm, design and methodology employed by the researcher were identified in this chapter, and an outline of the different chapters of this study was provided.

In Chapter 2, the literature review and theoretical framework that governed the study were explored. The conceptualisation of CP was thoroughly delineated, and the defining characteristics and different types, classifications and causes of CP were stated. Then, the risk factors and various cognitive, sensory and physiological problems associated with CP were discussed in depth. In addition, management and support for individuals with CP in the African context were examined, which included a specific focus on rural families and the impact of CP on these family systems. This examination was done with Bronfenbrenner's bio-ecological systems theoretical framework in mind, with a discussion and application of these systemic assumptions.

Chapter 3 focused on a document analysis, which is a form of qualitative research in which a systematic procedure is used to analyse documentary evidence to answer specific questions. The document analysis of the policies and legal frameworks that govern CP in South Africa was done to contextualise the study. The WPF, the WPF-R, EWP6, the WPRPD, the *Constitution of the Republic of South Africa* and the *South African Schools Act* were analysed.

The research paradigm, the research design, the methodology employed and the ethical considerations of the research are presented in Chapter 4. In this research, three research methods were employed to collect data, namely a literature review, a document analysis and in-depth interviews. The researcher used triangulation to validate and ensure the reliability of the collected data. For ethical considerations, the researcher applied for and received ethical clearance from the EMTEL Ethics Committee of the North-West University (see Annexure C). The researcher also requested permission from the North West Department of Health to conduct the research, as participants were sought from the register of this department. The Department granted permission (see Annexures D and E). The potential participants were then given letters of consent that clearly stipulated that participation was voluntary and participants could discontinue with the study at any time they wanted to (see Annexure H). These letters were signed by those who participated.

In Chapter 5, the researcher focused on the analysis and interpretation of the collected data. The research study followed a reflective thematic analysis, which is a technique through which themes are systematically identified and analysed. The following five main themes were identified: knowledge about CP; the impact of CP; resources for the families of children with CP; psychosocial experiences and support; and possible interventions.

6.3 REFLECTING ON THE THEORETICAL FRAMEWORK OF THE STUDY

The theoretical framework that was used to ground this study was Bronfenbrenner's bio-ecological systems theory. This theory, as was indicated earlier, has five ecosystems, namely the microsystem, mesosystem, exosystem, macrosystem and chronosystem. Each of these systems, as argued by Bronfenbrenner (2005), can be either enabling or constraining for family life. In this study, looking through this lens, the researcher was able to document how each system influenced these families in the Bojanala District, North West (see Figure 6-1).

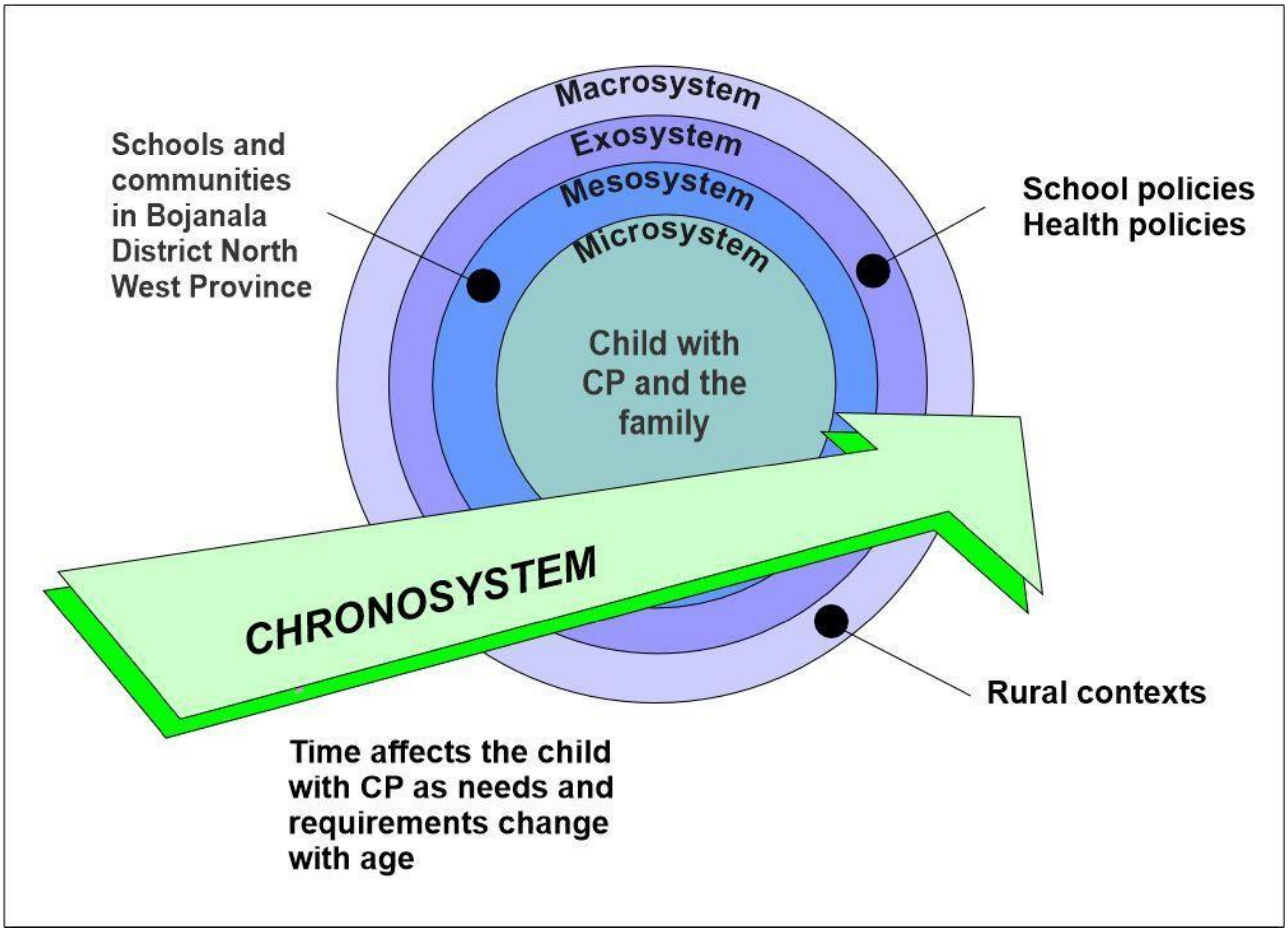


Figure 6-1: The integration of the theoretical framework of Bronfenbrenner into the research study.

Bronfenbrenner (2005) argues that in the microsystem, the environment has an impact on the individual, and in return, the individual has an impact on the environment. In the Bojanala District of North West – a poor rural district – this microsystem of the individual is extremely fragile and interrelated, with the microsystems of the families of children with CP being absolutely dependent on their environment and situation. It is, therefore, important to acknowledge and (as far as possible) manage the relationship between all the aspects of these microsystems, namely the parents, the child with CP and the extended families, as any influence can affect the development of the child either negatively or positively. For example, in this study, one of the participants had a child with CP who was kept indoors and not allowed to interact with other children or attend school for fear of the child being mocked or laughed at. Obviously, this situation negatively affected all role players, from the children themselves to the parents, caregivers and members of the extended family.

The mesosystem, a system that, in this study, can be seen as a school and place of work, forms part of the ecosystemic model (Bronfenbrenner, 2005). School and work environments are directly influenced by a child who remains at home, as the mother cannot go to work or attend social events because she is worried about leaving the child all by him- or herself. These environments are also influenced by the results of the stigma that the community attaches to these families. Thus, isolation from work and school environments within the mesosystem compounds the isolation of these families. Five of the mothers who participated in this study were not employed; one left her job immediately after giving birth to the child with CP. While various reasons were provided for these children not attending school, the main one was that there were no schools that catered for children with CP in the vicinity. The researcher is of the opinion that the availability of these unemployed mothers is in a way encouraging the situation: the mothers are available to take care of their children; hence, there is no need for them to attend school. It is apparent that all role players are negatively affected by this situation. One child with CP had been withdrawn from a school as the parents felt that he had not been well taken care of at the school. The researcher wonders whether this would have been done if the mother was not readily available to take care of the child.

Although children with CP and their families are not directly involved in the processes of the exosystem (Bronfenbrenner, 2005), this “indirect environment” in the rural district of Bojanala refers to, among other things, the implementation of the educational policy on inclusion (EWP6) and everything that has an impact on children with CP and their families. As was stated earlier, there are very few schools that have been converted to full-service schools in the rural parts of the Bojanala District. Obtaining physical resources and well-trained teachers within these schools remains a challenge. In this study, EWP6 does not seem to benefit children with CP or their families; hence, their staying at home and not being in schools. While the *Constitution of the Republic of South Africa* and the WPRPD protect the rights of children with CP, in reality it seems that they are just good on paper. The majority of the children in this study did not attend school, as there were no schools they could attend in the area. Consequently, their right to education was being ignored. While South African policies and legislation protect the rights of people with disabilities, including CP, it is apparent that community members’ beliefs about and lack of knowledge of CP and the causes of the condition have a negative impact on the implementation of these policies. The majority of the families in this study depended on a disability grant provided to the child with CP. The fortunate ones were the three children whose fathers were employed; at least their situation was better compared to that of the other families.

According to Thuketana (2018:215), the macrosystem, which is the fourth layer of Bronfenbrenner’s bio-ecological systems, is the bio-ecological system encompassing belief systems, culture, religion and laws in the ecological systems. In the current study, it is seen that children with CP are being laughed at and questions about them are asked, which causes great concern regarding aspects of understanding and stigmatisation in the community. In two of the families, close family members attributed the disability to witchcraft. Another concern is the community's lack of empathy, understanding and simple medical knowledge, which has affected the families and children with CP negatively. Some families in this study resorted to keeping their children indoors as a way of protecting them. This has also negatively affected the families, as they ended up being isolated and stigmatised in their community. However, the belief systems and cultural beliefs of communities can be positively influenced if they are provided with insightful, appropriate and applicable information regarding CP, its causes and treatment for the condition. Better understanding can lead to better support and more encouragement, backing and empathy.

The chronosystem, which is the outer layer of the ecosystem (time-related) (Bronfenbrenner, 2005), is seen as the changes or transitions that happen throughout a person's lifetime. In the context of this study, it includes, among other things, full implementation of inclusive education and full implementation of the WPF in South Africa. These can have a positive impact on children with CP throughout their lifetime. As children grow, their needs and requirements change. Accordingly, children with CP will obviously have developmental needs that will change over time, resulting in different needs and different requirements as the children mature. If these policies can be implemented as expected, those affected by CP will benefit the same as other South African citizens, which, in short, is a legal requirement.

6.4 FINDINGS OF THE RESEARCH

In this section, both the literature and the empirical findings of the study are briefly discussed. The literature findings are derived from Chapters 2 and 3, whereas the empirical findings are derived from the data presented, analysed and interpreted in Chapters 4 and 5.

6.4.1 Findings related to the literature

The literature findings in Chapters 2 and 3 are centred on the conceptual framework of CP, including policies and legal prescripts that ground the study. While CP is common in South Africa, also in the Bojanala District, the causes thereof are not really known to many families with children who suffer from this condition. There is a tendency that families with children who have CP are left all by themselves to take care of their children. Resources such as physical, human and financial support are not readily available, and if available, many vulnerable families are not fully aware of what is available to support them. This situation occurs in most rural parts of many African countries (Adugna *et al*., 2020:2; World Health Organisation, 2011), and South Africa is no different. The South African Constitution and various policies protect people with disabilities; however, many of these policies are not fully implemented everywhere, especially in many rural areas. These findings and implications are discussed in the next section.

6.4.1.1 Findings related to the literature regarding the concept of cerebral palsy in relation to the research study

According to the literature, CP is a heterogeneous condition that presents with multiple associated disorders and medical complications (Mahendra, 2017:76). During the interviews with the families of children with CP, this aspect was also prominent. In line with what was raised in the Cerebral Palsy Guide (2019:1), the most common signs of CP that were observed were spastic and involuntary movement, a lack of coordination and difficulties with motor skills, late developmental milestones, such as crawling and walking, and a lack of bladder control and bowel movement. These developmental deficiencies and challenges were also evident from the responses of the participants, and it was clear that they posed many challenges to children with CP living in rural areas.

The age at which CP develops is still not clear, as was also noted by various authors (e.g. Bertule & Vetra, 2020:1; Novak *et al.* 2017:897). Furthermore, the causes of CP differ from case to case but are, in general, attributed to post-neonatal events. During the interviews, many of the participants revealed that they were not aware that their children had CP until later in life, especially when the children did not reach key developmental milestones at specific ages or were observed not to be developing normally. The six mothers gave different causal factors regarding the disability of their children. Three indicated that it was because of insufficient oxygen during the birth of the child, one reported that the baby was born with the umbilical cord around his neck, and another one associated the disability with witchcraft. The other mothers stated that they did not know exactly what the cause was but linked it to long labour. Another mother reported having been informed by the doctor of the disability of the child months before she gave birth.

Sondrum *et al.* (2005, as cited by Lourens, 2016:13) state that in developing countries, there is a higher occurrence of post-natal acquired CP cases due to birth asphyxia, central nervous system infections and bilirubin toxicity. In rural areas, there seems to be a similar tendency, as some mothers attribute this affliction to a lack of oxygen that their babies experienced during delivery. In the study of Sondrum *et al.* (2005, as cited by Lourens, 2016:13), there were, however, no reports of central nervous system infections or bilirubin toxicity. It is, therefore, posited that the reason for this could be that rural sites often lack adequate medical support and medical documentation of births, as well as suitable pre- and post-natal care. Furthermore, in the literature (e.g. Rosenbaum *et al.,* 2007:8; McLennan *et al.,* 2019:473), it is stated that CP is frequently accompanied by sensory, perceptual, cognitive, communicative and behavioural impairments, as well as epilepsy and secondary musculoskeletal problems. Stern (2020:1) posits that since CP is caused by damage to the brain, that is, the centre that transmits accurate information, several neurological pathways may be impaired.

The responses of the participants in this study mirrored the problems mentioned above. Various participants reported that some of the children who presented with CP did not understand what they saw or heard, while some mothers stated that their children with CP were fed only soft food, as they could not swallow other food. This was in line with the statement made by Miller *et al.* (2017:49) that the majority of children with CP have problems with chewing and swallowing. Many of the participants also noted the aspect of epilepsy when they indicated that their children had fits. One mother said that the first time their daughter had an epileptic attack, it lasted for five hours. This again makes one wonder about the medical care provided to rural patients. From the participants' responses, it was deduced that seven of the children could not communicate properly. One participant indicated that her child became very angry when they could not understand what he was saying. This reflects the statement made by Rosenbaum *et al.* (2007:8) and McLennan *et al.* (2019:473) that children with CP frequently experience sensory, perceptual, cognitive and communication challenges, as well as Stern's (2020:1) statement that CP is caused by damage to the brain.

Furthermore, the literature states that people with CP continually experience barriers in their daily lives, with lifelong physical, medical, educational and social challenges (Honan *et al.,* 2021:49). All of these challenges, which often remain unaddressed, can be directly associated with CP (Honan *et al.,* 2021:49). This was evident during the interviews with all the participants – the mothers, fathers and caregivers of the children with CP in this study. Almost all of the families indicated that they did not receive support from close family members and members of the community regarding any of the challenges they experienced in the areas that were highlighted by Honan *et al.* (2021:49). In the South African rural context, these barriers are even more prominent, with educational facilities being unavailable and families being expected to look for appropriate schools far from home. This has, unfortunately, resulted in most children with CP in the rural parts of the Bojanala District staying at home. The following statement by Funda and Beere (2020:14) makes the situation in South Africa clear:

> In the literature review, despite the regulatory framework guaranteeing the right to education for children with disability, there has been a persistent pattern of human rights violations at special schools and hostels as well as lack of access to any schooling for thousands of learners with disabilities, and a complete failure to provide reasonable accommodation and support for learners with disabilities in ordinary schools.

Socioeconomic factors have further negatively compounded these families' very existence and, for some families, made it extremely difficult for them to live from day to day. The literature (e.g. Ankam *et al.,* 2013; Chin *et al.,* 2020:398; Newman, 2017) clearly states that there is no cure for CP, but treatment can assist in managing the condition. Two of the mothers indicated that they had anticipated an improvement and, ultimately, recovery in the condition of their children with CP, which did not happen. Again, this points towards insufficient knowledge regarding CP. However, with proper knowledge and support, this situation would not have occurred. Moreover, proper management of the condition by means of effective treatment and assistance would have ameliorated the situation.

To conclude this section on the findings related to the literature on CP, the specific context of the African people must be addressed. Many Africans have negative attitudes towards people with CP and, therefore, isolate them for fear of being bewitched themselves (Mostert, 2016:9). As Mostert (2016:9) points out, the key factors of stigmatisation in Africa are directly related to the lack of understanding and awareness in communities regarding the causes and characteristics of people with a disability; CP is no different. The current study also reflected this trend, with many of the families in the study indicating that the condition of CP brought them isolation, uncomfortable comments and stigmatisation. These negative responses were often from their own family members, keeping these individuals isolated and stigmatised even within their own close family circle, as well as in the broader community.

This is in line with Alaee *et al.* (2015, as cited in Madzhie *et al.,* 2022:5), who posit that there is a lack of supportive interaction and environmental engagement from families, with especially mothers experiencing stigma from various family members and friends. It also came to the fore that fathers tended to abandon these children. In line with this, it is noted by Madzhie *et al.* (2022:5) that fathers often find it difficult to accept their children with CP, resulting in the family unit being broken up, as they often separate from the mothers. In this study, only three fathers were available for the interviews. While one was at work and could not attend the interviews although he was still involved with his child, two other fathers were uninvolved in their children's lives and not available for the interviews. One mother raised her frustration because of the father's complete lack of attention and stated that if they met him on the street, he would just pass them by without even greeting them. The unavailability of these fathers has resulted in extra financial hardship for the mothers who cannot seek employment due to the challenges of being a single parent who must take care of a child with CP.

To conclude, comparing the literature with the study, it can be noted that many of the identified aspects within the literature were reflected in the real-life situation of the families in the Bojanala District that were studied. Thus, to address CP through inclusive citizenship education by comparing the literature review and the responses given in the interviews, the researcher can highlight that applicable and appropriate information provided to all community members is the crux of inclusive citizenship education for communities and can ameliorate the situation.

6.4.1.2 Findings related to the policies and legal prescripts: comparing what is legally required and what occurs at the grassroots level

The researcher reviewed policies and legislation to establish the South African legal stance on the topics of the educational system. These included inclusion, family support, health support and children with CP, as well as human rights and citizenship. The following legal documents and policies were reviewed: the WPF, the WPF-R, EWP6, the WPRPD, the *Constitution of the Republic of South Africa* and the *South African Schools Act*.

In general, from insight gained from these legal documents and frameworks, the findings suggest that the South African legal structure protects the rights of all, especially vulnerable populations. Included in these populations are those with disabilities, including but not limited to individuals with CP. As noted by Tigere and Makhubele (2019:2), due to South Africa being a signatory to the United Nations Convention on the Rights of the Child in 1995 and the UNCRPD in 2007, the country is viewed as having the best policies for children with disabilities. However, in listening to the responses from this small sample group, it became evident that these policies had not been properly implemented, and if they were, they were not optimally functional. The current situation for these families in the Bojanala District reflects failed policy implementation that provides no constructive change in the lives of these children with disabilities and the families that support these children.

In the Bojanala District, the norms and standards that have been put in place for uprooting barriers that continue to encourage the exclusion of persons with disabilities are not effective. These rights include the right of children to be allowed to attend school and be comprehensively included in a school of their choice or that their parents prefer. In reality, this did not occur, and the families that were interviewed, who had children with CP, indicated that these children did not attend school, either because the child resided too far from an appropriate school or because there were no schools that would accommodate the child or because the travelling arrangements were problematic. This touched on a further challenge, namely that of transport being expensive, if available, or not appropriate due to the condition of the child with CP. In this study, the participants specifically indicated that transport was available in the areas where they lived, but it was not always capable of accommodating children with CP, their wheelchairs (if they had one) and the parents, who were expected to pay extra fees for all the equipment that was needed by these children. Therefore, this situation has a negative impact on these children getting to school and back daily. Either way, it is clear that inclusive policies are not fully implemented within the Bojanala District, North West.

While the vision of the WPRPD is supposed to create a free and just society that is inclusive of all persons with disabilities, the reality in the Bojanala District is that children with CP, as well as their families, are being excluded and isolated. This was confirmed by the families and community members who were interviewed. The WPF (Department of Social Development, 2013:8), which was approved in 2013, envisaged well-functioning families that are loving, peaceful, safe, stable and economically self-sustaining. However, during the interviews, all these families with children with CP indicated that their financial struggles, community problems and daily living conditions were not in line with the promised support stated in the legal framework documents.

Another aspect that is in contradiction with other South African policies is the Care Dependency Grant, which is the primary form of social protection grant available to the caregivers of children with disabilities in South Africa (Trafford & Swartz, 2021:2). Three families that participated in this study indicated that they did not receive this grant that was administered by the South African Social Security Agency. One of these three families indicated that they had never been informed of the grant and, as such, had not applied for it. The second family was struggling to get the necessary documents that were required to access the grant, while the father of the third family simply stated that they were planning to apply for a grant for their 11-year-old. He did not explain why they were still intending to apply. From these submissions, it became apparent that the people who were expected to benefit from this assistance by the government were either in the dark and did not have the necessary information or the red tape involved in this process and difficult requirements were making it difficult for them to benefit from the support, leaving them excluded. The three families that were receiving the grant raised concerns about the grant being very limited and did not adequately cater for the needs of the children, especially as they grew older. The participants all suggested that to ameliorate this situation, they should be assisted financially by the government in a more realistic and fitting manner that was in line with the economy and inflation of the country.

6.4.2 Findings of the empirical data

This section presents the empirical findings derived from the methodological section presented in Chapter 4 and the analysis and interpretation of the data presented in Chapter 5. Information was acquired from the participants with whom in-depth interviews were conducted. The main findings derived from these interviews are presented below. The headings given were formulated from the identified themes in the study (see Table 5-2).

6.4.2.1 Knowledge about cerebral palsy

From the interviews of the four different groups – community members, fathers, mothers and caregivers from the Bojanala District, North West – it was evident that the majority of these individuals did not have adequate knowledge of or insight into CP or the causes thereof. When responding to this question, the majority of the community members showed a lack of knowledge and insight regarding this affliction. Furthermore, it was evident that the mothers had a better understanding of CP, especially what the medical condition entailed and the causes of CP. This was probably because the mothers of children with CP tended to have closer ties with their children and would have wanted to know more about the condition.

The researcher is inclined to agree with the literature findings that "little has been published on CP in Africa, and that large gaps remain in our knowledge of its aetiology across the continent" (Burton, 2015:876). This was also evident in the literature that was reviewed for this study. Sources were difficult to find, and most of those available were outdated. Therefore, it is imperative that new knowledge regarding this topic is provided to all communities, especially rural communities in the Bojanala District, in an effort to address CP. It is strongly suggested that the distribution of knowledge of CP can be done through inclusive citizenship education, whereby all members of the community and individual family members can be informed and educated on the condition.

6.4.2.2 Impact of cerebral palsy

Most of the participating families in the rural Bojanala District viewed CP as having negatively affected their lives. Two fathers indicated that they were still young and had dreams, such as travelling the world and going out to eat at restaurants. However, having a child with CP who could not walk shattered their dreams. Furthermore, this condition also was a preventative factor in these individuals' choice to extend their family for fear of having another child with CP. The lives of these adults were, therefore, severely affected – financially, socially, workwise and personally – especially as many of the individuals and families were isolated or stigmatised. This situation cannot be magically changed and the child with CP wished away; however, with more education that is aimed at inclusion and producing better citizenship, the researcher strongly feels that more understanding and community empathy will be engendered for these families who carry a heavy burden. With understanding comes sympathy; with sympathy comes empathy; and with empathy comes acceptance and solidarity.

6.4.2.3 Resources for families with members living with cerebral palsy

In the interviews, community members, fathers, mothers and caregivers from the Bojanala District acknowledged the need for the families of children with CP to be provided with physical, financial and human resources. A major form of support should be provided by social workers who must visit these families and offer them personal support. The participants indicated that the situation of mothers who did not work due to the demands of a child with CP posed a serious challenge to the finances, socialisation and mental health of these families. Many of the participants in this study expressed their opinions regarding the assistance that should be given to these vulnerable children and their families. Furthermore, the provision of schools in the area and assistive devices, such as wheelchairs and electronic aids, were also seen as resources that could alleviate the stress and pressure of daily living for these families.

Thus, in order to address the situation of CP within a family situation, inclusive citizenship education would entail educational support, which would be directed at informing families on how to access appropriate resources for their children. This type of education should include information that provides aspects regarding individual and children's rights, policy information and legal matters, all provided to empower rural communities and enable them to know what support is provided by the government and how to access these resources.

6.4.2.4 Psychosocial experiences and support

The families of children with CP indicated that they received little to no support from close family members and the community. The participating community members were also in agreement. It was apparent that only those community members who were close to families with children with CP were supportive, while others did not even know about the existence of the child with CP, as some families opted to keep them indoors. Due to a lack of support for families with children with CP, many of these families were isolated, resulting in their being left alone and only having one another for company and companionship. This situation obviously created a stressful situation for these families. In order to address this situation of exclusion and isolation, inclusive citizenship education would provide information on CP as a disability and create an understanding of its challenges, as well as support for the individual and family who must contend with this affliction. Knowledgeable family and community members are bound to improve the situation by supporting these families and children with CP. This would make a difference for these families by reducing their feeling of being overwhelmed and alone, as creating opportunities for sharing and communication would create a non-judgmental environment that would be supportive and empathetic.

6.4.2.5 Possible interventions

Possible interventions suggested ranged from the provision of local schools for children with CP or care centres with hostels, suitably trained support staff who is able to care for children with CP and knowledgeable, well-trained teachers. Assistive devices for children with CP and other resources in a form of finances and transport were also listed as necessary. Designated social workers should be readily available to provide support to these families. Inclusive citizenship education in this situation would include information on available resources in and around the area in which these families reside. Such information should include services that are available to families and children with CP, as well as support groups and community engagement efforts.

In the next section, a reflection on the research questions is presented.

6.5 REFLECTION ON THE RESEARCH QUESTIONS

In order to explore the topic, facilitate the collection of data and analyse the empirical research, the discussion focuses on answering the following research question:

Can inclusive citizenship education address the needs of families with members living with CP in the Bojanala District, North West Province?

In an attempt to answer the research question, the following sub-questions that guided the study were reviewed:

- What are the current practices and policy regarding inclusive education in the Bojanala District, North West Province?
- How does CP affect the families of people living with CP?
- What perceptions are evident in communities within which there are people living with CP?
- How can communities be assisted to transform their attitudes towards the families of people living with CP?
- What are the various role players' experiences of the support that is given to the families of people living with CP in order to accommodate them inclusively?
- What guidelines can be developed for a framework to support all role players?

6.5.1 Sub-question 1

What are the current practices and policy regarding inclusive education in the Bojanala District, North West Province?

As was indicated earlier, within the boundaries of the Bojanala District, there are 545 public schools, of which 70 are full-service schools. The majority of these full-service schools are designated primary schools that do not have the required resources. Some of these primary schools have been on a waiting list for infrastructural repairs and modifications for more than three years. Where school governing bodies were able to raise funds, the schools were able to attend to their infrastructural challenges. The district has 14 special schools, of which only one, Meerhof Special School, situated in Hartebeespoort, has been fully resourced to serve as a resource centre. It is a challenge for most inclusive schools within the district, as well as other special schools, to utilise this special school for support as proposed in EWP6, as it is far (approximately 242 kilometres) from the furthest school in the district. Most schools would need transport to access this special school. In this study, the majority of the children with CP who were studied did not attend school.

While EWP6 stipulates that all children, despite their disabilities, should be admitted to schools and be supported, many of the children with CP in the Bojanala District are kept at home. The reasons for this situation are that there are very few full-service schools in the rural parts of this district, and to compound the situation, these schools are hesitant to admit children with CP. This situation results in parents needing to look elsewhere for educational opportunities for their children with CP. It is this situation that necessitates parents to obtain suitable transport for their children with CP to attend schools further away from their homes. It must also be noted that in South Africa, most public transport is run by minibus taxis. These vehicles do not have suitable space to accommodate a physically disabled child or the equipment that must accompany children with disabilities, for example a wheelchair. If the taxi owner or taxi driver agrees to transport these disabled children, their fees are increased because of the extra space needed to accommodate the caretaker, the child and the necessary equipment. With these extra financial implications, families with children with CP often face financial challenges, which result in children with CP remaining at home and not being able to attend school.

Reflecting on this question on the current practices and policy regarding inclusive education in the Bojanala District, North West, the researcher believes that the inadequate training of teachers at full-service and special schools leaves children such as those with CP and other special needs in a compromised position. This situation is exacerbated by the insufficient provision of resources within these schools. Much must be done to provide physical, financial and human resources to assist in the proper implementation of the policy on inclusion. Thus, it can be stated that what appears in the policies regarding the laws, rules and promises of assistance does not materialise on the ground, as in reality, there is a total lack of support, resources and financial assistance for those who are in dire need of these. Therefore, the current practices and policy regarding inclusive education in the Bojanala District are not evident in practice.

6.5.2 Sub-question 2

How does CP affect the families of people living with CP?

The impact of CP on the participating families in the Bojanala District was seen as posing many challenges for these families. The different challenges noted were physical, financial, socioeconomic and social challenges. Physically, children living with CP were unable to help themselves. Financially these children were a drain on the family finances, resulting in the families struggling. Socioeconomically and socially, these families were isolated and, at times, ostracised by the community. Therefore, the impact that a child with CP has on his or her family is negative and often leads to a lower quality of life for these families.

6.5.3 Sub-question 3

What perceptions are evident among communities within which people with CP live?

In surveying the responses from the data obtained, it was evident that many negative perceptions were noted in the communities within which people with CP live. Many community members only knew that CP affected the physical aspects of the child, as these were the most prominent and observable. This primary focus eliminated and downplayed the psychological and emotional impact that this affliction had on the family and on the child with CP. The community members also believed that these children could not do anything for themselves and that their caretakers had to do everything for them. These beliefs mirrored the lack of insight, knowledge and understanding shown by these community members regarding the functioning and daily lives of children with CP and their families. Furthermore, it was clear from the interviews that the community members did not understand the special needs of children with CP, resulting in limited acceptance of the child and the family. Thus, looking from an overall perspective, the researcher would answer this question by commenting that the communities of the rural parts of the Bojanala District within which children with CP live are not fully aware of CP, the causes thereof and the management of the condition. There is a need to educate community members on all aspects of CP.

6.5.4 Sub-question 4

How can communities be assisted to transform their attitudes towards the families of people living with CP?

The general attitudes displayed by many communities in the Bojanala District revealed rather suspicious and derogatory outlooks. These negative attitudes resulted in the isolation of the families, the mocking of children with CP and the general unacceptance of these community members. The researcher believes that in order to assist these communities to transform their attitudes towards families living with CP, inclusive citizenship education can be used to bridge the gap and change people’s attitudes towards people living with CP to be more supportive of these families. According to the WPF (Department of Social Development, 2013:1), inclusion is a human right that is meant to embrace all people, irrespective of race, gender, disability or medical or other needs. Furthermore, it is also meant to provide equal access and opportunities to all by eradicating discrimination and intolerance by removing all barriers. This represents the essence of inclusive citizenship education, as citizenship education is defined by Muleya (2018:116) as the subject that teaches citizens how they ought to act as members of the community or prospective members of the community.

In conclusion, it is felt that in order to change the attitudes of communities, citizenship education can be used to produce active citizens with a commitment to particular public values and practices regarding political, moral and social responsibility and community involvement, such as helping out those that may require assistance (Muleya, 2018:117). Having noted the negative attitudes of these community members, the researcher hopes to educate them to fully understand CP and the challenges that go along with this affliction. With this education, it is believed that there can and will be a change in the attitudes of these communities for the better, in order to embrace and support vulnerable members of this rural society and make them part of their community.

6.5.5 Sub-question 5

What are the various role players' experiences of the support that is given to the families of people living with CP in order to accommodate them inclusively?

Considering the role players' experiences of the support that is given to the families of people living with CP, the members of the community who were interviewed believed, in general, that minimal support was given to the families of children with CP. Moreover, concern for the limited response from community members, in general, was evident, as many of the community members did not and could not envisage the complications and challenges these families encountered and experienced. Most of the community members simply stayed away and avoided any interaction with these families, pushing the affected families further away into isolation and exclusion. Furthermore, social workers were identified as not being supportive of families with children with CP. Social workers were few and far between and did not do any house visits or had one-on-one interaction with many of the families, as revealed by the participants. This presents an extremely concerning situation, as these children will fail to be noticed. In terms of education too, these children are marginalised, as the schools in the area are inappropriate or not prepared to accommodate them. Health services are also lacking, and it seems that these families and their children are not being fully accommodated. Long waiting hours and a lack of suitable health support are more challenges they face. Moreover, the mental health issues of these families are not addressed.

Thus, from this evidence, it can be noted that families in the Bojanala District living with children with CP are not supported or even perceived as needing support from those living with and around them. These families are left to their own devices and must traverse their way through their daily tasks, taking care of their children with CP, making a living and trying to survive without much information, financial assistance, physical support or human resources.

6.5.6 Sub-question 6

What guidelines can be developed into a framework to support all role players?

Grossman (2014:16), in linking citizenship to inclusion, believes that both citizenship education and inclusion share a common ethos and language based on concerns for human rights, social justice and a sense of community. This is in line with the definition posited by Muleya (2018:116), which underpins Grossman (2014:17), who argues that citizenship education and inclusion are grounded on common values of the acceptance and celebration of diversity and differences. This fundamental prerequisite of achieving inclusion through education will result in citizenship that embraces everyone, especially those with individual differences.

Grossman (2014:18) cites eight characteristics or traits that are needed for inclusive societies, inclusive schools and democratic societies to cope with undesirable trends and to encourage and nurture desirable ones. Grossman's characteristics can be developed into a framework to support all role players in understanding CP and embracing all people who are directly affected by the condition. These characteristics will have to be contextualised to suit the challenges that are being experienced by communities and families that come into contact with children and people with CP in the rural area of the Bojanala District. Contextualisation was done and is presented as information and guidelines for this study (see Annexures L and M).

6.6 CONCLUSION REGARDING THE RESEARCH QUESTION

Can inclusive citizenship education address the needs of families with members living with CP in the Bojanala District, North West Province?

The aim of this study was to explore whether inclusive citizenship education could address the needs of families who have members living with CP in the Bojanala District, North West. After many hours of contemplation, revision and interaction with the communities of the Bojanala District, the researcher feels that inclusive citizenship education can address the needs of families who have members living with CP within this rural area.

If inclusive citizenship education is introduced to all role players, such as community members, family members and the various professionals who are needed and involved in the support of these families and children living with CP, many of their needs will be understood and effectively addressed.

Furthermore, if inclusive citizenship education can be implemented effectively, these role players will be able to understand and have better in-depth knowledge of the disability (CP), and this will promote tolerance and empathy and enable families with children with CP to obtain better overall support from the various community agencies and the Departments of Education, Health and Social Development.

6.7 RECOMMENDATIONS

The following recommendations are made pursuant to research findings and conclusions derived from the views of the participants in this study:

- It is recommended that awareness of CP in communities with families with children living with CP, these children themselves and any professional dealing with CP be advocated. This can be done by district support teams within the educational system, local clinics and district hospitals, as well as community centres. The aim of this awareness should be to inform and empower the community about what CP is all about, including the causes and management thereof. It is assumed that knowledgeable people would be able to accept, embrace and incorporate people living with CP and their families in activities within their communities and in society. Knowledge would dispel all myths and prejudices about CP and promote understanding.
- EWP6 advocates for full-service schools. Challenges on the implementation of this policy have been raised by different stakeholders. Proper policy implementation, with the provision of the necessary resources to support the implementation thereof, is recommended. Proper resources would include, among other things, properly trained specialists. These specialists will assist children with CP living in rural areas to access proper schools in their areas.
- It is recommended that mobile clinics be made available to the rural parts of the Bojanala District in order for health care to be easily accessible to people living with CP.
- Strengthening the support provided by the Department of Social Development is recommended. The families interviewed in this study lamented the lack of support from social workers. The Department of Social Development should work closely with both the Departments of Health and Education in order to keep track of children who are diagnosed with CP. They should draw up a schedule for regularly supporting the families of these children by doing home and school visits.
- Support groups should be established by social workers in order for the families of children with CP to share, learn and support one another. This action will alleviate the stress and fear that some may harbour about taking care of a child with a disability.
- The government, through the South African Social Security Agency, must be encouraged to review the Care Dependency Grant, which is the primary form of social protection grant available to the caregivers of children with disabilities in South Africa. From all the

submissions, these families are struggling to make ends meet and need more financial support.

6.8 LIMITATIONS OF THE STUDY

This study was limited to participants who were purposefully selected based on specific criteria, including having knowledge and experience of families that had children with CP in the Bojanala District. Therefore, one limitation is that this study cannot be generalised to other situations. Another limitation is that only participants who were listed in the Department of Health registry were considered. There might have been other individuals who might have had relevant information that could have contributed to the study.

6.9 RECOMMENDATIONS FOR FURTHER RESEARCH

Recommendations for future study are made in this section. This research was conducted specifically in the rural parts of the Bojanala District, North West, South Africa. Further research can broaden the scope and look at the whole of the North West Province, as the province comprises four districts, all of which are faced with the same or very similar challenges of children who experience special needs. A similar comparative study could also be undertaken in the urban areas of the Bojanala District, as it is assumed that urban communities are better informed and schools in urban areas are better resourced compared to those in rural areas.

6.10 CONCLUSION

> *You cannot hope to build a better world without improving the individuals. To that end each of us must work for his own improvement and, at the same time, share a general responsibility for all humanity, our particular duty being to aid those to whom we think we can be most useful.* (Marie Curie)

It is with this quotation that the researcher confidently states that inclusive citizenship education can be used to build a better world by improving individuals, providing knowledge, creating understanding and promoting empathy, all of which can facilitate the personal improvement and well-being of vulnerable people in any circumstance and assume general responsibility for all of humanity by aiding those who are vulnerable and need help.

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ANNEXURES

Annexure A: Semi-structured interview schedule

Aim of the study

To address Cerebral Palsy through inclusive citizenship education in Bojanala District, North West Province

Questions for biological parents or/and extended family members(caregivers) who take care of people living with cerebral palsy

Introductory sentence for relationship building:

As you read on the poster you noted that we want to do research about how people care, cope and live with someone who has Cerebral Palsy (CP). Please remember that you must be 18 years or older to participate in this study. This interview will take between 30 and 60 minutes and it will be audio recorded. You have already signed a consent form, however if you feel at any time you want to withdraw you can, without any negative consequences. Thank you once again for your willingness to assist me.

1. What is your understanding of CP?
2. What is the cause of CP?
3. In your own opinion, do you think close family and community members know and understand the condition that your child lives with?
4. What are the challenges you experience regarding taking care of your child living with cerebral palsy?
5. How has having a child with cerebral palsy changed your life?
6. How did you feel when you were informed of your child’s condition?
7. Is there any support that you get from close family members regarding these challenges?
8. Is there any support that you get from close community members regarding challenges you experience when taking care of this child?
9. Are there any services that you get regarding care and support for your child with cerebral palsy? Please mention them.
10. Do you think that these services that are provided are sufficient?

    If No: What would you recommend that would improve services for children living with cerebral palsy?
11. What do you think the government can do to support people living with CP and their families?

Annexure B: Semi-structured interview schedule

Aim of the study

To address Cerebral Palsy through inclusive citizenship education in Bojanala District, North West Province

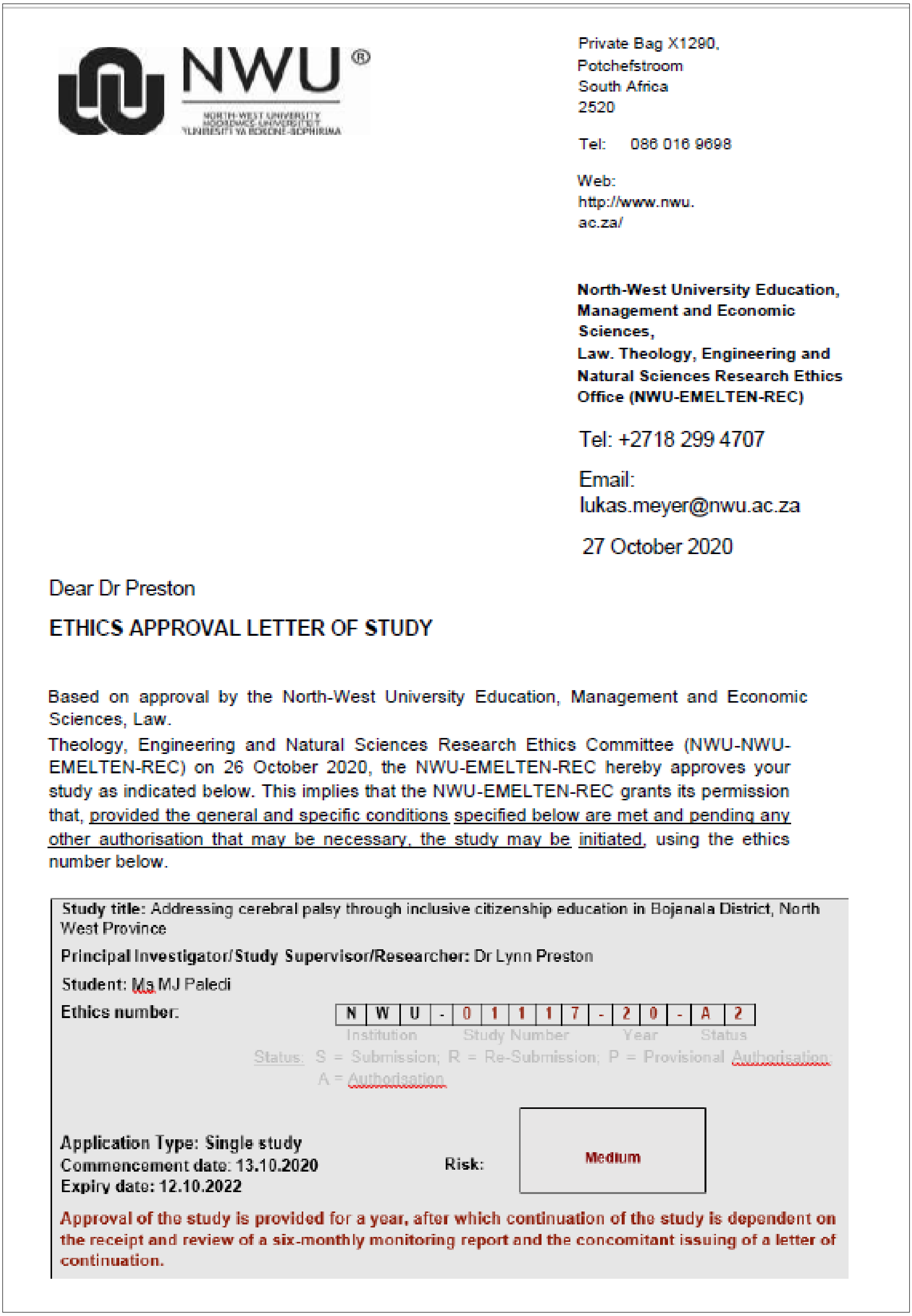
Questions for community members who reside in the same locality as the person living with cerebral palsy

Introductory sentence for relationship building:

As you read on the poster you noted that we want to do research about how people care, cope and live with someone who has Cerebral Palsy (CP). Please remember that you must be 18 years or older to participate in this study. This interview will take between 30 and 60 minutes and it will be audio recorded. You have already signed a consent form, however if you feel at any time you want to withdraw you can without any negative consequences. Thank you one again for your willingness to assist me.

1. What is CP?
2. What are the causes of CP?
3. Do you think community members understand and are appreciative of families and people living with cerebral palsy?
4. What do you think are challenges faced by families living and caring for people with cerebral palsy?
5. What do you think are the needs of people caring for a person living with cerebral palsy?
6. In your own opinion, do you think the community is supportive of families with people living with cerebral palsy?
   If yes: what support are they giving g to these families?
   If no: what support do you think should be given to families living and taking care of people with cerebral palsy?
7. How can communities be encouraged to support families of and people living with cerebral palsy?
8. Are there any services of care and support that families of children with cerebral palsy get? If so please mention them.
9. In your opinion, do you think the government is doing enough to support people living with cerebral palsy?
10. Do you have any support intervention strategy suggestions for families of children living with cerebral palsy?

Annexure C: Ethics approval letter



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South Africa
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Tel: 086 016 9698

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North-West University Education, Management and Economic Sciences,
Law. Theology, Engineering and Natural Sciences Research Ethics Office (NWU-EMELTEN-REC)

Tel: +2718 299 4707

Email:
lukas.meyer@nwu.ac.za

27 October 2020

Dear Dr Preston

ETHICS APPROVAL LETTER OF STUDY

Based on approval by the North-West University Education, Management and Economic Sciences, Law.

Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-NWU-EMELTEN-REC) on 26 October 2020, the NWU-EMELTEN-REC hereby approves your study as indicated below. This implies that the NWU-EMELTEN-REC grants its permission that, provided the general and specific conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province

Principal Investigator/Study Supervisor/Researcher: Dr Lynn Preston

Student: Ms MJ Paledi

Ethics number:

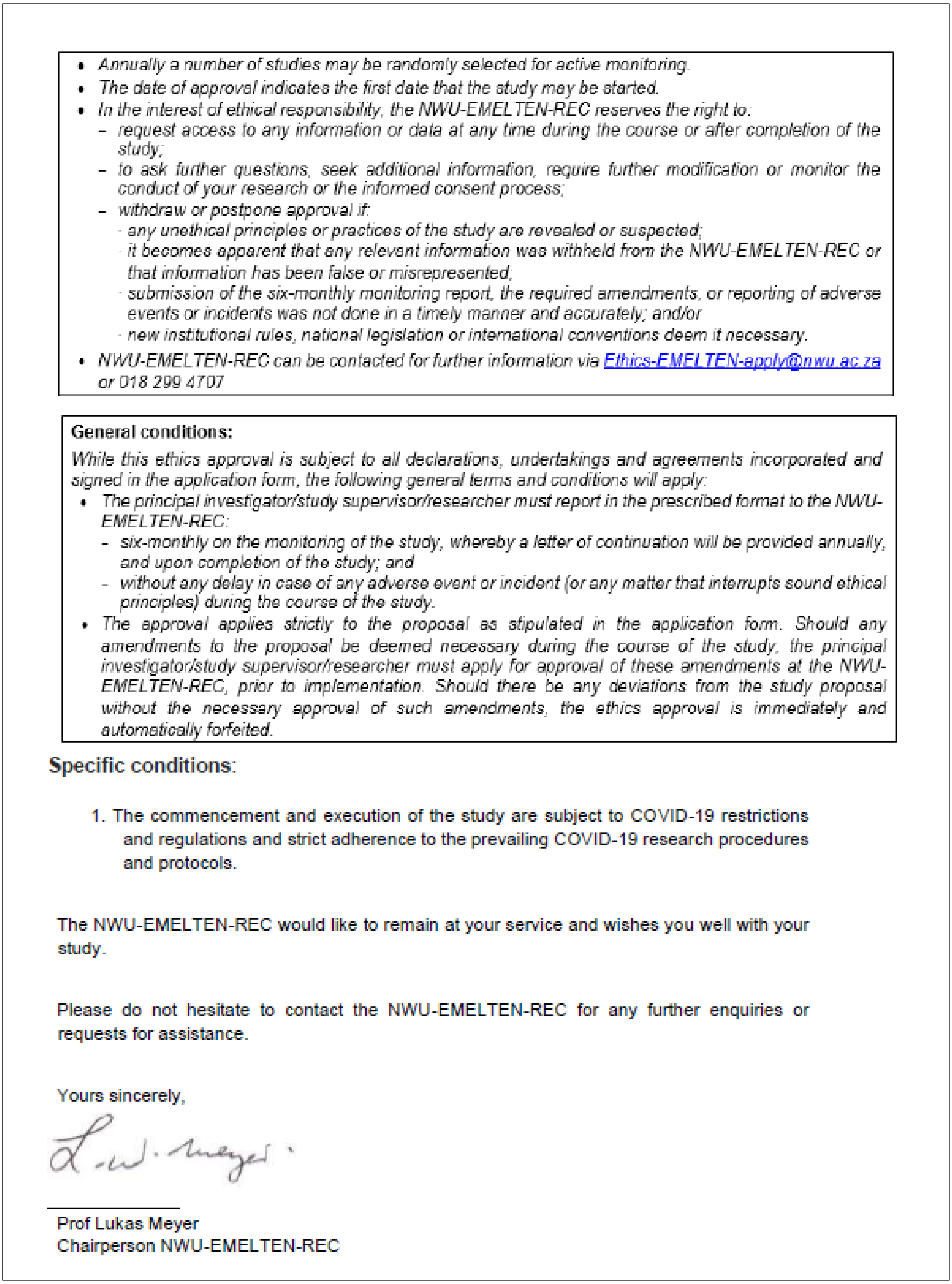
N	W	U	-	0	1	1	1	7	-	2	0	-	A	2
Institution				Study Number						Year			Status	

Status: S = Submission; R = Re-Submission; P = Provisional Authorisation;
A = Authorisation

Application Type: Single study
Commencement date: 13.10.2020
Expiry date: 12.10.2022

Risk: **Medium**

Approval of the study is provided for a year, after which continuation of the study is dependent on the receipt and review of a six-monthly monitoring report and the concomitant issuing of a letter of continuation.



- *Annually a number of studies may be randomly selected for active monitoring.*
- *The date of approval indicates the first date that the study may be started.*
- *In the interest of ethical responsibility, the NWU-EMELTEN-REC reserves the right to:*
  - *request access to any information or data at any time during the course or after completion of the study;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the study are revealed or suspected;*
    - *it becomes apparent that any relevant information was withheld from the NWU-EMELTEN-REC or that information has been false or misrepresented;*
    - *submission of the six-monthly monitoring report, the required amendments, or reporting of adverse events or incidents was not done in a timely manner and accurately; and/or*
    - *new institutional rules, national legislation or international conventions deem it necessary.*
- *NWU-EMELTEN-REC can be contacted for further information via Ethics-EMELTEN-apply@nwu.ac.za or 018 299 4707*

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply:

- *The principal investigator/study supervisor/researcher must report in the prescribed format to the NWU-EMELTEN-REC:*
  - *six-monthly on the monitoring of the study, whereby a letter of continuation will be provided annually, and upon completion of the study; and*
  - *without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.*
- *The approval applies strictly to the proposal as stipulated in the application form. Should any amendments to the proposal be deemed necessary during the course of the study, the principal investigator/study supervisor/researcher must apply for approval of these amendments at the NWU-EMELTEN-REC, prior to implementation. Should there be any deviations from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.*

Specific conditions:

1. The commencement and execution of the study are subject to COVID-19 restrictions and regulations and strict adherence to the prevailing COVID-19 research procedures and protocols.

The NWU-EMELTEN-REC would like to remain at your service and wishes you well with your study.

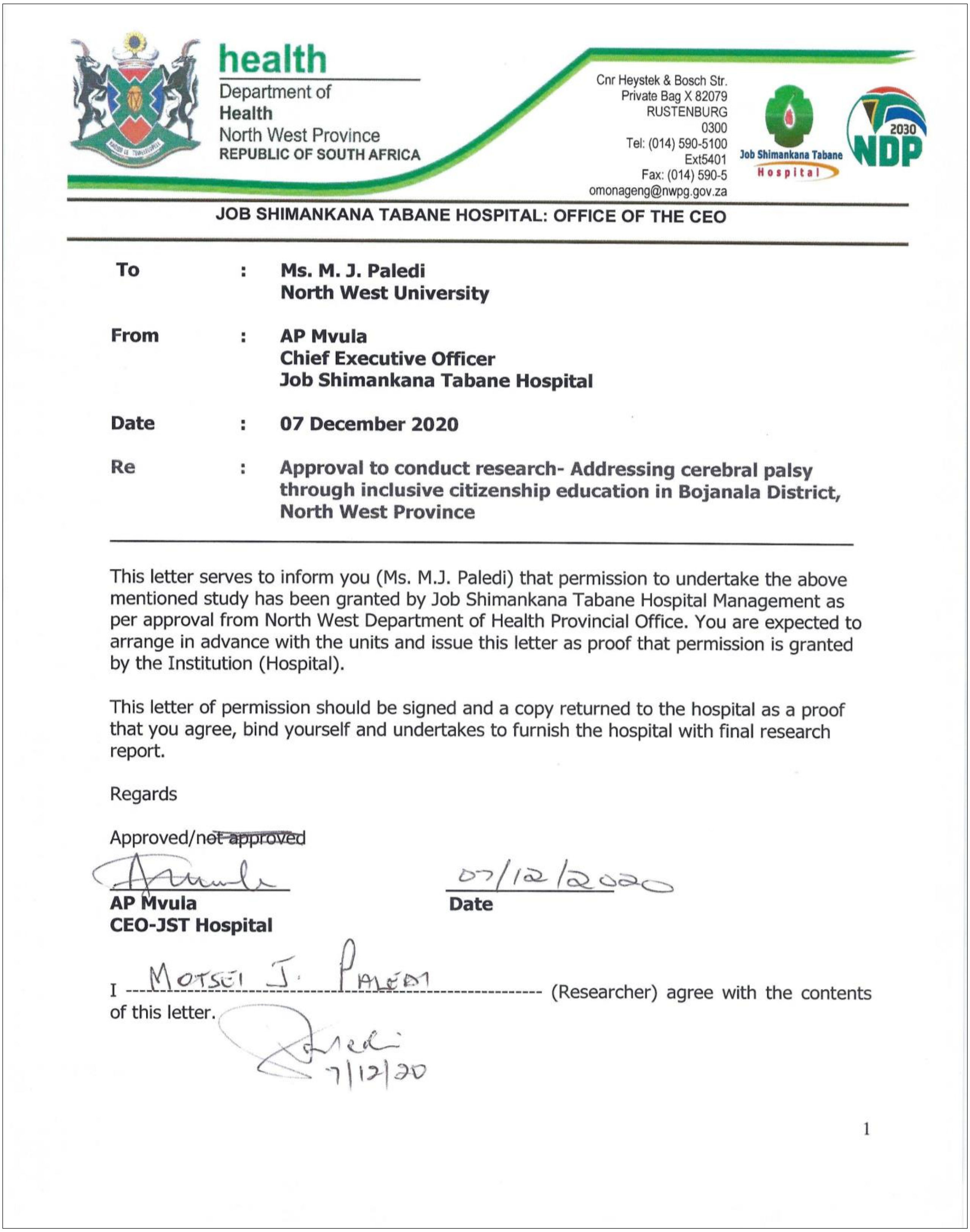
Please do not hesitate to contact the NWU-EMELTEN-REC for any further enquiries or requests for assistance.

Yours sincerely,

L.W. Meyer

Prof Lukas Meyer
Chairperson NWU-EMELTEN-REC

Annexure D: Research approval letter



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Job Shimankana Tabane Hospital

2030 NDP

JOB SHIMANKANA TABANE HOSPITAL: OFFICE OF THE CEO

To : **Ms. M. J. Paledi**
North West University

From : **AP Mvula**
Chief Executive Officer
Job Shimankana Tabane Hospital

Date : **07 December 2020**

Re : **Approval to conduct research- Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province**

This letter serves to inform you (Ms. M.J. Paledi) that permission to undertake the above mentioned study has been granted by Job Shimankana Tabane Hospital Management as per approval from North West Department of Health Provincial Office. You are expected to arrange in advance with the units and issue this letter as proof that permission is granted by the Institution (Hospital).

This letter of permission should be signed and a copy returned to the hospital as a proof that you agree, bind yourself and undertakes to furnish the hospital with final research report.

Regards

Approved/~~not approved~~

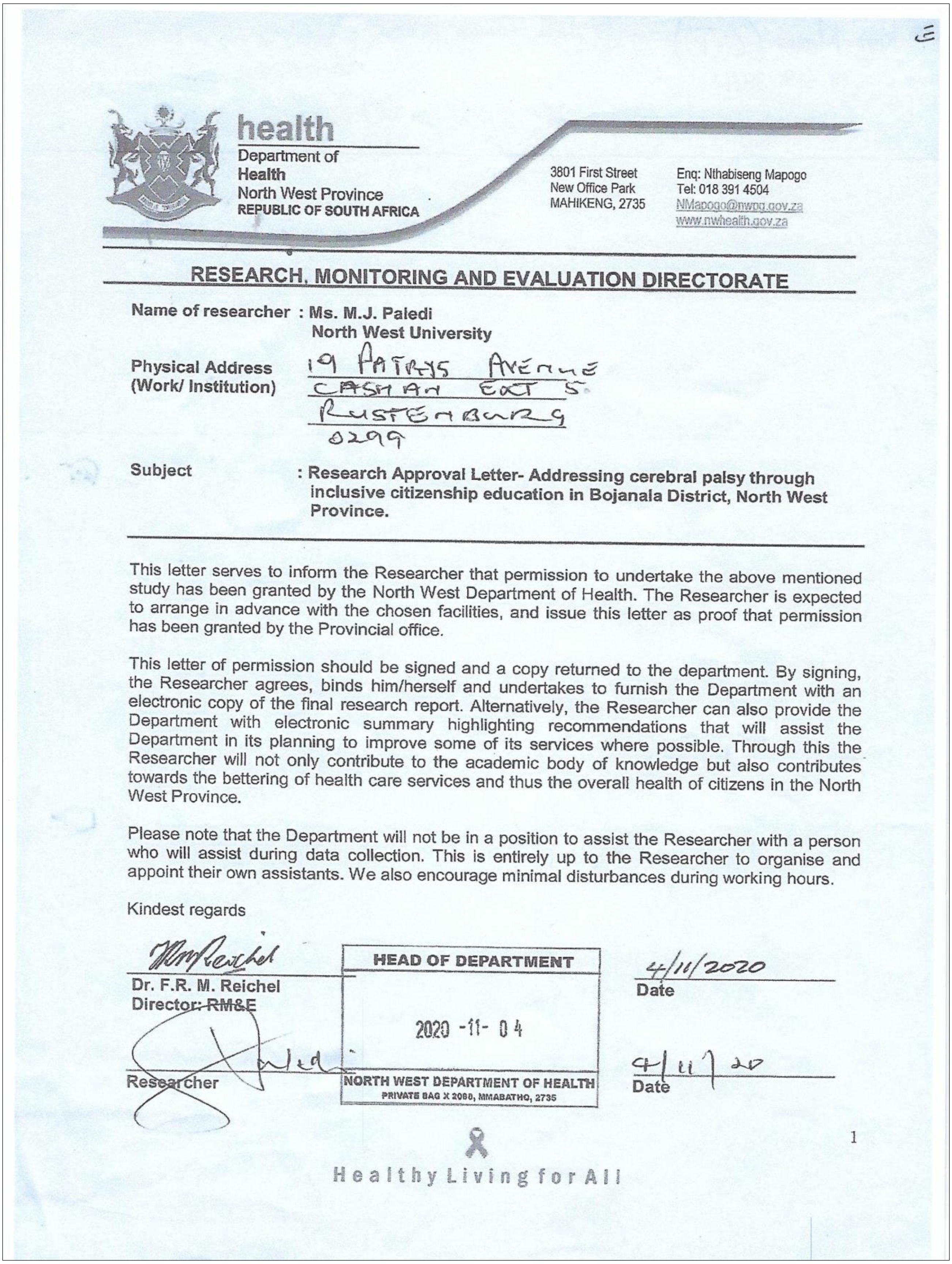
AP Mvula
CEO-JST Hospital

07/12/2020
Date

I MOTSEI J. PALEDI -- (Researcher) agree with the contents of this letter.

Paledi
7/12/20

Annexure E: Approval



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NMapogo@nwpg.gov.za
www.nwhealth.gov.za

RESEARCH, MONITORING AND EVALUATION DIRECTORATE

Name of researcher : **Ms. M.J. Paledi**
North West University

Physical Address (Work/ Institution)
19 PATRYS AVENUE
CASHAN EXT 5
RUSTENBURG
0299

Subject : **Research Approval Letter- Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province.**

This letter serves to inform the Researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The Researcher is expected to arrange in advance with the chosen facilities, and issue this letter as proof that permission has been granted by the Provincial office.

This letter of permission should be signed and a copy returned to the department. By signing, the Researcher agrees, binds him/herself and undertakes to furnish the Department with an electronic copy of the final research report. Alternatively, the Researcher can also provide the Department with electronic summary highlighting recommendations that will assist the Department in its planning to improve some of its services where possible. Through this the Researcher will not only contribute to the academic body of knowledge but also contributes towards the bettering of health care services and thus the overall health of citizens in the North West Province.

Please note that the Department will not be in a position to assist the Researcher with a person who will assist during data collection. This is entirely up to the Researcher to organise and appoint their own assistants. We also encourage minimal disturbances during working hours.

Kindest regards

Dr. F.R. M. Reichel
Director: RM&E

4/11/2020
Date

HEAD OF DEPARTMENT
2020 -11- 04
NORTH WEST DEPARTMENT OF HEALTH
PRIVATE BAG X 2068, MMABATHO, 2735

Researcher

4/11/20
Date

1

Healthy Living for All

Annexure F: Permission letter

Private Bag X6001,
Potchefstroom
South Africa 2520

Tel: 018 299-1111/2222
Web: http://www.nwu.ac.za

Faculty of Education School of Psycho Social Education
Educational Psychology
Tel: 2994765
Email: 10521402@nwu.ac.za

21 August 2020

Dear Ms/Mr
PERMISSION LETTER

I am a PHD part time student at North West University, and I would like to conduct research regarding the impact Cerebral Palsy has on families and members in the immediate community. The research topic is:

Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province.

Through this study I would like to give parents or/and close family members as well as community members, an opportunity to share their experiences, regarding the impact of Cerebral Palsy on and in their lives.

Perceptions and experiences as well as attitudes of community members with regard to people living with Cerebral Palsy will be explored. This process will however be guided by North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-EMELTEN-REC). I am in the process of obtaining ethical approval from NWU-EMELTEN-REC, to continue with this study, and this goodwill letter will assist the committee.

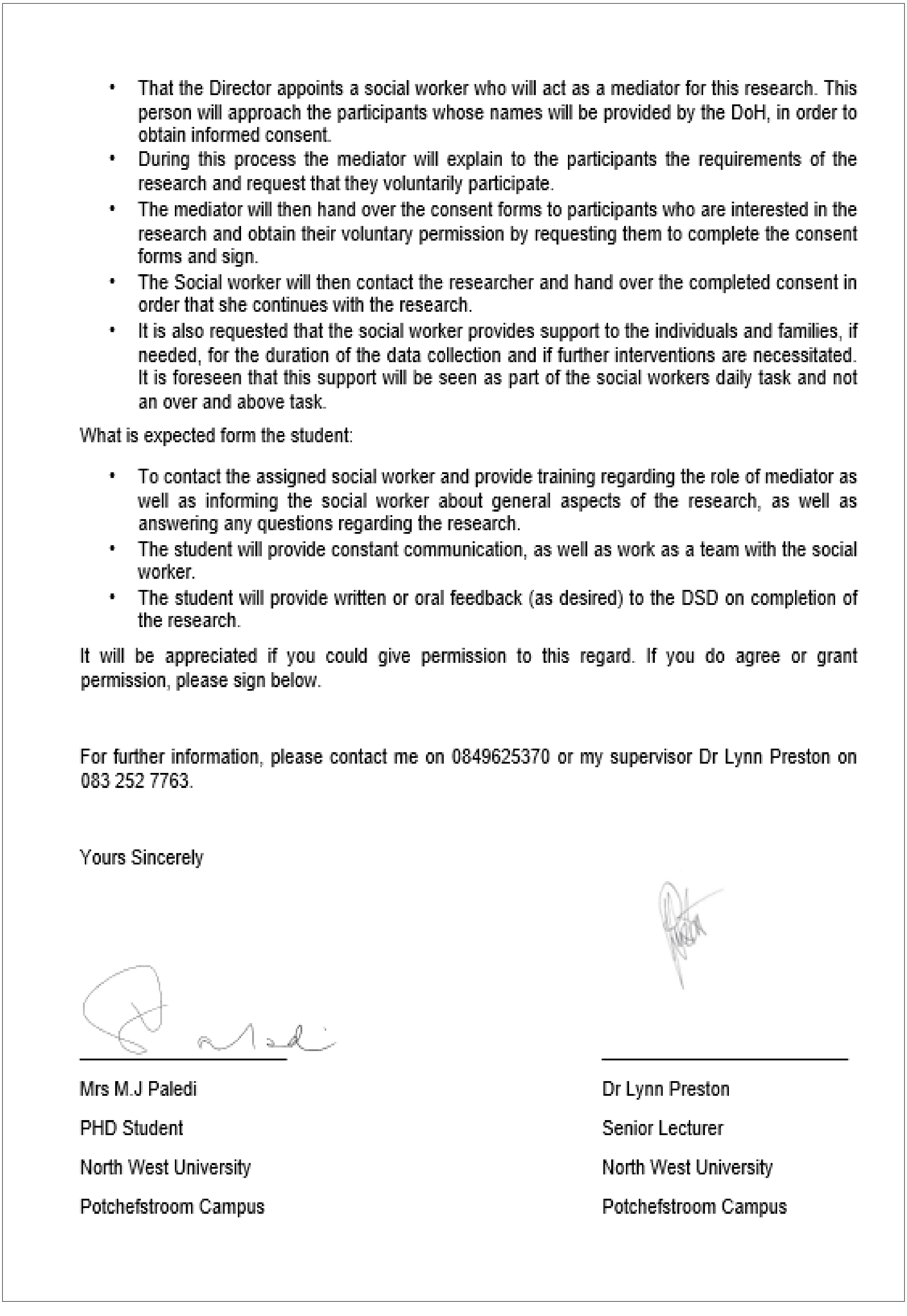
I am doing this research in conjunction with the Department of Health (DoH), therefore once ethical approval has been obtained the DOH and DSD will be notified in writing.

To obtain the necessary data I will perform interviews with the participants. These interviews will take the form of semi-structured questions and will take place at the participants' homes or any other convenient place as requested by the participant. The duration of the interviews will be between 30 and 60 minutes.

I am planning to start with the interviews in December 2020/January 2021 pending the approval of NWU-EMELTEN-REC.

Participation will be voluntary and participants will give voluntary, written consent before the interviews take place. DSD will also be involved to provide assistance in the form of a social worker who will assist in the administration of participants in obtaining unbiased and voluntary consent from the participants.

What will be expected of you:



- That the Director appoints a social worker who will act as a mediator for this research. This person will approach the participants whose names will be provided by the DoH, in order to obtain informed consent.
- During this process the mediator will explain to the participants the requirements of the research and request that they voluntarily participate.
- The mediator will then hand over the consent forms to participants who are interested in the research and obtain their voluntary permission by requesting them to complete the consent forms and sign.
- The Social worker will then contact the researcher and hand over the completed consent in order that she continues with the research.
- It is also requested that the social worker provides support to the individuals and families, if needed, for the duration of the data collection and if further interventions are necessitated. It is foreseen that this support will be seen as part of the social workers daily task and not an over and above task.

What is expected form the student:

- To contact the assigned social worker and provide training regarding the role of mediator as well as informing the social worker about general aspects of the research, as well as answering any questions regarding the research.
- The student will provide constant communication, as well as work as a team with the social worker.
- The student will provide written or oral feedback (as desired) to the DSD on completion of the research.

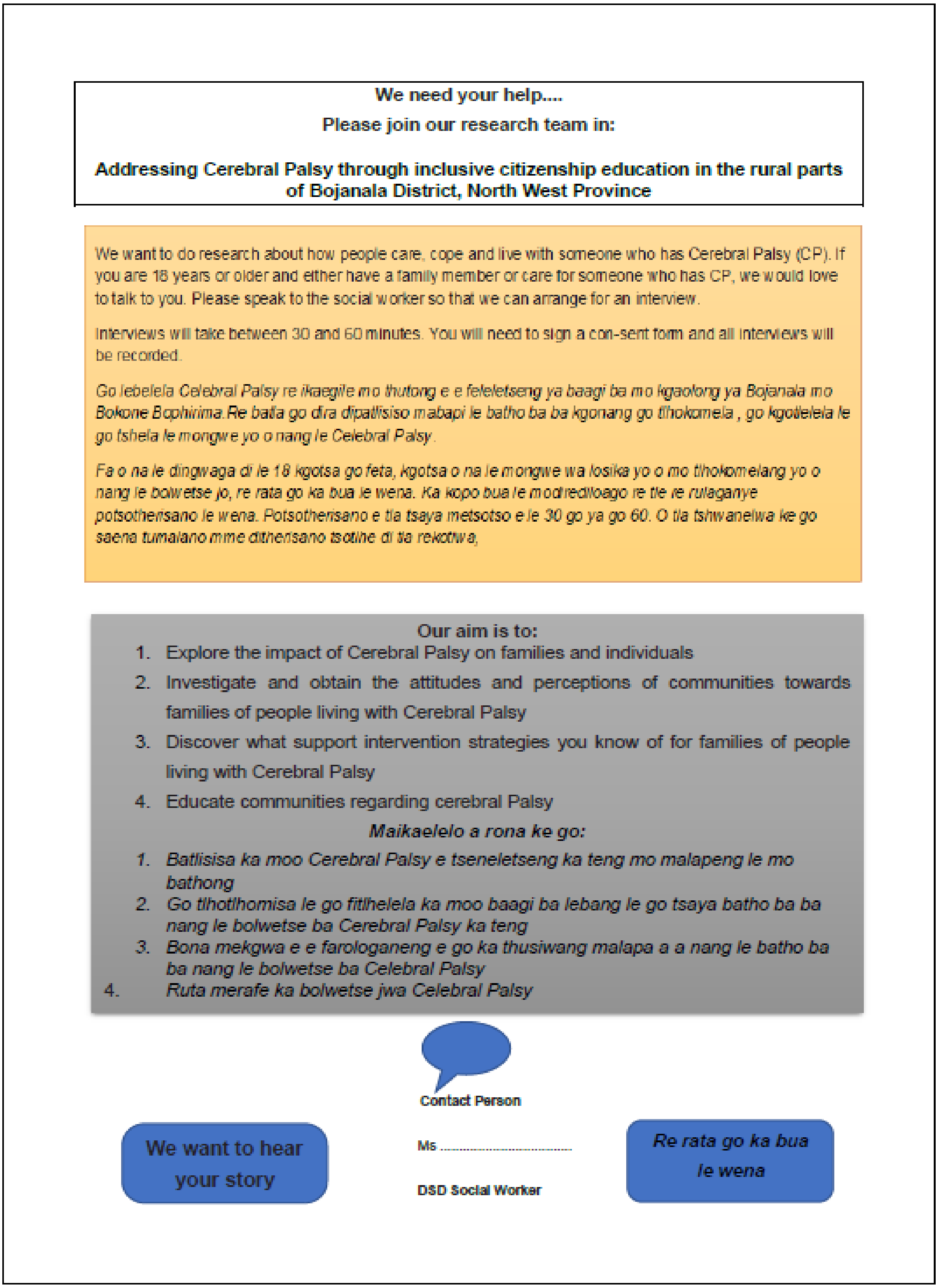
It will be appreciated if you could give permission to this regard. If you do agree or grant permission, please sign below.

For further information, please contact me on 0849625370 or my supervisor Dr Lynn Preston on 083 252 7763.

Yours Sincerely

Mrs M.J Paledi	Dr Lynn Preston
PHD Student	Senior Lecturer
North West University	North West University
Potchefstroom Campus	Potchefstroom Campus

Annexure G: Advertisement



We need your help....

Please join our research team in:

Addressing Cerebral Palsy through inclusive citizenship education in the rural parts of Bojanala District, North West Province

We want to do research about how people care, cope and live with someone who has Cerebral Palsy (CP). If you are 18 years or older and either have a family member or care for someone who has CP, we would love to talk to you. Please speak to the social worker so that we can arrange for an interview.

Interviews will take between 30 and 60 minutes. You will need to sign a con-sent form and all interviews will be recorded.

Go lebelela Celebral Palsy re ikaegile mo thutong e e feleletseng ya baagi ba mo kgaolong ya Bojanala mo Bokone Bophirima.Re batla go dira dipatlisiso mabapi le batho ba ba kgonang go tlhokomela , go kgotlelela le go tshela le mongwe yo o nang le Celebral Palsy.

Fa o na le dingwaga di le 18 kgotsa go feta, kgotsa o na le mongwe wa losika yo o mo tlhokomelang yo o nang le bolwetse jo, re rata go ka bua le wena. Ka kopo bua le modiredikoago re tle re rulaganye potsotherisano le wena. Potsotherisano e tla tsaya metsotso e le 30 go ya go 60. O tla tshwanelwa ke go saena tumalano mme ditherisano tsotlhe di tla rekotwa,

Our aim is to:

1. Explore the impact of Cerebral Palsy on families and individuals
2. Investigate and obtain the attitudes and perceptions of communities towards families of people living with Cerebral Palsy
3. Discover what support intervention strategies you know of for families of people living with Cerebral Palsy
4. Educate communities regarding cerebral Palsy

Maikaelelo a rona ke go:

1. *Batlisisa ka moo Cerebral Palsy e tseneletseng ka teng mo malapeng le mo bathong*
2. *Go tlhotlhomisa le go fitlhelela ka moo baagi ba lebang le go tsaya batho ba ba nang le bolwetse ba Cerebral Palsy ka teng*
3. *Bona mekgwa e e farologaneng e go ka thusiwang malapa a a nang le batho ba ba nang le bolwetse ba Celebral Palsy*
4. *Ruta merafe ka bolwetse jwa Celebral Palsy*

Contact Person

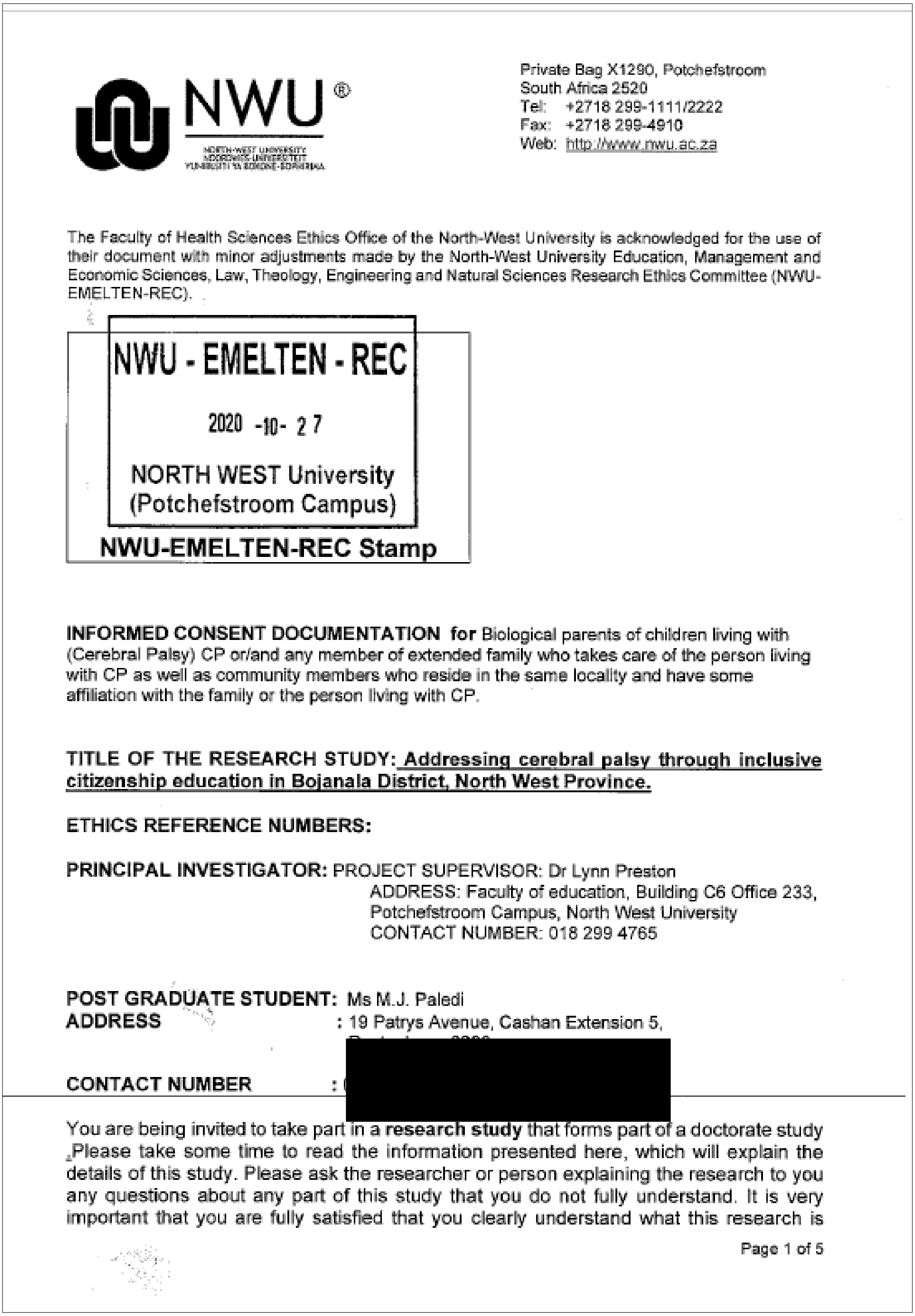
Ms ....

DSD Social Worker

We want to hear your story

Re rata go ka bua le wena

Annexure H: Informed consent



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Fax: +2718 299-4910
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The Faculty of Health Sciences Ethics Office of the North-West University is acknowledged for the use of their document with minor adjustments made by the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-EMELTEN-REC).

NWU - EMELTEN - REC
2020 -10- 27
NORTH WEST University
(Potchefstroom Campus)

NWU-EMELTEN-REC Stamp

INFORMED CONSENT DOCUMENTATION for Biological parents of children living with (Cerebral Palsy) CP or/and any member of extended family who takes care of the person living with CP as well as community members who reside in the same locality and have some affiliation with the family or the person living with CP.

TITLE OF THE RESEARCH STUDY: Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province.

ETHICS REFERENCE NUMBERS:

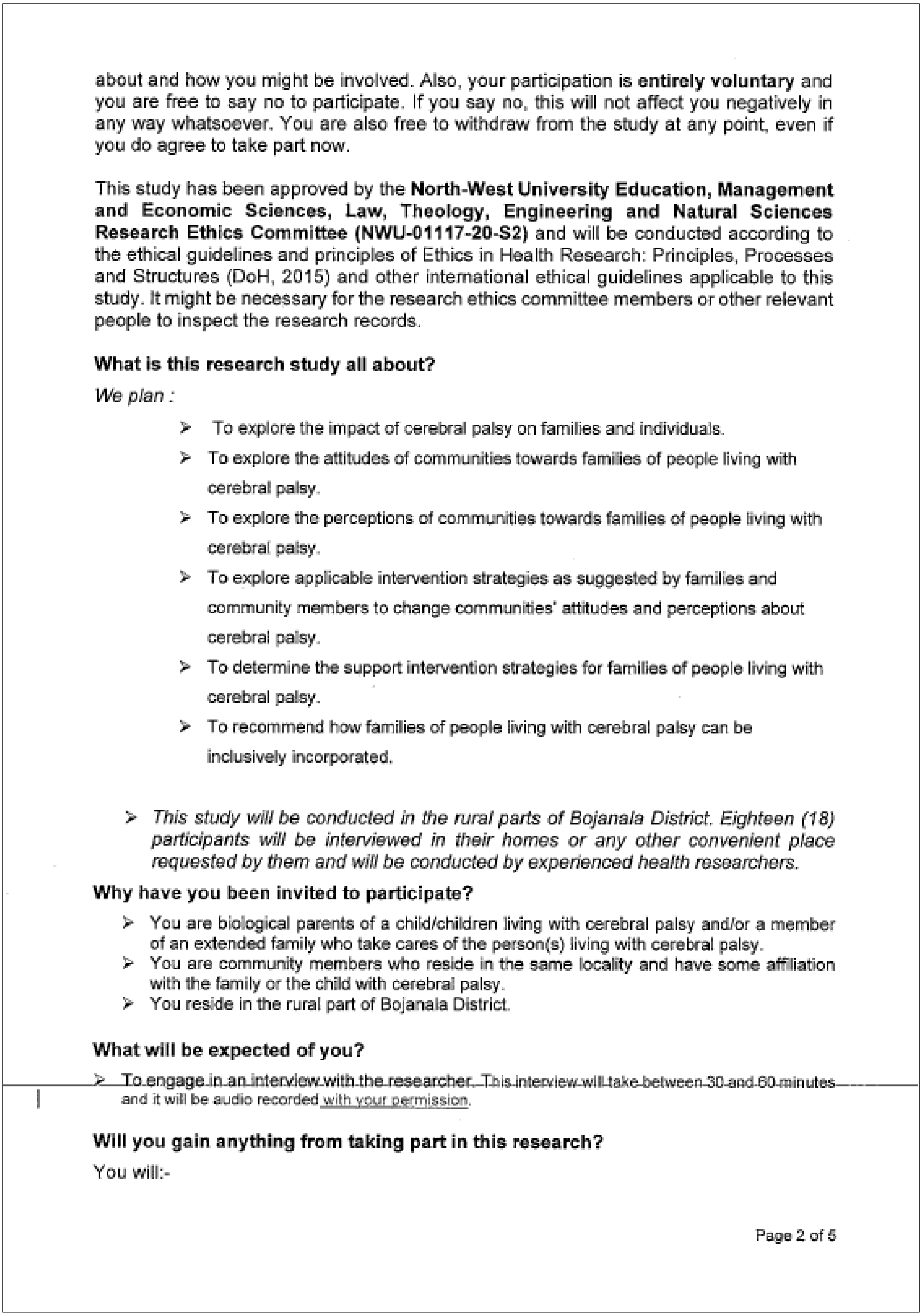
PRINCIPAL INVESTIGATOR: PROJECT SUPERVISOR: Dr Lynn Preston
ADDRESS: Faculty of education, Building C6 Office 233, Potchefstroom Campus, North West University
CONTACT NUMBER: 018 299 4765

POST GRADUATE STUDENT: Ms M.J. Paledi
ADDRESS : 19 Patrys Avenue, Cashan Extension 5,

CONTACT NUMBER : [redacted]

You are being invited to take part in a **research study** that forms part of a doctorate study ,Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher or person explaining the research to you any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is

Page 1 of 5



about and how you might be involved. Also, your participation is **entirely voluntary** and you are free to say no to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part now.

This study has been approved by the **North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-01117-20-S2)** and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures (DoH, 2015) and other international ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

What is this research study all about?

We plan :

- To explore the impact of cerebral palsy on families and individuals.
- To explore the attitudes of communities towards families of people living with cerebral palsy.
- To explore the perceptions of communities towards families of people living with cerebral palsy.
- To explore applicable intervention strategies as suggested by families and community members to change communities' attitudes and perceptions about cerebral palsy.
- To determine the support intervention strategies for families of people living with cerebral palsy.
- To recommend how families of people living with cerebral palsy can be inclusively incorporated.

- *This study will be conducted in the rural parts of Bojanala District. Eighteen (18) participants will be interviewed in their homes or any other convenient place requested by them and will be conducted by experienced health researchers.*

Why have you been invited to participate?

- You are biological parents of a child/children living with cerebral palsy and/or a member of an extended family who take cares of the person(s) living with cerebral palsy.
- You are community members who reside in the same locality and have some affiliation with the family or the child with cerebral palsy.
- You reside in the rural part of Bojanala District.

What will be expected of you?

- To engage in an interview with the researcher. This interview will take between 30 and 60 minutes and it will be audio recorded with your permission.

Will you gain anything from taking part in this research?

You will:-

- Gain more knowledge on the concept of cerebral palsy.
- Gain more knowledge on ways and programmes that you can use for your own support.
- Gain more knowledge on ways and programmes that you can use for the support of those living with cerebral palsy.
- Learn ways on how people living with cerebral palsy can be inclusively incorporated.
- Learn ways on how families of people living with cerebral palsy can be inclusively incorporated.

Are there risks involved in you taking part in this research and what will be done to prevent them?

- Some emotional discomfort could be experienced as you recollect your experiences. If you experience emotional discomfort during the interview, you may choose to end the interview, or you may choose not to answer questions that may cause emotional discomfort to you. A professional person will be available, should you need emotional support.
- COVID-19 research protocols and procedures will be strictly followed to minimize the risk of COVID-19 infections.
- There are more gains for you in joining this study than there are risks.

How will we protect your confidentiality and who will see your data?

- As soon as data has been transcribed, voice recordings will be deleted from the recorders
- No personal information will be reflected in any form in the transcriptions, the reports or the final dissertation.
- No names or identifying detail will be indicated in the findings.
- No personal information will be shared with any person without your permission.

What will happen with the data?

- *The data of this study will only be used for the purposes of this study, and for publication in scientific journals.*

How will you know about the findings of this research?

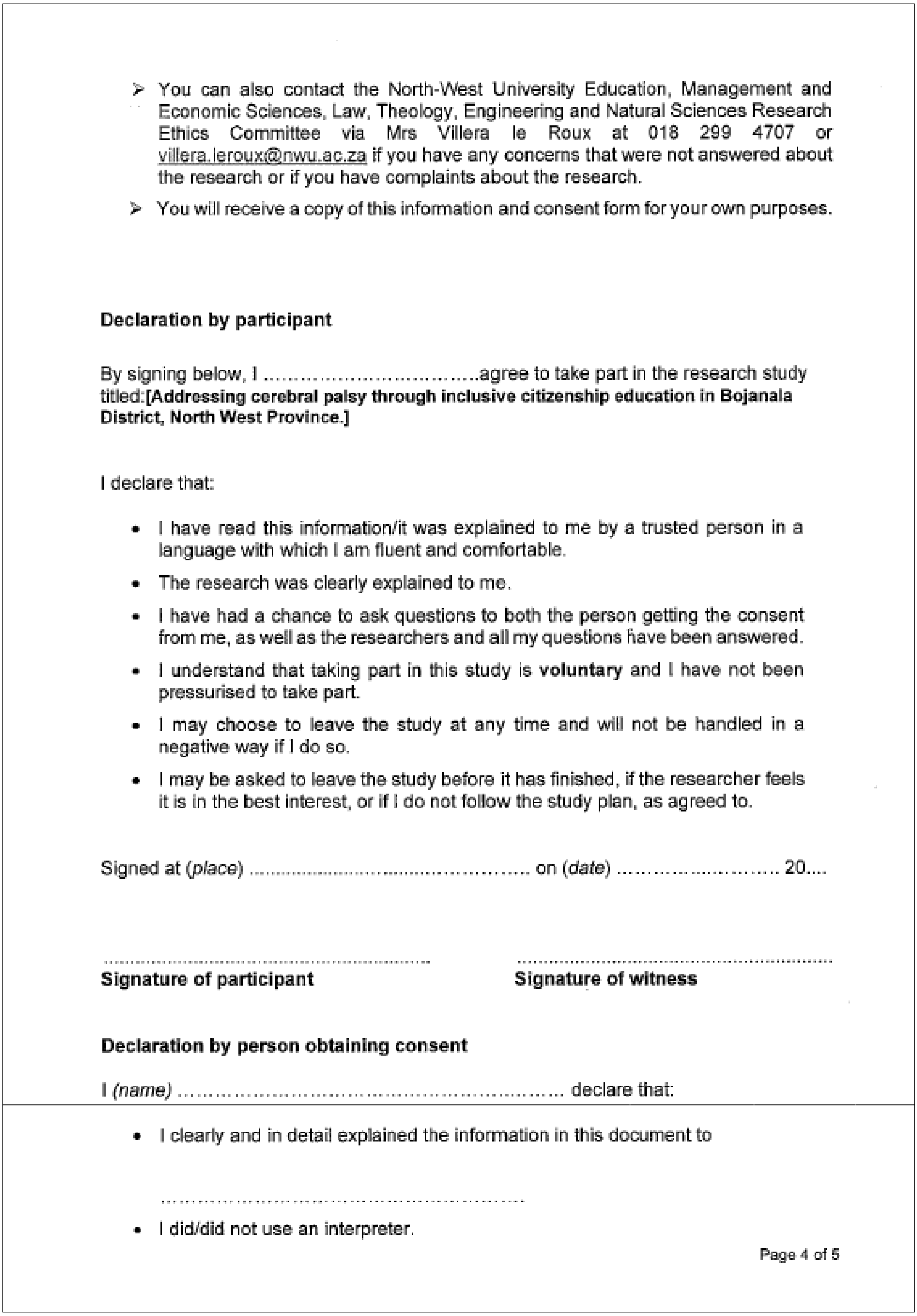
- A printed executive summary of the findings will be made available to all participants. The Department of Health and the Department of Social Development will be given an electronic copy of the dissertation.

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

- You will not be paid to participate in this study
- There will be no costs involved for you, if you do take part in this study.
- A small token of appreciation will be given to you for your participation in the research.

Is there anything else that you should know or do?

- You can contact Mrs M.J Paledi at 072 747 6266 if you have any further questions or have any problems. You are also welcome to contact Dr Lynn Preston, the Principal Investigator, should you need more information. Her telephone number is: 018 299 4765.



- You can also contact the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee via Mrs Villera le Roux at 018 299 4707 or villera.leroux@nwu.ac.za if you have any concerns that were not answered about the research or if you have complaints about the research.
- You will receive a copy of this information and consent form for your own purposes.

Declaration by participant

By signing below, I ……………………………..agree to take part in the research study titled:**[Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province.]**

I declare that:

- I have read this information/it was explained to me by a trusted person in a language with which I am fluent and comfortable.
- The research was clearly explained to me.
- I have had a chance to ask questions to both the person getting the consent from me, as well as the researchers and all my questions have been answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be handled in a negative way if I do so.
- I may be asked to leave the study before it has finished, if the researcher feels it is in the best interest, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .... on (*date*) ………….……….. 20....

....

Signature of participant **Signature of witness**

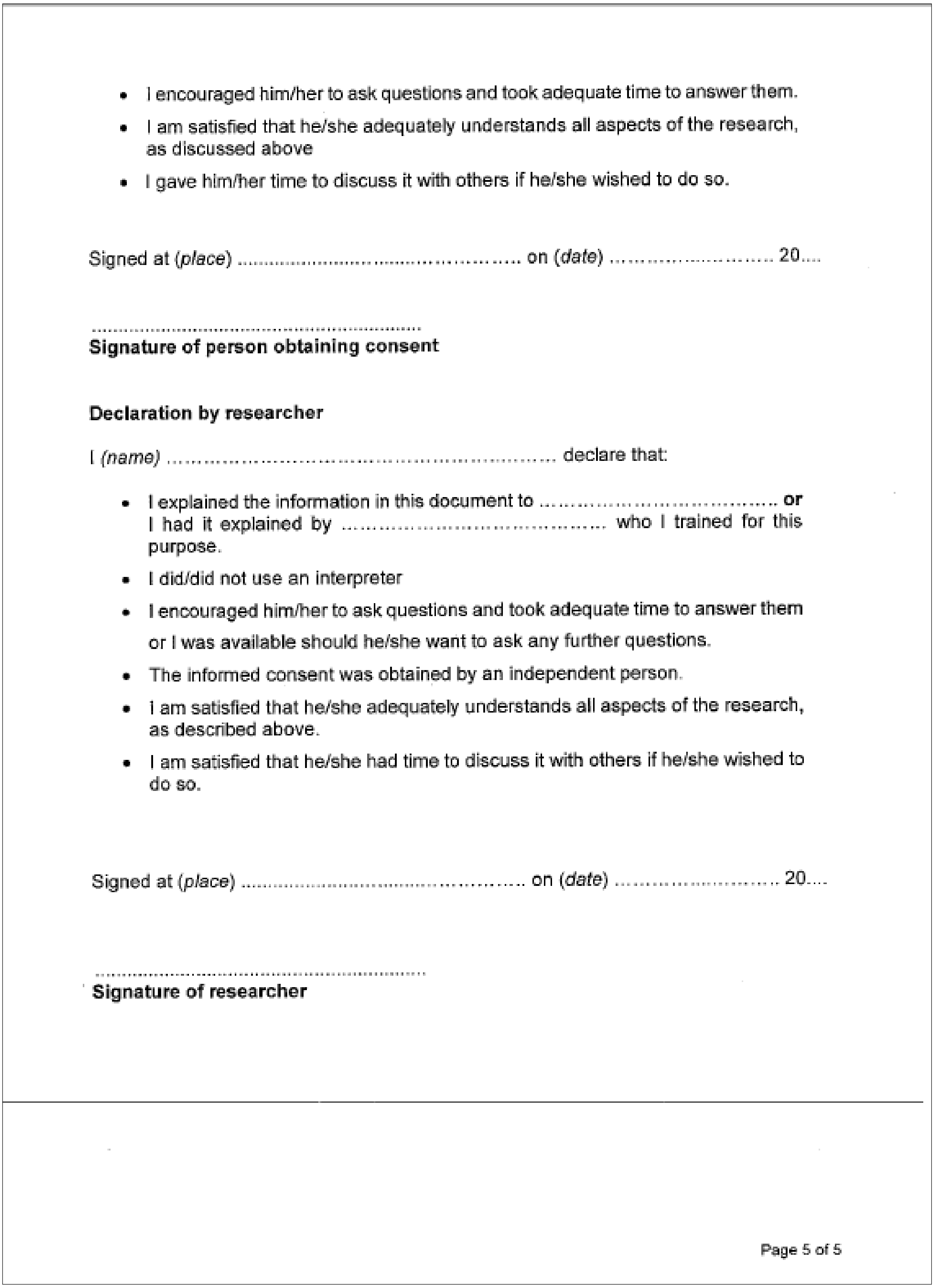
Declaration by person obtaining consent

I *(name)* ……………………………………………………… declare that:

- I clearly and in detail explained the information in this document to

  ………………………………………………………

- I did/did not use an interpreter.



- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I gave him/her time to discuss it with others if he/she wished to do so.

Signed at (*place*) .... on (*date*) .... 20....

....

Signature of person obtaining consent

Declaration by researcher

I (*name*) .... declare that:

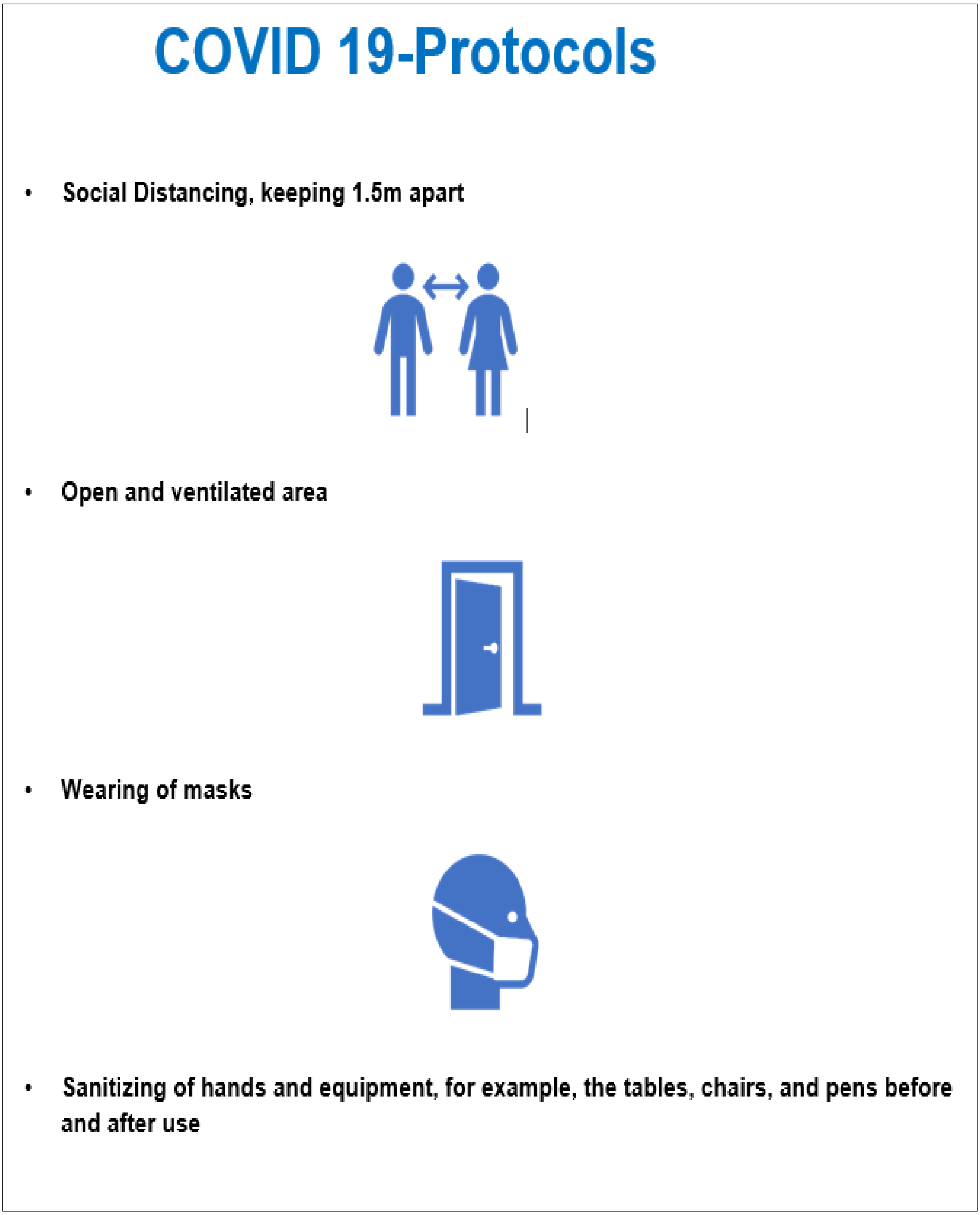
- I explained the information in this document to .... **or** I had it explained by .... who I trained for this purpose.
- I did/did not use an interpreter
- I encouraged him/her to ask questions and took adequate time to answer them or I was available should he/she want to ask any further questions.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (*place*) .... on (*date*) .... 20....

....

Signature of researcher

Annexure I: Covid-19 protocols



COVID 19-Protocols

- Social Distancing, keeping 1.5m apart
- Open and ventilated area
- Wearing of masks
- Sanitizing of hands and equipment, for example, the tables, chairs, and pens before and after use

Annexure J: Indemnity form

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: 018 299-1111/2222
Web: http://www.nwu.ac.za

Ethics Committee of the

Faculty of Education

(EduREC)

The Faculty of Health Sciences Ethics Office and Education, Management, Humanities and Social Sciences Research Ethics Committee (EMHS-REC) of the North-West University are acknowledged for the use of their document with minor adjustments made by the Ethics Committee of the Faculty of Education (EduREC) of the North-West University.

INDEMNITY FORM (EduREC)

I, the undersigned

hereby indemnify the North-West University ("NWU") and/or any of its office-bearers and staff (temporary or permanent) against any liability in respect of personal losses and/or damages suffered by me or any other person arising from or resulting as a consequence of my participation in the research entitled

Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province

(Ethics number) ***NWU-01117-20-A2***

(the "Research"), and hereby hold harmless the NWU against above-mentioned liability.

I confirm that I voluntarily consent to participate in the Research, and that I was in no way forced or coerced by the NWU to participate in the Research, and that the waiver and release shall apply to any claims that may arise during and/or after the Research.

I declare that I am aware of the risks involved in the Research, as explained to me, and of the implications of this waiver and release, and agree that this document will also be binding upon my executor, curator or other assigns.

____

Signature

____

Date

Annexure K: Confidentiality form

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

CONFIDENTIALITY UNDERTAKING entered

into between:

I, the undersigned

Prof / Dr / Mr / Ms: Ms M. J. Paledi

Identity Number: 6412170730080

Address: 19 Patrys Avenue, Cashan Exension 5
Rustenburg, 0299

hereby undertake in favour of the **NORTH-WEST UNIVERSITY**, a public higher education institution established in terms of the Higher Education Act No. 101 of 1997

Address: Office of the Institutional Registrar, Building C1, 53 Borcherd Street, Potchefstroom, 2520

(Hereinafter the "NWU")

Title of study/project: Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province

---

Ethics number: ***NWU-01117-20-A2***

---

1 Interpretation and definitions

1.1 In this undertaking, unless inconsistent with, or otherwise indicated by the context:

1.1.1 “Confidential Information” shall include all information that is confidential in its nature or marked as confidential and shall include any existing and new information obtained by me after the Commencement Date, including but not be limited in its interpretation to, research data, information concerning research participants, all secret knowledge, technical information and specifications, manufacturing techniques, designs, diagrams, instruction manuals, blueprints, electronic artwork, samples, devices, demonstrations, formulae, know-how, intellectual property, information concerning materials, marketing and business information generally, financial information that may include remuneration detail, pay slips, information relating to human capital and employment contract, employment conditions, ledgers, income and expenditures and other materials of whatever description in which the NWU has an interest in being kept confidential; and

1.1.2 “Commencement Date” means the date of signature of this undertaking by myself.

1.2 The headings of clauses are intended for convenience only and shall not affect the interpretation of this undertaking.

2 Preamble

2.1 In performing certain duties requested by the NWU, I will have access to certain Confidential Information provided by the NWU in order to perform the said duties and I agree that it must be kept confidential.

2.2 The NWU has agreed to disclose certain of this Confidential Information and other information to me subject to me agreeing to the terms of confidentiality set out herein.

3 Title to the Confidential Information

I hereby acknowledge that all right, title and interest in and to the Confidential Information vests in the NWU and that I will have no claim of any nature in and to the Confidential Information.

4 Period of confidentiality

The provisions of this undertaking shall begin on the Commencement Date and remain in force indefinitely.

5 Non-disclosure and undertakings

I undertake:

5.1 to maintain the confidentiality of any Confidential Information to which I shall be allowed access by the NWU, whether before or after the Commencement Date of this undertaking. I will not divulge or permit to be divulged to any person any aspect of such Confidential Information otherwise than may be allowed in terms of this undertaking;

5.2 to take all such steps as may be necessary to prevent the Confidential Information falling into the hands of an unauthorised third party;

5.3 not to make use of any of the Confidential Information in the development, manufacture, marketing and/or sale of any goods;

5.4 not to use any research data for publication purposes;

5.5 not to use or disclose or attempt to use or disclose the Confidential Information for any purpose other than performing research purposes only and includes questionnaires, interviews with participants, data gathering, data analysis and personal information of participants/research subjects;

5.6 not to use or attempt to use the Confidential Information in any manner which will cause or be likely to cause injury or loss to a research participant or the NWU; and

5.7 that all documentation furnished to me by the NWU pursuant to this undertaking will remain the property of the NWU and upon the request of the NWU will be returned to the NWU. I shall not make copies of any such documentation without the prior written consent of the NWU.

6 Exception

The above undertakings by myself shall not apply to Confidential Information which I am compelled to disclose in terms of a court order.

7 Jurisdiction

This undertaking shall be governed by South African law be subject to the jurisdiction of South African courts in respect of any dispute flowing from this undertaking.

8 Whole agreement

8.1 This document constitutes the whole of this undertaking to the exclusion of all else.

8.2 No amendment, alteration, addition, variation or consensual cancellation of this undertaking will be valid unless in writing and signed by me and the NWU.

Dated at ____Rustenburg______________ this ________30th of July 2020____

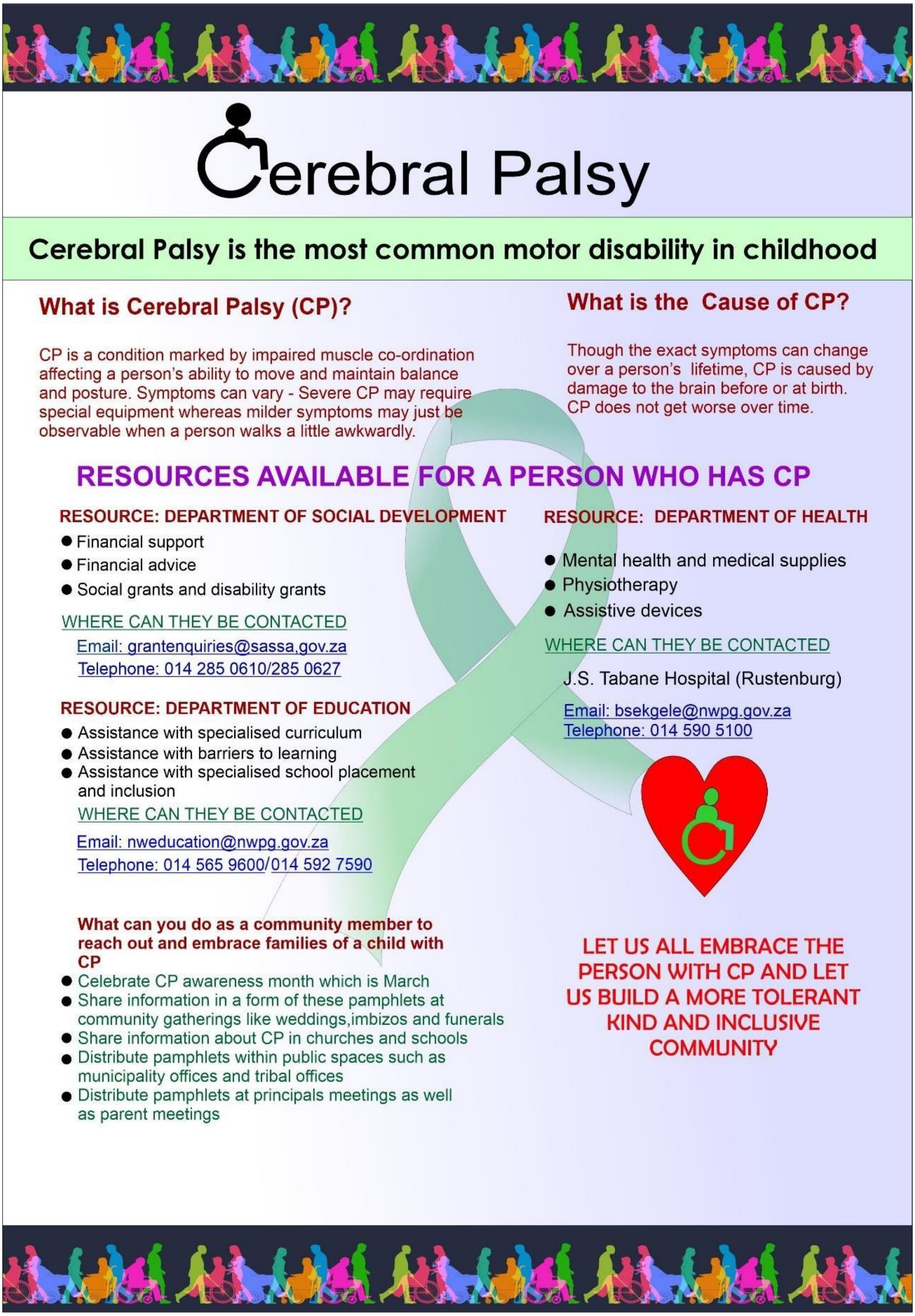
Witnesses:

1 ....

2 ....

(*Signatures of witnesses*)   (*Signature*)

Annexure L: Cerebral palsy poster (English)



Cerebral Palsy

Cerebral Palsy is the most common motor disability in childhood

What is Cerebral Palsy (CP)?

CP is a condition marked by impaired muscle co-ordination affecting a person's ability to move and maintain balance and posture. Symptoms can vary - Severe CP may require special equipment whereas milder symptoms may just be observable when a person walks a little awkwardly.

What is the Cause of CP?

Though the exact symptoms can change over a person's lifetime, CP is caused by damage to the brain before or at birth. CP does not get worse over time.

RESOURCES AVAILABLE FOR A PERSON WHO HAS CP

RESOURCE: DEPARTMENT OF SOCIAL DEVELOPMENT

- Financial support
- Financial advice
- Social grants and disability grants

WHERE CAN THEY BE CONTACTED

Email: grantenquiries@sassa,gov.za
Telephone: 014 285 0610/285 0627

RESOURCE: DEPARTMENT OF EDUCATION

- Assistance with specialised curriculum
- Assistance with barriers to learning
- Assistance with specialised school placement and inclusion

WHERE CAN THEY BE CONTACTED

Email: nweducation@nwpg.gov.za
Telephone: 014 565 9600/014 592 7590

RESOURCE: DEPARTMENT OF HEALTH

- Mental health and medical supplies
- Physiotherapy
- Assistive devices

WHERE CAN THEY BE CONTACTED

J.S. Tabane Hospital (Rustenburg)

Email: bsekgele@nwpg.gov.za
Telephone: 014 590 5100

What can you do as a community member to reach out and embrace families of a child with CP

- Celebrate CP awareness month which is March
- Share information in a form of these pamphlets at community gatherings like weddings,imbizos and funerals
- Share information about CP in churches and schools
- Distribute pamphlets within public spaces such as municipality offices and tribal offices
- Distribute pamphlets at principals meetings as well as parent meetings

LET US ALL EMBRACE THE PERSON WITH CP AND LET US BUILD A MORE TOLERANT KIND AND INCLUSIVE COMMUNITY

Annexure M: Cerebral palsy poster (Setswana)

BOLWETSE JWA MESIFA

Bolwetse jwa mesifa ke bolwetse jo bo atileng thata mo baneng

BOLWETSE JWA MESIFA KE BOFE?

Bolwetse jo bo tlholwa ke go se dire sentle ga mesifa Bolwetse jo bo sitisa motho go itsetsepela le go ema sentle. Matshwao a bolwetse jo ga a tshwane.Go na le jo bo etegetseng mme bona bo tlhoka didiriswa tse di kgethegileng go tshegetsa mmele fa jo bo bofefo bona bo ka lemogiwa fa motho a tsamaya ka mokgwa o o saeng.

BOLWETSE JO BO TLHOLWA KE ENG?

Bolwetse jo bo bakwa ke tshenyego mo bobokong pele motho a belegwa kgotsa morago ga go belegwa. Matshwao a bona a ka fetoga mo tswelelong ya botshelo jwa motho.

DITHUSO TSE DI LENG TENG GO MOLWETSE WA BOLWETSE BA MESIFA

MOTSWEDI: LEFAPHA LA KATLAATLELOLOAGO

- Tshegetso ya matlole
- Thebolelo ya madi a loago le a bogole
- Dikgakololo mabapi le tiriso ya madi
- THUSO: Lefapha la Katlaatleloloago
  BA KA BONWA KAE:
  Maranyane: grantenquiries@sassa.gov.za
  Mogala: 014 285 0610/285 0627

MOTSWEDI: LEFAPHA LA THUTO

- Thuso kharikhulamo e e kgethegileng
- Thuso mabapi le dikgwetlho tse di kgoreletsang go ithuta
- Thuso mabapi le go kwadisiwa le go tsenngwa mo dikolong tse di kgethegileng
  THUSO: lefaphala la thuto
  BA KA BONWA KAE:
  Maranyane: nweducation@nwpg.gov.za
  Mogala: 014 592 7590 / 014 565 9600

MOTSWEDI: LEFAPHA LA BOITEKANELO

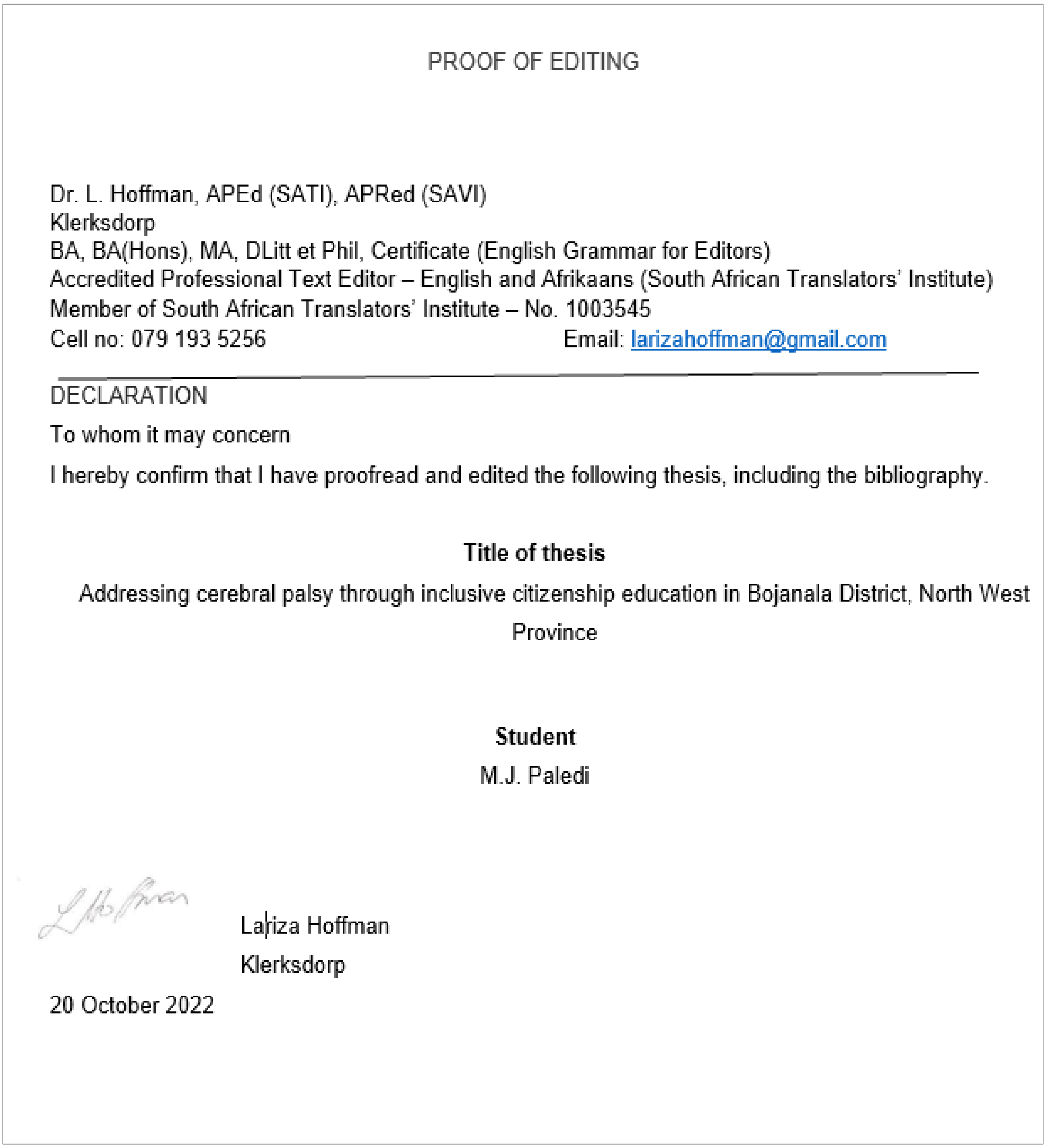
- Boitekanelo ba tlhaloganyo le didiriswa tsa bongaka
- Tshidilo ya mmele
- Didiriswa tse di thusang
  BA KA BONWA KAE:
  Bookelo ba J. S. Tabane (Rustenburg)
  Maranyana: bsekgele@nwpg.gov.za
  Mogala: 014 590 5100

Ke eng se o ka se dirang jaaka moagi go fitlhelela le go amogela malapa a a nang le bana ba bolwetse jwa mesifa / bana ba ba tshelang ka bolwetse jo?

- Keteka kgwedi ya Mopitlwe e e leng ya tlhokomediso ya bolwetse jwa mesifa
- Aroganya tshedimosetso ka ga bolwetse jo ka go neelana ka diphamfolete kwa dikokoanong tsa baagi jaaka kwa manyalong, dipitsong kgotsa diphitlhong
- Aroganya tshedimosetso ka ga bolwetse ba mesifa kwa dikerekeng le kwa dikolong
- Neelana ka diphamfolete kwa mafelong a baagi jaaka dikantoro tsa masepala kgotsa dikantoro tsa morafe
- Neelana ka diphamfolete kwa dikopanong tsa bagokgo le tsa batsadi

A ROTLHE RE AMOGELENG MOTHO WA BOLWETSE JWA MESIFA MME RE AGENG SETSHABA SE SE TLHALOGANYANG THATA, SE SE MOLEMO LE GO TSENYELETSA BOTLHE

Annexure N: Proof of editing



PROOF OF EDITING

Dr. L. Hoffman, APEd (SATI), APRed (SAVI)
Klerksdorp
BA, BA(Hons), MA, DLitt et Phil, Certificate (English Grammar for Editors)
Accredited Professional Text Editor – English and Afrikaans (South African Translators' Institute)
Member of South African Translators' Institute – No. 1003545
Cell no: 079 193 5256 Email: larizahoffman@gmail.com

DECLARATION

To whom it may concern

I hereby confirm that I have proofread and edited the following thesis, including the bibliography.

Title of thesis

Addressing cerebral palsy through inclusive citizenship education in Bojanala District, North West Province

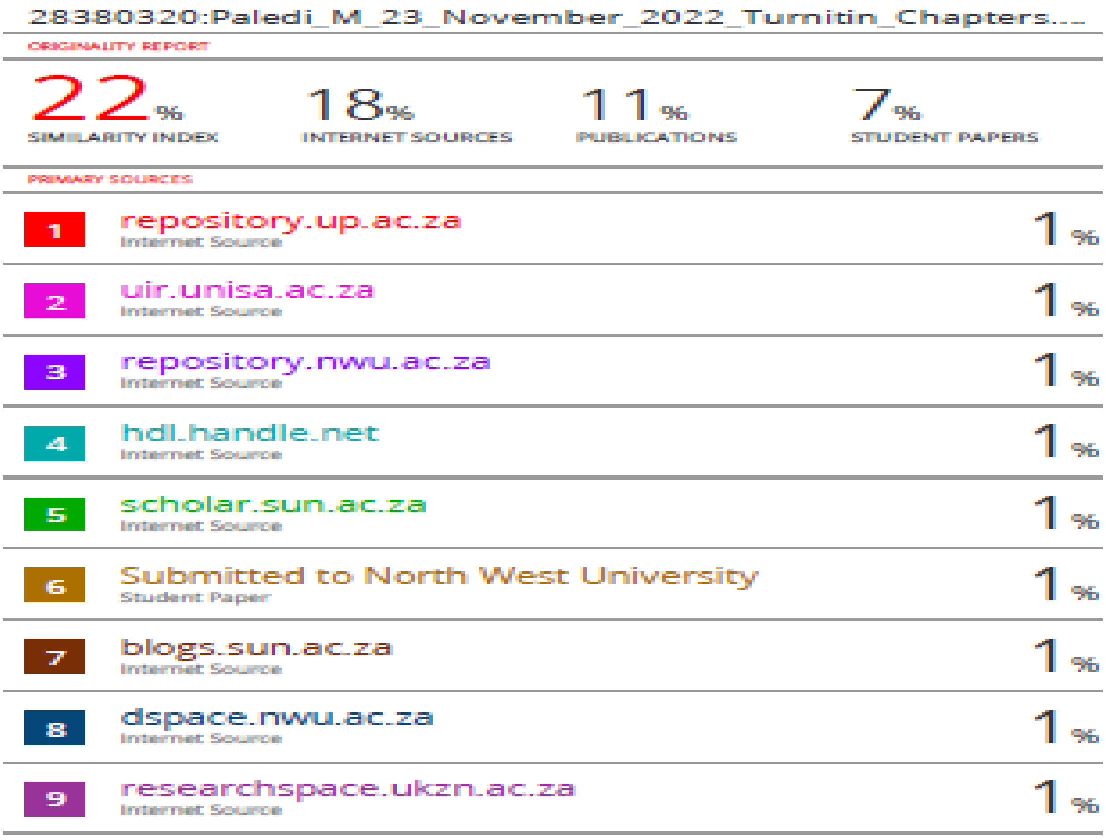
Student

M.J. Paledi

Lariza Hoffman
Klerksdorp

20 October 2022

Annexure O : Turnitin Report



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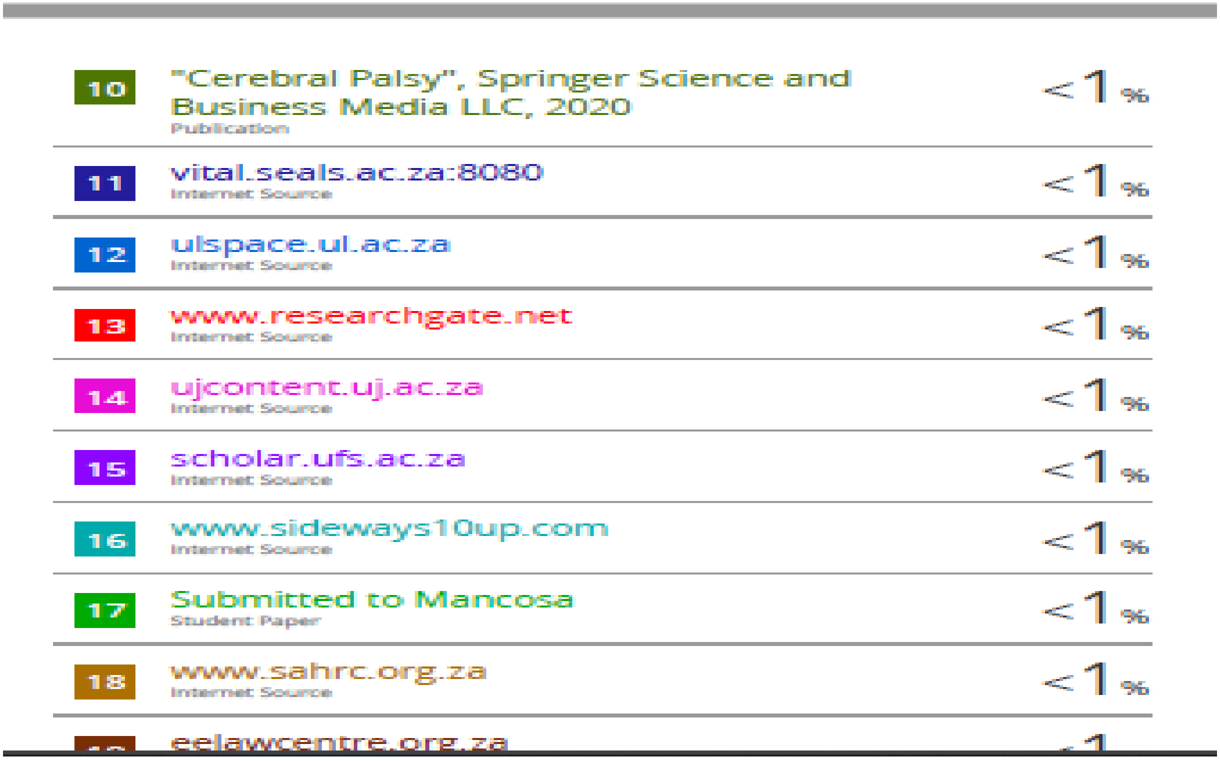

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