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**EXPLORING THE EXPERIENCES OF CAREGIVERS RAISING
CHILDREN LIVING WITH DISABILITY**

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Submitted in partial fulfilment of the requirement for the degree of MSocSc
(Clinical Social Work)

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DECLARATION

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Signed by candidate

Signature:

Date: 11/08/2022

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ABSTRACT

According to the World Health Organisation, more than a billion people are living with a disability, with the vast majority being in low- and middle-income countries. In low-income communities, caregivers of children with a disability face multiple challenges related to poverty and lack of resources, which make it difficult for them to raise their child. This study explored the experiences of caregivers raising children with disabilities in South Africa. The aim of the study was to understand the experiences and needs of the caregivers of children with disabilities, through gathering sufficient primary and secondary data to reach a deep and broad understanding of the phenomenon. Twenty primary caregivers of children living with disability from the two disadvantaged communities – Khayelitsha and Gugulethu, both Cape Town townships participated in the research. The caregivers were all the biological mother of the child and living with the child at home. This research took the form of a qualitative exploratory study, (which is the research method that will be used in as a form of research method which we will be used in the paper) allowed for obtaining data in a flexible manner and to engage with the participants within their natural setting. Due to the COVID-19 pandemic in-depth telephonic interviews were conducted with the participants. A semi-structured interview schedule was used to facilitate the discussion, which was recorded using an audio recorder. The findings revealed that caregivers experienced different challenges in caring for a child with a disability. This led to them feeling isolated in their role, which was reinforced by a lack of community resources and social welfare support services; a lack of services delivery from government social services including social work intervention for caregivers of CWD left them often feeling hopeless. In these circumstances, it is recommended that the Department of Social Development incorporate systematic efforts to provide services to caregivers of children with disabilities. In addition, training should be provided to social workers to acquire skills on how to work with families of CWD. Disability should further be incorporated in the curriculum as part of social work studies.

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ACRONYMS

| | |
|---------|--|
| CRPD: | The Convention on the Rights of Persons with Disabilities |
| CWD: | Child with disability |
| DSD: | Department of Social Development |
| LMICs: | Low- and middle-income countries |
| UNCRPD: | The United Nations Convention on the Rights of Persons with Disabilities |
| UNICEF: | The United Nations Children's Fund |
| WHO: | World Health Organisation |
| WPRPD: | White Paper on the Rights of Persons with Disabilities |
| ID: | Intellectual disability |
| CDG: | Child disability grant |
| SA: | South Africa |
| EC: | Eastern Cape |
| WE: | Western Cape |
| ECD: | Early childhood development |
| UN: | United Nations |

CHAPTER 1: BACKGROUND AND INTRODUCTION

1.1 Introduction

Globally, more than a billion people live with disabilities, with the vast majority living in low- and middle-income countries (World Health Organisation, 2020). Disability may be congenital or acquired at any stage of life through accident or illness, and may take many forms. It can be physical, as in the case of a limb amputation, muscular or neurological dysfunction, or sensory, as in the case of blindness or deafness, or cognitive, as in the case of brain damage (WHO, 2020). Disabilities can be a major impediment to participation in society. To live with a disability means to have lost functioning in some area of life, making access to resources such as public transport, shopping centres and healthcare facilities extremely difficult for some. This is particularly the case where developers and architects have not thought to provide wheelchair ramps for those in wheelchairs. Disability can be hard to adapt to when one is not born with the disabling condition. It can also be very isolating in effect (Dombeck, 2020).

Studies show that the majority of people with disabilities live in low-income countries, and represent nearly a quarter of the world's poorest people (Emerson 2007; Groce et al. 2011a, 2011b). According to Couper et al (2002), in South Africa, the percentage of children with a disability is estimated to be between 5.2% and 6.4%. These include children with a range of motor, sensory and intellectual disabilities. Furthermore, research confirms that in South Africa, approximately 1 million children (persons under the age of 18 years) were living with disability in 2001 (Ijsselmuiden et al, 2006). Children with disabilities are one of the most vulnerable groups in South Africa. Very often their basic human rights are not met, in areas such as access to education and healthcare services, in addition to the community exclusion they experience. In a survey on access to education conducted by the Department of Basic Education in 2017, it was shown that over a quarter of 110 000 children aged 7 to 15 years had some disability (Department of Education, 2017). In addition, a report by the child protection system that tracked child abuse among children showed that children living with disability are more at risk of sexual abuse than their peers without a disability (Helton et al,2018).

The United Nations Children's Fund (UNICEF, 2013) states that among people with disabilities, children with disabilities (hereafter referred to as CWD) are the most marginalised group, experiencing exclusion from society and widespread violation of their rights. This

results in caregivers of children with disabilities facing many challenges daily; mothers, who are often the main caregivers of CWD, experience far more psychological and physical challenges than mothers who care for a child without a disability (McConkey et al. 2008). In low- and middle-income countries (LMICs) poverty and disability are believed to operate in a cycle, with conditions associated with poverty (lack of access to healthcare, inadequate water and sanitation, malnutrition and poor living conditions) making it even harder for caregivers to raise a child with disability (Yeo, 2001). The World Health Organisation states out that there has been a rapid growth in the number of people living with disability in recent years, with a particular increase in LMICs. The higher prevalence of disability in LMICs leads to unmet needs, including lack of access to resources and services, preventing those with disability from participating in society and family life (Switzerland, 2011).

This study examined the experiences of caregivers raising a child with a disability in two disadvantaged townships in the Western Cape – Gugulethu and Khayelitsha .The aim was to understand the experiences of caregivers within the context of their family life and their social setting, including the aspect of social work service delivery, which is supposed to act as a support service to caregivers of children with disabilities. This chapter outlines the statement of the problem, rationale and significance of the study, the main research questions, research objectives, main assumptions, clarification of terms and ethical considerations.

1.2 Statement of the problem

According to the South African Human Rights Commission (SAHRC, 2017), people with disabilities in South Africa face a number of challenges, including discrimination in various social activities and in terms of social welfare service provision. Access to healthcare services, employment and education are ongoing challenges that have been recognised as major limitations for persons with disabilities in South Africa. In addition to these challenges, the SAHRC observes that one of the driving forces of social exclusion is the stigma that communities continue to attach to disability. Further, inadequate living conditions severely affect children with disabilities, who are more likely to live in informal settlements and in overcrowded living conditions without adequate toilet facilities than are children without disabilities. Lack of access to sanitation and adequate housing adds enormous stresses to caregivers and families of children with disabilities (UNICEF, 2012).

The government has attempted to take action on these challenges, according to the SAHRC (2017). A document entitled 'Children with disability short changed' (SAHRC, 2017) highlights the very limited progress made by the government in addressing the limitations on the rights of CWD and in implementing the stipulations of the Convention on the Rights of Persons with Disabilities.

In South Africa, very little focus is placed on the role of caregivers of children with disabilities. Previous research has mainly focused on the needs of persons with disabilities and not on caregivers tasked with caring for CWD, particularly in low-income populations (Sandy et al, 2013). Furthermore, very little information is available on the challenges caregivers face, including the circumstances that can lead to the violation of their rights. From the paucity of data on this research topic, it is evident that there is a gap in research on disability with regard to the experiences of caregivers raising children with a disability. This gap is even more apparent with regard to the experiences of caregivers in impoverished black communities such as Gugulethu and Khayelitsha, characterised by complex social challenges and poor living conditions. An examination of these experiences is important, as it will allow caregivers the opportunity to be heard, to be understood and, it is hoped, to be included in decision making in matters that affect their lives.

This research focused on the experiences of caregivers in Gugulethu and Khayelitsha raising children living with disabilities. The research provided opportunities for caregivers to share their experiences and explain how they have been affected by the disability of a child, thus providing new data relevant to care and caregiving in the context of disability. The study therefore addresses a significant research gap, yielding data that may benefit the social work profession, policies related to child disability, and academic training in this field.

1.3 Rationale and significance of the study

In the developing world there are few research studies on children with severe disability. Research studies that have been conducted tend to focus on the child and on a certain type of disability rather than on caregivers who provides care to the CWD (Sandy et al, 2013). At the same time, caregivers have been identified as a major element in the care of children with a disability, strongly affecting their functioning and wellbeing. Goldner and Drentea (2009) state that it is important to analyse the effects of caregiving on caregivers of CWD themselves, as such an analysis allows one to understand the impact of disability on family functioning. The

authors assert that the family is a system, with child disability affecting the whole family system, not only the child and the caregiver.

In South Africa, studies conducted on disability tend to focus on physical disability (Sandy et al, 2013). Research on the experiences of caregivers who face enormous challenges is important. Such research will provide insights on the experiences of caregivers and their needs, as well as on the needs of children with disabilities. Research that focusses on the family, rather than on the child only, allows a more in-depth and holistic understanding of the caregiving role and the services that would make this role easier.

The findings of this study add value to current and future research in making it possible for caregivers of CWD to be heard and providing valuable data on their experiences and needs. This data will contribute to effective service delivery to CWD and their families. The data can also positively contribute to policies on disability, including on the formulation of principles relevant to caregivers and children with disabilities. These finding can also inform curricula for social workers in the field of disability.

1.4 Main research questions

The study explored the experiences of caregiver raising children with disabilities. The aim was to understand the experiences of caregivers of children with disabilities in their family and social contexts, which could guide appropriate services to this group. Twenty primary caregivers of CWD from Khayelitsha and Gugulethu participated in the research. The caregivers were all the biological mothers of the CWDs and lived with the child at home. The research employed a qualitative design using semi-structured interviews to understand the caregivers' experiences of caring for a CWD. The study was intended to be based on in-person interviews, but because of the pandemic restrictions, the researcher had to conduct telephonic interviews.

The main research questions were:

- How do caregivers understand the disability of their child?
- What are the challenges experienced by caregivers of CWD?
- How does caring for a CWD affect caregivers' family life?
- What support including welfare services do caregivers receive while caring for CWD?

1.5 Research objectives

The research objectives for this study are:

- to explore caregivers' understanding of the disability of their child;
- to uncover how caregivers understand the meaning of the diagnoses of their child;
- to explore the challenges experienced by caregivers caring for CWD;
- to examine how caring for a CWD affects caregivers' family lives;
- to examine what support including welfare caregivers receive while caring for CWD;

1.6 Main assumptions

Assumptions are the thoughts or beliefs through which one interprets one's world or reality; in research, they are realistic expectations about something believed to be true, but lacking empirical evidence and therefore taken on faith (Simon, 2011). Research assumptions provide a basis for the development of theories and research instruments, and influence the research process (Polchan, 2015). Methodological assumptions consist of assumptions made by the researcher pertaining to the research method used to conduct the research, and are based on the researcher's own experiences of collecting and analysing data (Creswell, 2003).

From a methodological perspective, the researcher assumed that a qualitative research approach would be ideal for this study and that caregivers would be the best participants to share information on raising a CWD, since they have direct experiences of the day-to-day care of such children. Qualitative research allows the participants to express their feelings, opinions, and experiences in a natural setting. It further allows participants to share experiences on issues in a language they understand (Chalhoub-Deville & Deville, 2008). The research also assumed that a qualitative approach would provide caregivers of CWD the opportunity to share their experiences in a meaningful way, expressing themselves in their language of choice. It would yield the kind of in-depth data needed to properly inform service provision in the field of caregiving for children with disabilities.

The researcher also held general assumption about the topic. She believed that the experiences of caregivers of CWD would provide insights on the emotional, physical and family challenges of caring for CWD. Further, she assumed that some degree of child neglect may exist because of difficulties associated with caring for a CWD, and that caring for a CWD affects a family's functioning as a system. Lastly, the researcher assumed that cultural beliefs would affect the way caregivers understood the disabilities of their children. The research process and findings allowed for these assumptions to be tested, as discussed further in Chapter Four.

1.7 Clarification of terms

1.7.1 Disability

There are several definitions of disability.

The White Paper on the Rights of Persons with Disabilities (WPRPD) defines disability in the same way as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), placing the focus on the disabling role of society: ‘Disability is imposed by society when a person with a physical, psychosocial, intellectual, neurological and/or sensory impairment is denied access to full participation in all aspects of life, and when society fails to uphold the rights and specific needs of individuals with impairments.’

The World Health Organisation (WHO, 2020) defines disability as ‘... an umbrella term for impairments, activity limitations or participation restrictions “conceiving” a person’s functioning and disability . . . a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors, including the social, attitudinal, and physical environments and personal attributes’. This study uses the definition of disability as articulated by the WHO, which provides for a broad, inclusive understanding of disability aligned with the parameters of this study.

1.7.2 Severe disability

A severe disability refers to a condition of both physical and mental impairment which seriously limits one or more of a person’s functional capacities, such as mobility, communication, self-care, self-direction and interpersonal skills. An individual with severe disability requires full-time care from a caregiver to function on a day-to-day basis (WHO, 2019).

1.7.3 Childhood disability

According to UNICEF and the WHO (2012), a child is considered to have a disability when they have any impairment or condition that affects their ability to perform the activities of daily living, including independent feeding, mobility and communication. These organisations describe childhood disability as a condition or impairment that affects a child’s development from childhood to adulthood, and which may have a lifelong physical, mental, emotional and social impact on their life and their participation in certain activities (WHO, 2012). Children with childhood disability may require special care such as healthcare and education and may

need to negotiate significant social and environmental barriers to allow them to fully participate in everyday life. Childhood disability in this study refers to any child who has a disability from birth to 18 years of age, as noted in the UNICEF and WHO definitions. A CWD is considered a child who had been diagnosed with a physical or mental disability or both, regardless of the severity of their condition.

1.7.3 Impairment

According to the Oxford Dictionary (1998), an impairment is ‘the condition of being unable to perform as a consequence of physical or mental unfitness. A symptom of reduced quality or strength’.

According to the World Health Organisation (2020), an impairment is a problem in the body’s functioning or structure. It includes an activity limitation encountered by an individual with disability in executing a task or action. For a person who has a disability, inability to participate in the normal activities of others is an impairment experienced as a restriction, preventing the person from being fully involved in various normal life situations (WHO, 2020). A review study conducted by Capri et al (2018) revealed that the majority of people with an impairment related to disability are from low-income countries, and represent over a quarter of the world’s poorest people. The participants of this study fit this demographic as they were from impoverished, resource-scarce communities.

1.7.4 Caregiver

According to the Oxford Dictionary, a caregiver is ‘a person who tends to the needs or concerns of a person with short- or long-term limitations due to illness, injury or disability’.

There are different types of caregivers that provide specific care, such as family caregivers and respite caregivers (Reinhard, 2008). In the care of persons with a disability, caregivers regularly assist the person to carry out daily tasks and offer support to individuals in need. Masfeld et al (2021) indicate that most people who play a caregiver role for children with a disability are the mothers of the children. This was the case in this study.

1.8 Ethical considerations

Ethical issues arise at various stages in social research. Researchers cannot ignore ethical issues, as they relate directly to the integrity of the study and the welfare of the participants involved in the study (Brymans, 2016). According to Brymans (2016), it is important for social

workers to understand, recognise and act in accordance with the required code of conduct and the ethics of research if successful practice and research is their goal. Strydom et al (2021), Fouché and Delpont (2005:56) describe ethics in research as follows: ‘Ethics is a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents and other researchers’. Babbie and Mouton (2001:520) likewise note that the researcher needs to take care and be aware of general agreements about what is proper and improper in the conducting of studies.

This section discusses the ethical dimensions of this study. It discusses how the researcher remained ethical during the course of conducting the study, while having to consider the social context at the height of the Covid-19 pandemic.

1.8.1 Harm to participants

In conducting research, harm to participants can reflect in a number of ways. It is therefore crucial for the researcher to be aware of ways in which they may inadvertently cause harm to participants or any other people involved in the study.

Because of the Covid-19 pandemic, this study made use of semi-structured telephonic interviews. As social workers are trained in conducting interviews, the researcher, also a social worker, followed the guidance of Drisko (2013), whose stated that any researcher who conducts a qualitative narrative inquiry needs to be aware of the principles of confidentiality and respect, since participants tend to share lot of personal information and may be left feeling exposed.

To ensure that participants felt protected, the researcher made use of her training in empathetic skills, adopting an affirming tone while listening, responding and speaking to the participants. This created a safe and non-judgemental setting during the interviews. To reinforce this safe and non-judgmental space, the researcher assured the participants that all information shared would be treated confidentially and used only for the purposes of the research. Participants were aware that they had the right to stop sharing at any point should they feel uncomfortable. These are aspects of interviewing that ensure that participants’ rights are upheld and that participants are safeguarded against harm (Barrow et al, 2021).

At times, the interviews evoked strong emotions, and some participants cried as they shared their difficulties. In such cases, at the end of the interview, the researcher offered participants referrals to organisations working with disability, making use of her social work network. Of

the twenty participants, five were given such referrals, using the social work referral letter. Reasons for these referrals included struggles with accepting the child's disability, family conflicts related to the disability, and self-blame, where participants blamed themselves for the challenges they were experiencing. The high emotions and difficulties that participants expressed in voicing their troubles were further dealt with through debriefing, which is an aspect of ethical studies used when called for.

1.8.2 Debriefing of respondents

Debriefing facilitates therapeutic communication with participants, allowing them the opportunity to address emotions and affirming feelings experienced during interviews or discussions. It provides participants with the opportunity to address any questions and misconceptions they might have developed during the study (Gilston, 2021).

To debrief participants in this study, the researcher offered participants the opportunity to talk about their experience of participating in the research and any sensitive issues that emerged during the interviews. The need for such engagement was clear from the way in which the participants spoke about their experiences during interviews. Strong emotions were detected in the tone of voice that changed when participants were sharing certain information. The researcher also paid attention to silences, which suggested that participant needed time to process feelings or thoughts before responding. The researcher used her social worker knowledge and skills, having worked in the field of disability services, to identify organisations that could assist the participants with their caregiving challenges. Participants were therefore referred to organisation that work with disability, namely, Uhambo Foundation and the Western Cape Autism Centre. The researcher followed up with social workers in these organisations afterwards to ensure that participants could access the service when they wanted to do so.

1.8.3 Informed consent

The study made use of voluntary participation, a basic principle of ethical research in which participants are not forced to participate in any study (Sheff et al, 2018). Participants were given a choice of whether or not to participate in the study. The researcher made it clear to

the participants there would be no negative consequences of refusing participation, or of withdrawing at any time during the research.

According to De Vos et al. (2011:117), informed consent is the provision of full knowledge about participation in research. It allows researchers the opportunity of resolving or relieving any possible tension, insecurity or resistance by the participants before research begins. The principle of informed consent means that prospective research participants are given as much information as they need to make an informed decision about whether or not to take part in the research (Bryman, 2016), without any pressure to do so. Informed consent implies that participants are well informed not only about the research topic, but also about the research process and what will be expected of them. Once informed, participants who wish to proceed are asked to sign informed consent forms to participate in the study (Bryman, 2016). In this case, forms could not be signed before the interviews, but were hand delivered to the participants after they had been given verbal information on all aspects of the study and their role in it.

In explaining a research study to participants, researchers need to be absolutely clear about all aspects, including specific procedures and actions envisaged, using language that is clear and understood by participants (Sheff, 2018). By doing so, the researcher gives the participant an opportunity and a right to refuse or withdraw from the research should they wish to do so (Sheff, 2018). In this study, the researcher read the consent form to the participants in IsiXhosa, their main language. She allowed the participants to ask questions and raise any concerns they might have regarding the consent form. The researcher explained the topic and purpose of the study and provided her contact details and those of her university. All participants confirmed and verbally consented to their participation telephonically.

As a result, the researcher hand delivered copies of the consent form to the participants. (See Appendix A for a copy of consent form.) Prior to delivering the forms, the researcher contacted the participants to confirm that their addresses were still the same. At the point of delivery, the researcher had the opportunity to meet the participants and answer any further questions they might have about the study. Many confirmed that they had enjoyed the discussion and appreciated the opportunity to speak to someone who was not part of their family. They seemed to greatly appreciate the opportunity to share experiences which they had been bearing, mostly alone, for a long time.

1.8.4 Deception of participants

Bryman (2016) notes that deception occurs when a researcher represents their work as something other than it is. Bryman further asserts that it is the duty of a researcher to ensure that they do not pursue methods of inquiry that are likely to infringe on human values and sensibilities. To avoid deception in this study, the researcher designed the questionnaire prior to doing the interviews, and explained the information written on the questionnaire before each interview. She ensured that the participants were aware of what to expect and were not subjected to a situation of unexpectedly being asked sensitive questions. The researcher also clarified fully what the information would be used for, and allowed the participants to ask questions about the study, to which she provided full details.

1.8.5 Privacy, anonymity and confidentiality

Confidentiality refers to the handling of information in a confidential manner. Confidentiality may be viewed as a continuation of privacy, especially when it comes to agreements between persons, in that others are not given access to private information (De Vos, 2011). To ensure confidentiality in this study, real names were not used and participants were given numbers. To avoid any violation of privacy, before each interview, the participants were asked by the researcher if the interview could be recorded. Recordings were made only with their consent. Participants were not pressured into saying any more than they wished to, to protect them from feeling violated or coerced into revealing information. In social work practice, confidentiality is also recognised as a core value when working with clients (De Vos, 2011). Keeping this value in mind, the researcher gave participants reassurance that any information they shared would be treated with confidentiality and would not be shared in any way that could publicly identify them. During the transcription of the interviews, the transcripts were anonymised using codes. Anonymity also extends to all other aspects of the research, including the dissertation or thesis itself; in this case, neither participants names nor any details that might identify them are mentioned. All records of interviews were kept in a safe location away from the place where interviews were conducted. The recorder used was password protected so that the interviews could not be accessed by anyone. All the transcriptions were kept in a safe computer drive accessible only to the researcher. Privacy was also ensured by conducting interviews in a private place at times chosen by the participants, who were encouraged to choose a time and place that would be suitable, based on their home conditions.

1.8.6 Actions and competence of the researcher

Research competence is fundamental to the conduct of ethical human research. It allows for an ethics committee to consider whether the researcher conducting the study has the appropriate research skills and experiences to conduct the research they propose to undertake (Mooney-Somers & Olsen, 2017). In this study, the researcher is a trained social worker, who has experience in working in the field of disability with both parents as caregivers and children with disabilities. The researcher further worked with an academic supervisor for ongoing support and monitoring of the research process. The research was assessed by the UCT Social Development ethics committee and verified as ethically sound to be undertaken and was then implemented accordingly.

1.8.7 Release of publication of findings

The findings and publications of this study will be published for academic or professional purposes through the university library. In the case of the study being published as an academic paper, the identities of the participants will remain confidential and will not be disclosed for any reasons

1.9 Conclusion

This chapter has provided background to the topic under investigation and an outline of the study, giving a clear description of the research parameters, including the research topic and a statement of the problem. It discussed the rationale, significance of the study and research methodology used, referring to the research design, research questions and research objectives. The research assumptions were discussed and the main concepts relevant to this study were clarified. The chapter concluded with an overview of the ethical considerations and how the researcher upheld the principles of ethical research in the study.

The following chapter presents a literature review on the topic, giving an overview of the findings of other authors on the topic or related topics, the relevant policies and legislation, and the theoretical frameworks that guided analysis in this study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

A literature review is an overview of a topic; an explanation of what other researchers have found, and an examination of how each research study or publication contributes to an understanding of a topic (Hart, 2006). It also includes a discussion on any relevant legislation and the theoretical frameworks that underpin the study. A good literature review methodologically analyses and synthesises quality literature on a topic, providing a firm foundation for the subsequent primary investigation. The literature review also provides a stable foundation for the selection of a research methodology, showing how the proposed research will contribute to the overall body of knowledge of the topic under review (Machi & McEvoy, 2018). Through the literature review, a researcher may identify gaps in research.

In this literature review, the researcher discusses previous research that has been conducted on caregivers raising children with disabilities. Many studies were reviewed, starting with those conducted in South Africa on disability and moving on to studies conducted in the African context. To enhance the literature review, the researcher added findings from international studies when it was necessary to expand on certain statements. This was considered a feasible strategy since limited information is available on caregivers' experiences related to CWD in South Africa.

In addition to a review of the literature, this chapter outlines two theoretical frameworks as well as policies relevant to the study. Gabriels (2013) defines a theoretical framework as the structure that holds or supports a research study. A discussion of the theory should give an introduction and description of the theory and explain why it is relevant to the topic under investigation. The researcher selected theories to explain, predict and understand phenomena and to challenge existing knowledge within the limits of critical bounding assumptions (Gabriels, 2013).

The two theories used in this study are Systems Theory Poole (2014) and Winnicott's Object Relations Theory (1965). Systems Theory was chosen as the primary theory because it provides a good basis for understanding society and the family as interrelated systems, each with various components that interact with one another and affect the whole. In social work, System Theory is viewed as a valuable theory as it is based on the notion that behaviour is influenced by a variety of factors that work together as a system; these factors include families, friends and the

environmental setting. By understanding the entire system, and how the various parts affect one another, social workers can put together a family's story and understand its dynamics from the point of view of the whole system (Walker, 2019). This holistic understanding of the caregiver's world was sought in this research, and so the theory was deemed suitable.

The other theory discussed in the study is Winnicott's (1965) Object Relations Theory. This theory aligns with the clinical dimension of this research. To explore the phenomenon of maternal care, which is a dominant theme of studies focused on the mother as primary caregiver, and evident in this research, this theory was useful, since it enabled an understanding specifically of the maternal experiences of caregivers of children with disabilities from a clinical social work perspective. The researcher chose this theory to examine and provide an explanation of the relationship between a caregiver and the child with a disability, and to explore how the child's disability shapes the relationship between the mother and the child.

The policies that are examined in relation to the study topic are the Constitution of the Republic of South Africa 1996, the White Paper on the Rights of Persons with Disability (WPRPD), and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2007).

2.2 Findings from the literature

2.2.1 The context of disability and care in South Africa

In South Africa, it is estimated that about 7,5% of the country's population is living with disability. According to StatsSA (2014), black Africans had the highest proportion of persons with disabilities, at 7,8% of the black African population, while 6,5% of the white South African population are disabled. These differences may be traced to the history of the country, which still battles the effects of the apartheid era. StatsSA (2014) maintains that policies and interventions were put in place to ensure that persons with disabilities had equal rights and access to basic services, including education and employment opportunities. Statistics show that Free State and Northern Cape provinces have the highest percentage of persons living with disability, with the high percentage of 11% in Free State and 11% Northern Cape speculated to be a result of mining activities. Northwest and Eastern Cape follow, at 10% and 9,6% respectively. The Western Cape and Gauteng have the lowest percentage of persons with disabilities (both 5%). Across provinces, StatsSA (2014) states that females are more likely to have a disability than males, with 8,3% of females having mild and severe difficulties across

types of difficulties, while 6,5% of males have disabilities. Looking at the percentage provided for the country, children between the ages of 5 and 9 years have slightly higher rate of disability than the general population. According to StatsSA (2014), it is difficult to provide proper results for children as many parents misreport the developmental stage or condition of their children.

With regard to disability and education, the South African Constitution recognises the right to education of all children, with the government placing particular emphasis on the Early Childhood Development (ECD) programme. In ECD, policies mandated five years ago make it compulsory for all children between ages of 7 and 16 years to be enrolled in a registered education programme. However, while the policies have been implemented, gaps in access to education still exist between children who live with disability and those who do not live with disability. According to StatsSA (2014), school attendance in children aged 5 to 9 years is highest among children with no disability and lowest among children with severe difficulties in walking, communication and hearing; 35,5% children with these difficulties do not attend school. Disparities in school attendance exist across population groups, disability types and geographical areas. Results for attendance of secondary school were similar to those of primary school, with children with disabilities less likely to be attending school than those with no disabilities. These results are evidence of the burden of care experienced by caregivers of children with disability, as they reflect that many children with disability are not attending school and remain at home almost continually. Caregivers have to be present and attend to their needs, which places a great strain on them emotionally and physically. This also places financial strain on parents, since one parent – quite often the only parent present – is unable to go out and seek work and depends on the child support grant for survival.

2.2.2 Caregivers' understanding of disability

Globally and in South Africa, limited information and research exists on caregivers and their experiences of caring for children with disabilities. In a study conducted by Mathye and Eksteen (2016) on the causes of childhood disabilities, for example, caregivers had an opportunity to share their perspectives on what caused childhood disability. However, their experience of caring for these children was excluded. Green (2013), likewise, conducted a study in Florida, USA, on mothers caring for a child with a disability and found that there was limited literature on caregivers caring for children with disabilities. Nonetheless,

available research indicates that caregivers of CWD understand the causes of disability in different ways. According to the World Health Organisation (2013), people in low- and middle-income countries often consult with traditional healers for various conditions, including disability, as traditional healers are seen as credible practitioners who can provide a suitable medical service. In these conditions, while families believe disability can be caused by biomedical and genetic factors, they also strongly believe religious or spiritual factors to be the underlying cause of disability, especially in children. Mkabile and Swartz (2022) confirmed this finding in an exploratory qualitative study conducted with traditional healers on intellectual disability in Khayelitsha. Their findings revealed a strong belief among traditional healers that intellectual disability may be understood as a spiritual affliction. Fifteen practicing traditional healers – ten females and five males – shared some of the causes for disability as they understood them; these included evil spirits, unhappy ancestors, curses and witchcraft. One of the participants further stated that at times a child may develop a disability when one of the parents has abandoned their traditional customs, or ancestors are punishing them through their offspring.

These findings on the causes of disability in the South African context are similar to findings of a study by Bingham (2017), on caregivers of persons with disability in rural South Africa. Kistern-Bingham explored the experiences of caregivers of children with disabilities in DICAG-affiliated centres a semi-rural area near Cape Town. Her study made use of a qualitative research design and semi-structured interviews in focus group discussions. The caregivers in the study shared their experiences and understandings of the causes of childhood disability. One important experience was the feeling of disappointment they experienced when told of their child's disability. While some caregivers expressed disappointment about having a child with a disability, others viewed the child as a 'gift from God' (Bingham, 2017:22).

These findings were similar to those of a study by Makgatho and Eksteen (2016), who conducted research on the care of children with disabilities in the rural community of Giyani in Limpopo. The aim of this qualitative study was to explore views on childhood disability in this community, using an exploratory and descriptive approach. Whilst some caregivers understood the cause of childhood disability to be genetic factors, others interpreted the phenomenon spiritually; God had given them a gift, or, in some cases, the child had been given to them as payment for their sins (Makgatho & Eksteen, 2016:7). The authors added that their findings verified those of a previous study conducted by Hebert and Koulouglioti

(2010). This was a systematic review of the literature examining parental beliefs regarding the causes of autism. In that study, most caregivers described the cause of their child's autism as a result of genetic factors. However, they also believed that access to healthcare services and the environment in which the CWD lived worsened the disability of the child, especially where families had to struggle with resources. Adnams (2010) stated that in South Africa, services for children with intellectual disabilities are scarce, particularly in impoverished communities. As a result, the majority of these families seek help from traditional healers; in other words, their turning to traditional practices is not only a result of their belief system but also of the scarcity of welfare services.

Muller-Kluits (2017) conducted a study on caregivers caring for adults and children with a physical disability associated with Tygerberg Hospital and receiving services from the Association for the Physically Disabled (APD). The study made use of a qualitative research method and examined perceptions of caregivers of caring for persons with physical disabilities. Here the findings were a little different from those of the above studies, in that the predominant experience was of grief. Caregivers also expressed feelings of guilt around the events that may have led to the person's disability. Their sense of guilt expressed itself as self-blame linked to their belief system, in that they felt they were paying for their sins. This finding was similar to that of Kistern-Bingham (2017), who relates how a participant went home feeling confused and disappointed, as the disability was quite unexpected.

While the causes of disability may be interpreted differently, as the above studies show, it is evident that caregivers recognise biomedical and genetic factors, but that for many, cultural explanations underlie these factors.

2.2.3 Caregiver challenges

Coetzee (2016) confirms that in South Africa, families caring for children with disabilities are exposed to additional stressors that are not common in developed countries. Such stresses leave families feeling overwhelmed, discouraged and displeased. The finding of the aforementioned study by Kistern-Bingham (2017) on caregivers of children with intellectual disabilities confirmed that family caregivers found their role stressful, especially when they had to do other household chores; they found it difficult to multitask owing the constant demands of the child. This experience can be viewed as common to most caregivers of CWD. According to Ahmann (2013), the complexities of caring for a child with a disability often lead to caregivers isolating themselves from their extended families, friends and community. This is as a result of the

burden of care, which makes it difficult for caregivers to participate in other areas of life. Thus, isolation increases for caregivers, the bulk of whose time is spent in caring for the CWD, leaving little time to spend with family and friends or to get involved in community matters.

Mmangaliso and Lupuwana (2021) explored the psychosocial experiences of family caregivers of children with intellectual disabilities in the rural town of Alice in the Eastern Cape, South Africa. The study made use of a qualitative research method, using snowball sampling to recruit 15 family caregivers of children with intellectual disabilities. The ages of the caregivers ranged from 20 to 65; all were African males or females. The participants confirmed that they had difficult relationships with their families and community members because of their caregiving role. These findings draw attention to the devastating impact that caring for a child with a disability can have on the family system, and the difficulty faced by caregivers on a day-to-day basis. The findings further reveal the burden of care for caregivers. Caregivers confirmed a need to adjust their social lives to accommodate the needs of the child. The caregivers viewed the adjustment as a source of stress as they no longer had time for themselves. As a result, the entire family system was weakened, with conflicts often arising among family members who resented their exclusion from attention and the constant demands of the person with special needs.

In addition to the burden of care, research conducted on children with disabilities shows the societal expectations of parents with CWD. The prevailing societal discourse holds that the more one achieves, the higher one's value; as a result, persons with disabilities are often considered to have little value (Priestley, 2003). Parents, too may have very low expectations of such children. Societal attitudes certainly present a major challenge to caregivers. Opuku et al (2020) confirm that parents with CWD are exposed to negative societal attitudes which reinforce caregivers' perceptions that their role is burdensome and that their children will never achieve much.

Caregivers of children with disabilities experiences a host of additional challenges which emanate from social circumstances and negative societal perceptions of person with disabilities. These perceptions affect the wellbeing of caregivers, CWD and their families, and place CWD at risk of being the victims of violence and abuse. Capri et al (2017) conducted a mixed methods study on the rights and inclusive citizenship of children with intellectual disabilities in South Africa. They found that children with intellectual disabilities experienced discrimination in a number of ways, and that their rights to education and socio-political participation were limited. This speaks to the issues of discrimination. As Capri et al.

(2017) assert, society views CWD as being inferior human beings, which makes them more prone to abuse and exploitation. Carey (2003) and Kamga (2016) indicate that it is difficult to overcome stigmatisation and disenfranchisement without advocacy; thus, children with intellectual or physical disabilities experience rejection and stigma, especially when resources and interventions on their behalf are limited. Ali et al. (2015) concur that these conditions make persons with disabilities prone to abuse. Ali et al.'s (2015) study identified sexual abuse as one of the challenges faced by female children with intellectual disability, with the perpetrator of sexual abuse often a close relative. Phasha and Myaka (2014) observed that the sexual abuse of CWD may be associated with the idea that children with a disability have a higher than average sex drive, possess unusual powers, feel no pain, and that sex with them can cure a perpetrator of disease. Similar misconceptions were found among individuals who contracted HIV, where 'virgin rape' with disabled in children was practised in the belief that the perpetrator would be cured on HIV; a phenomenon that has contributed to consistently high rape figures in South Africa (Groce & Traci, 2004).

In a quantitative study by Huuset et al (2016) in rural and urban areas of South Africa, 219 primary caregivers were interviewed on their awareness of the human rights of their children with intellectual disabilities. The findings revealed that 85.5% percent of the caregivers recognised that their child had rights, whilst 14.5% were unaware of their children's rights.

The findings of Huuset's study are similar to the findings of others with regard to the prevalence of sexual abuse among children with disability. These findings are relevant to the current study as they confirm the increase of sexual abuse among female children with disability in South Africa. It is evident from the studies that in rural areas, especially, caregivers do not report these cases. In the study by Huuset et al (2016), on the question of why they thought their child did not have rights, the response had to do with fears that the child would not 'cope' with having rights; that the child was not up to the task of accepting responsibility for these rights. This shows a misapprehension on the nature of human rights.

The above findings reveal the many challenges experienced by caregivers of CWD on a day-to-day basis as they raise their child. They show that even though caregivers may be able to provide the necessary care for their CWD, many other factors, including poor family relationships, isolation from friends and community and social stigma strongly affect their experience of caregiving, making it difficult for them to cope in their caregiver roles. Thus, Jennifer et al (2012) state that parents of CWD experience enormous challenges leading to

poor quality of life, a fact which is confirmed by Manee et al (2016) and Zuurmond, Mahmud, Polack, et al. (2015).

2.2.4 Support systems and services for caregivers

In low-income countries such as South Africa, caring for a child with a disability can be challenging because of lack of support services for caregivers. This is compounded by social problems and poor living conditions. Caregivers carry a great responsibility for ensuring that the needs of CWD are met and at times this responsibility can bring high levels of stress that have a negative impact to the daily functioning of the caregiver (Kgole & Mavundla, 2013). Kgole and Mavundla (2013) illustrate this in their study, which they undertook in Limpopo in South Africa. Limpopo Province is one of the poorest provinces in South Africa and, according to the authors, has very limited resources for caregivers caring for CWD, particularly those with a learning disability. Their study looked at the support needs of caregivers, making use of a case study design based on three families of children with learning disabilities.

The finding showed that caregivers need support in the form of education on the specific disability of the child. Caregivers' responses when asked about education and training indicated a lack of or limited knowledge about learning disabilities. Their lack of knowledge compounded the distress and anxiety they felt while caring for their child, and many expressed the need for training from medical practitioners.

In addition, participants were in dire need of financial support. They explained that the social grant they received was not enough, as many were unemployed and unable to work because they had to be available to the child 24 hours a day. This contributed to their financial difficulties (Kgole & Mavundla, 2013). These findings are consistent with an important statement by Mitra et al. (2017) who note that caregivers and persons with disability are among the most vulnerable in any population as result of the direct and indirect costs associated with disability. Trafford and Swartz (2021), examining grant aid for children with disabilities in South Africa, made use of six in-depth, semi-structured interviews with five participants at various levels of government, including administrators and managers who managed cases of different genders and races. The participants were asked how they thought caregivers spent the Child Disability Grant (CDG). All raised concerns about the human resources needed to provide consistent care to the CWD and the costs that come with caring for a child with disability. One of the participants shared that some of the caregivers rely on the CDG, since

their burden of 24-hour-a-day care left them unable to seek work. While this is the case for most caregivers of CWD, one of the officials said that the CDG is not intended to cover all the costs associated with providing for a child with disability. Unfortunately, however, it is the reality. The findings show the very limited funds are available to caregivers of CWD and that they struggle with severe deprivation. The amount provided is unrealistic, as is the idea that it will supplement the family's income rather than constitute its sole source. In most cases, it is the entire source of income. This shows that the burden of care and associated responsibilities are not incorporated into funding and grants for caregivers, and that caregivers and their CWD struggle a great deal in their daily lives.

The caregiving experience of children with disability is affected by additional factors, including lack of education. Access to education is one of South Africa's core rights and values, whether or not an individual has a disability. According to the census data of StatsSSA (2015), only 35.5% of children with severe disability in South Africa attend school. This data remains the latest census data related to children with disabilities. A more recent report by United Nations (UN, 2019) entitled 'Disability and development report: Realizing the sustainable development goals by, for and with persons with disabilities 2018', found that 600,000 children with disabilities in Gauteng alone remained out of school, and that caregivers experienced an extra care burden as a result. According to this UN (2019) report on access to education by persons with disabilities, education is a sector in which persons with disabilities are marginalised.

Boshoff et al. (2019) identify one of the benefits of welfare support for CWD as the overall mental and physical wellbeing of the caregivers. Welfare support can further improve caregiving styles and have a positive effect on the quality of interactions in the family.

Social support, in the form of strong family and community relationships, play a crucial role in creating a sense of competency and wellbeing in caregivers of CWD. Guralnick (2011) discusses the importance of social support, stating that social support can encourage positive caregiving style that lead to competence in caregiving and in nurturing the child's self-esteem. According to Gallagher (2014), social support helps to improve caregiving quality which in turn leads to better developmental outcomes for the CWD. Kaufman et al (2014) state that through social support, families of CWD can improve their resilience and quality of life.

All of these studies recognise that caring for a CWD is stressful, and that both welfare and social support can considerably lighten the load. According to Green (2013), social support is

an essential protective factor for families of CWD. Through social support, families develop resilience and wellbeing is increased (Newland, 2014).

When family wellbeing is increased, caregivers are better able to accept their role and adapt to it, providing a higher quality of support to the child. Fuentes-Pelaez, Balsells, Fernández et al. (2014) expand on adaptability, stating that social support is vital as it can facilitate caregivers' wellbeing at emotional, psychological, physical, informational, instrumental and material levels. Thus, it is crucial for caregivers of CWD to be able to access suitable social support services, including support provided by their communities. In a study by Boshoff et al (2019), the authors identify and describe the tools used to measure the social support provided to primary caregivers, including parents and grandparents. The findings show that all caregivers needed social support. In a study entitled 'The role of informal childcare in mothers' experiences of care and employment', Correa et al. (2011) point out a strong role played by informal networks of single mothers of children with disabilities, which act as a viable support system.

Added to the findings of this study, Britner et al (2003) reviewed the support of marital partners for caregivers raising a child with a disability. Britner et al (2003) findings are similar to the findings of the above studies, in that caregivers of CWD who enjoyed satisfactory marriages found pleasure in raising their child with disability, since they felt supported. According to Duvdevany and Abboud (2003), social support can reduce parenting stress and increase the wellbeing of mothers raising a child with an intellectual disability. Added to this, Sipal and Sayin (2013) found that social support lowered depression and contributed to positive parenting among caregivers of deaf children, while lack of support among caregivers of children with cerebral palsy was associated with a high rate of depression. Caregivers of children with autism linked social support to reduced depression and an increased sense of wellbeing.

In terms of support systems, services and resources are limited for CWD and caregivers of CWD. However, support systems also have individual or personal aspects, with many caregivers finding ways to view their situation positively. In a study conducted in the US on the benefits and burdens of mothers caring for a CWD, Green (2013) found that maternal care and responses were different. Some caregivers felt that having a CWD provided them companionship as they stayed with them in the house and helped them to become more organised with daily tasks. On the other hand, Green (2013) referred to studies that suggested that parents who hold positive attitudes towards raising a child with a disability may be

‘pathologised’ as being unrealistic and being unable to accept their ‘tragic’ situations. In these cases, positive caregiver responses were interpreted as a denial of the child’s disability. Although this is a fairly old study, it has relevance to this research, as it reports on how caregivers coped with their situation.

Overall, support systems in various forms constitute an important requirement in the care of CWD. In South Africa, interventions are required to ensure that the rights of CWD are upheld.

2.3 Theoretical framework

This section outlines the theoretical frameworks, showing their relevance to the study.

2.3.1 Systems Theory

In social work, the development of appropriate intervention strategies for a client requires consideration of the individual in relation to a larger social context. The principles and concepts derived from Systems Theory provide a framework for such assessment and intervention (Friedman & Allen, 2014). Systems Theory is a way of elaborating on complex systems across a continuum that encompasses the person-in-environment (Anderson, Carter & Lowe, 1999). Systems Theory allows one to understand the components and dynamics of client systems to gain an understanding of the client’s problems, and to develop balanced interventions and strategies with the goal of enhancing how the individual fits into their environment (Anderson, Carter & Lowe, 1999). In the context of families, it functions as an organising conceptual framework or metatheory for understanding family functioning (Friedman & Allen, 2014). Goldstein et al (1990) indicate that although social work as a profession has struggled to identify an organising framework for practice that describes the nature of what social workers do, most researchers identify Systems Theory as a viable organising framework.

Bertalanffy is one of the pioneers of Systems Theory. His work introduces Systems Theory as a framework that looks at organisms and social entities through relationships and interactions with other systems, as a mechanism of growth and change. Using this perspective, people change the way they look at families, communities, companies and other social entities, and begin to speak about and view systems, with a basic assumption that ‘the whole is more than the sum of its parts’ (Robbins, Chatterjee & Canda, 2006). Systems Theory furthermore looks at basic concepts that profoundly rely on a linear cause and effect to elaborate on the growth

and change in living organisms. These properties depend on two aspects; the interactions between parts and the conditions that govern the relationships between them.

This study aimed to explore the experiences of caregivers of CWD, examining various individual, family and social dimensions of this phenomenon. The researcher believed that Systems Theory was best suited to assessing these dimensions and their relationships as a whole, which prevented a too narrow focus on the caregiver alone. Systems Theory is recognised as a suitable framework in the social work profession as a method of understanding interactions among components of a larger organism (Walker, 2019). In this study, Systems Theory yielded an understanding of the family and social interactions of the person caring for the child with a disability. The theory provides a clear indication of the impact of disability on family functioning, shedding light on how complex and interrelated the individual, family, community and wider social, political and economic systems affects the other.

2.3.2 Object Relations Theory

Object Relations Theory is an established theory that was developed by Winnicott (1965) to explain the nature of the bond between a mother and her infant child. Winnicott believed that an infant does not exist in isolation but only in relation to their bond with their mother. He argued that the emergence of the infant's psyche and personality is a mutual process that is influenced by the person caring for the child, especially the mother, and does not develop as an independent process (Winnicott, 1965). In reviewing this theory, Modell (1985) states that Winnicott believed that the infant and mother together form an inseparable unity and that therefore the infant's development and sense of self is inextricably tied to the biological, physiological, emotional and social support provided by its mother. Winnicott's theory is apt in this study, as the theory focuses on the parent-infant relationship, particularly the mother (Modell, 1985), who forms part of the object of study in this research.

The theory has a number of components, but the concept of interest in this study is the notion of the 'good enough mother' (Winnicott, 1953:586). A mother who can meet the needs of her infant is believed by Winnicott to be the 'good enough' mother. The good enough mother begins with an almost complete adaptation to the needs of the infant and provides ongoing care according to the infant's growing abilities, which facilitates the ability of the child to face life's challenges at later stages of life (Winnicott, 1953).

Thus, the ‘good enough’ maternal environment occurs when a mother is attuned to the needs of the child. A good enough mother is one who can attend to the infant’s needs before they demand it, such as breastfeeding the infant to facilitate a moment of pleasure referred to as ‘illusion’. According to Winnicott (1953) illusion goes some way to explaining the parent-infant relationship. Illusions are those moments where the good enough mother takes their baby to the most blissful world, where every need is satisfied, because she is ‘in love’ with her infant (Modell, 1985:104). Furthermore, Winnicott communicates that a good enough mother provides support to strengthen the infant’s immature ego. She is a mother who provides satisfactory care, creating a total environment where the infant feels loved, an environment that the mother has accomplished known as a ‘holding environment’ (Modell, 1985:105). A good enough mother in a holding environment promotes her infant’s development, allowing them to become persons by developing the inner self that connects them with reality and the outside world in a way that distinguishes the self and non-self.

Object Relations Theory helps the researcher to understand the role of the primary caregiver in raising a CWD, and their relationship during the various developmental stages of the child. In explaining object relations, Michael (2000) states that the first object a person encounters is usually an internalised image of the mother, father or primary caregiver.

The framework was deployed in this study to shed light on the personal, emotional experiences of caregivers raising children with disabilities, and to explore the maternal care of caregivers from a clinical perspective. While cognisant of the reality of South African society, the aim was to use this theory and critically assess its suitability for this context. It was envisaged that some challenges might be encountered in its use, such as whether or not it could explain the relationship between a couple and their child, or a father and their child, or any other family setup that might pertain in a child’s life. However, it turned out that in this study, all the primary caregivers were the biological mothers of the CWD. This meant that the framework was directly applicable to the context.

2.4 Policy and legislation

This section examines policies and legislation on disability relevant to this research. These include the Constitution of the Republic of South Africa, 1996, the White Paper on the Rights of Persons with Disabilities, The United Nations Convention on the Rights of Persons with Disabilities, and the Social Assistance Act of 2004.

2.4.1 Constitution of the Republic of South Africa, 1996

In the Constitution, the Bill of Rights, Section 9 states

Everyone is equal before the law and has the right to equal protection and benefit of the law. Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken (The Constitution of the Republic of South Africa, 1996).

Section 8 c (2) of the Disability Services Act states that the purpose of personal assistance is to assist a person with a ‘severe’ disability to make his or her own choices in everyday activities, work and studies, hobbies, social participation and social interaction.

The Constitution is a core document that informs or guides all policies and legislation in South Africa, including on disability; legislation on children with disabilities and their caregivers has to align with the principles of the Bill of Rights, which forms part of the Constitution. The South African Constitution is expressed in several national policies and legislation that aim to promote and support the complete equalisation of opportunities of persons with disabilities and their integration into society, using the social model and human rights policy framework (Constitution of the Republic of South Africa, 1996). The Constitution ensures that persons with disabilities are not discriminated against, neglected or marginalised as in the past. It encourages the building of an inclusive society which respects the human rights and dignity of all citizens, including those with disabilities. It further aims to provide children with disability with fairness, and the ability to give expression to their rights as they are entitled to an equal opportunity in life.

In a report released by the South African Government in 2013 entitled ‘Treat our disabled people with dignity’, the government emphasised the need to remove obstacles such as poor access to facilities, poor education, lack of transport, lack of funding and the unavailability of equipment for children with disabilities. The Constitution is the founding document for all attempts to ensure that every South African with disability enjoys a life without discrimination and is treated as an equal citizen.

2.4.2 The White Paper on Human Rights of Persons with Disability (2016)

The WPRPD (2016) was developed over a period of time in consultation with organisations of and for persons with disabilities, government departments, municipalities, public entities, the private sector and civil society at large, as well as the South African Human Rights Commission (SAHRC). The WPRPD is built on nine pillars: removing barriers to access and participation; protecting the rights of persons at risk of compounded marginalisation; supporting sustainable integrated community life; promoting and supporting the empowerment of children women, youth and persons with disabilities; reducing economic vulnerability and releasing human capital; strengthening the representative voice of persons with disabilities; building a disability equitable state machinery; promoting international co-operation; and monitoring and evaluation. The WPRPD promotes ‘a free and just society inclusive of all persons with disabilities as equal citizens’, and shows that all policies and legislation, across all spheres of government and in every socio-economic sector, affect the lives of persons with disabilities.

In South Africa children with disabilities and their caregivers are entitled to social protection through a government grant. The government also makes provision for a care dependency grant for primary carers of a children requiring permanent care or support services owing to mental or physical disability (Social Assistance Act, 2004). According to the United Nations Research Institute for Social Development (UNRISD, 2010) Social protection is concerned with preventing, managing, and overcoming situations that badly affect people’s overall well-being. Whilst care dependency grant is defined as social grant intended to provide support to caregivers of child with severe mental health and or disabilities (DSD,2019).

The WPRPD (2016) indicated that in 2015, an estimated 127 139 children with disabilities received care dependency grants and 115 256 social grant beneficiaries accessed grants-in-aid. For a caregiver to qualify for the care dependency grant, they need to be in a certain income group. The CWD must undergo medical assessments and be able to provide proof of disability when applying for the grant (Republic of South Africa, 2004).

2.4.3 The United Nations Convention on the Rights of Persons with Disabilities, 2007

The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) states that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.

This policy guarantees persons with disabilities their political rights, supports opportunities for them to exercise this right on an equal basis with others, and ensures that persons with disabilities can fully participate in political and public life. This policy is an important part of empowering persons with disability to participate as citizens and as community members. As a signatory to the Convention, South Africa has to uphold the rights of persons with disabilities.

2.5 Conclusion

This chapter has discussed the literature relevant to the topic of this study. It introduced Systems Theory and Object Relations Theory as the theoretical frameworks used in this study, both of which help explain the caregiver experience of caring for a biological child with a disability. The chapter has further discussed legislation and policies pertaining to CWD and their caregivers, including the Constitution of the Republic of South Africa, 1996, the White Paper on the Human Rights of Persons with Disability, and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2007).

The following chapter discusses the research methodology used in the study.

CHAPTER 3: METHODOLOGY

3.1 Introduction

A research methodology is the process and approach taken to conduct a research study. It includes the assumptions, principles, and procedures used in an enquiry. In deciding on the most suitable methodology to adopt, a researcher should think about the kinds of problems that are worth investigating, what constitutes a researchable problem, how to frame the problem in such a way that it may be investigated using designs and procedures, and how to select and develop appropriate means of collecting data. These are all integral to a research methodology (Schwardt et al. 2007:195). As a strategy of enquiry that provides a set of procedures and a framework for research, it consists of methods used to acquire and analyse data to create knowledge (Petty et al, 2012).

This chapter covers the research design and methodology used in the study. It outlines the population and sampling and discusses the data collection approach, tools and analysis. In addition, the chapter reviews the data verification and trustworthiness of the study. An overview of the study's limitations concludes the chapter.

3.2 Research design

Durrheim (2004:29) describes a research design as a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research strategy. In qualitative research, researchers collect and analyse data in a non-numerical manner to better understand the experiences, concepts and opinions of subjects. This kind of study is used to gather in-depth insight into a problem and/or generate new ideas for study (Bhandari, 2020).

This study used a qualitative research design, which was explorative and descriptive in nature, seeking to explore, understand and describe the experiences of caregivers raising children with disabilities. Data was collected by conducting interviews with the caregivers of CWD, with the aim of understanding their experiences. According to De Vos et al. (2011:95-96), the aim of exploratory research is to gain insight into a phenomenon, situation, community or individual. Descriptive research, in turn, may be described as intensive analysis of phenomenon to gain a comprehensive understanding of it (Rubin & Babbie, 2005:125).

An explorative and descriptive approach was used to examine the challenges of caring for CWD. A qualitative research design was suitable for this study, as it allowed the researcher to gain an in-depth understanding of the experiences of caregivers of CWD and increase insights into the human condition, which is one of the core objectives of qualitative research (Bhandari, 2020). In addition, where limited information exists on a topic, a qualitative research method is suitable for forming new insights about it (Bhandari, 2020).

This study made use of the exploratory research method to allow the researcher to acquire a deep and broad understanding of the problem being researched (George, 2021). This type of study design is used when the researcher has no past data or few research papers to reference. An exploratory research design is ideal to use when one is conducting a study of a problem that has not been clearly defined. Through exploratory research, a researcher may gain a better understanding of the problem without having to provide conclusive evidence; it enables the researcher to make future recommendations as part of the solution to the problem being researched (Saunders, Lewis & Thornhill, 2012).

Exploratory research is further recognised as being low in cost while providing the researcher with flexibility and adaptability to change (George, 2021). This approach was suitable as the nature of the research was exploratory; the researcher had no pre-conceived ideas of what she would find and was interested in hearing about the experiences of caregivers raising a child with disability from their point of view. The design gave the researcher flexibility in her interactions with participants during data collection.

To understand the meaning that caregivers gave to their experiences, the study made use of a phenomenological approach. Phenomenology is an approach used in qualitative research where the focus is the commonality of lived experiences of members of a particular group. Through a phenomenological approach, the researcher seeks to construct the universal meaning of the event, situation or experience and arrive at a more profound understanding of the phenomenon. This approach was suited to this study as the focus was the lived experiences of caregivers of children with disabilities; the researcher was interested in hearing about the experience from the point of view of the participants, as expressed in their own words (Cresswell & Poth, 2018). The approach further allowed the researcher to construct the universal meaning of the participants' experiences, leading to deeper understanding of their day-to-day challenges as they raise children with disabilities.

3.3 Population and sampling

Babbie (2013: 134) describes a population as ‘the theoretically specified aggregation of the elements in a study’. In other words, the population refers to individuals who possess the characteristics that are important to the focus of a study, and sets the boundaries from which the participants may be drawn (Fritz & Morgan, 2012). The population for this study was primary caregivers of CWD in Cape Town.

The sample was a smaller group selected from the population; namely caregivers of CWD selected from two townships in Cape Town, Khayelitsha and Gugulethu. A total number of twenty participants, lived in various parts of these townships, with their housing including shacks in informal settlements, and government subsidised Reconstructions and Development Planning (RDP) houses. These are provided in impoverished areas in the country as part of the government’s post-apartheid social welfare transformation agenda.

Taking into consideration the aims of the study, purposeful sampling was selected as the most suitable technique to secure study participants. Purposive sampling allows the researcher to select the participants they are looking for in terms of the specific characteristics the researcher desires (Kogan et al, 2011). This technique is widely used in qualitative research for the identification and selection of information-rich cases related to the interest of the researcher. It enables the most effective use of limited resources (Palinkas et al, 2015). Purposive sampling involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest (Cresswell & Plano Clark, 2011). In addition, Bernard (2015) states that the importance of availability and willingness of participation, and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner, are important consideration when selecting the sample.

To access the sample, the researcher contacted the Early Childhood Development Centre that offers services to children with disabilities in Gugulethu and Khayelitsha, to get referrals to caregivers who would be suitable for the study. The researcher knew the organisation as she had previously worked there as a social worker, focussing on interventions in the context of disability. Once the referrals were received, the researcher contacted the caregivers to introduce herself and the purpose of the call, and thereafter made arrangements to conduct the interviews.

The sample criteria included the following: In terms of location, participants had to be from Gugulethu or Khayelitsha. The sample excluded caregivers caring for an adult with a disability, which was any person above 18 years of age living with a disability, as the study’s focus was

on caring for CWD. It also excluded any caregivers who were not related to the child, such as neighbours. In terms of inclusion, it included primary caregivers of the CWD either being biological parent of the CWD or caregiver living in the same house of CWD. During the data collection, all participants interviewed happened to be biological mothers of the child with the disability. The total number of participants was twenty.

3.4 Data collection

Qualitative data collection is a systematic process of gathering information in research. It might include observations or interaction with participants involved in the study. The collection process allows the researcher to gain first-hand knowledge and form original insights into problems being researched (Bhandari, 2020). Qualitative data collection makes use of different non-numeric methods to collect data, such as observations and interviews. Interviews are considered a good instrument for exploring the views, experiences, beliefs and motivations of participants on a specific topic (Bhandari, 2020). In addition, interviews in qualitative studies are believed to provide researchers with a deeper understanding of the problem being researched, through the sharing of experiences (Bhandari, 2020).

For this study, data collection was done by means of semi-structured telephonic interviews. Due to pandemic (covid-19), researcher was prohibited from conducted face-to-face interviews, thus interviews where telephonic A semi-structured interview schedule was prepared, which the researcher used as a guideline, without limiting the participants from expanding on certain topics (see appendix b). The interviews were recorded with the consent of the participants. The researcher then transcribed the interviews, which were translated from IsiXhosa to English as the interviews were recorded in the mother tongue of the participants. The use of the mother tongue was a distinct advantage in the study as allowed the participants to express themselves and convey their feeling and views in depth, enabling a deeper level of engagement by both participants and researchers.

3.5 Data analysis

According to Babbie and Monton (2010:378), qualitative data analysis is non-numerical analysis. It provides interpretations of observations to discover underlying meanings and patterns of relationships. Qualitative data analysis is the range of processes and procedure whereby researchers move from the qualitative data that has been collected into forms of explanation, understanding or interpretation of the participants and situations being researched. To analyse the data, the researcher made use of thematic analysis as formulated by Braun and Clarke (2015). Thematic analysis is defined by Braun and Clarke (2015) as a process of

identifying patterns or themes within qualitative data. This method incorporates seven steps: transcription, reading and familiarisation, coding, searching for themes, reviewing themes, defining and naming themes, and finalising the themes, fleshing them out in a meaningful way (Braun & Clarke, 2006). The researcher made use of thematic analysis as it is seen by Braun and Clarke (2006) as a technique that allows the researcher to employ a variety of theoretical vantage points that may be used to highlight and compare similarities across data; it also does not constrain findings to a set framework and can therefore be used to find unexpected results, which may be useful for informing policy development.

In applying thematic data analysis to the data, the researcher followed the steps of Braun and Clarke (2006). This involved becoming familiar with the data by reading the transcripts, all of which were translated from IsiXhosa to English, reading each one several times. After multiple readings of the transcripts, the researcher started applying the initial coding process. This was done by looking at each transcript individually and highlighting information that emerged repeatedly. This information was grouped and colour coded. Once grouping of the information was completed the researcher cross-checked the information by reviewing each transcript to look for similar topics across them all, and creating themes. Through ongoing coding, the researcher formulated themes, going through each interview script, and reviewing the themes using different colours and making notes to link units of information. As a last step, the researcher defined and named themes, which formed the basis of writing up the analysis.

3.6 Data verification

Data verification is a process of confirming that the data that has been collected is valid (Babbie & Mouton, 2001). For this study, data verification aligns with the requirements of qualitative research. De Vos et al (2011) state that there are five key criteria to be considered when establishing the truthfulness of a qualitative research project. These are credibility and authenticity, transferability, dependability, and conformability.

3.6.1 Credibility and authenticity

Credibility refers to the manner in which the data was gathered and reported on (Babbie & Mouton, 2001). For a study to have credibility, the researcher needs to ensure that the data is an accurate representation of what the participants actually said. According to De Vos (2011), the main goal of establishing credibility and authenticity in a research study is to ensure that the participants have been accurately identified, described and quoted. To ensure the credibility and authenticity of this research project, the researcher recorded the interviews and transcribed

them verbatim. Once transcription was done, the researcher further did member checking by giving participants a copy of the transcripts to confirm whether the information on the transcript was an accurate reflection of what they had shared during interviews.

According to Lincoln and Guba (2017), member checking in qualitative research allows for the establishment of credibility and trustworthiness. Accuracy and honesty in findings are ensured by member checking. In addition to checking the transcriptions, the participants were informed that the study will be shared in the university library research papers, researcher will be able to access them for academic purposes.

3.6.2 Transferability

De Vos et al (2011:420) state that to assess the quality of a research study, the researcher needs to ask whether the findings could be transferred from one specific situation to another situation. In qualitative research, the degree to which the results may be transferred to other contexts or settings is not determined by the researcher conducting the study but by the reader (Korstjens & Moser, 2017). The researcher can strengthen transferability by providing a clear description of the research context and the assumptions of the research study. Any researcher interested in transferring the findings of the study to a different context is therefore responsible for making the judgment of how sensible the transfer is (Coghlan & Brydon-Miller, 2014). This study provides insights into the experiences of caregivers of CWD in a certain context, which are not generalisable to all caregivers.

3.6.3 Dependability

De Vos et al (2011:420) state that for a researcher to ensure dependability they must assess whether the research process was logical, well documented and audited. In order to address the dependability issue more directly, the processes in the study should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results. For this study, all information, including transcripts and research fieldnotes, was systematically documented, and all processes were recorded to maintain an audit trail. The researcher documented all the information on a Google drive that could only be assessed by her and her supervisor to ensure the safety of the information.

3.6.4 Confirmability

According to De Vos (2011:346), confirmability in qualitative research is the degree to which study results can be confirmed by other researchers. This criterion ensures that the data and interpretations of the findings are not figments of the enquirer's imagination, but clearly

derived from the data (Moser & Korstjens, 2017). Confirmability ensures an accurate qualitative study by ensuring that the researcher understands the phenomenon from the point of view of the research participants (Given, 2012). Confirmability may also be seen as the degree to which the findings of the study are based on the research purpose and not influenced by researcher bias (Moser & Korstjens, 2017). To ensure confirmability, the researcher conducted a literature review of other studies on similar topics. In doing this, the researcher gained knowledge on topics related to this study. The researcher conducted the study with no preconceived ideas of the results and allowed the research process to unfold without directing it according to fixed ideas of what the outcomes would be.

3.7 Limitations of the study

The limitations of a study are the characteristics of the design or methodology that in some way limit the impact of the study or the analysis. They can further be seen as constraints on the ability to generalise the results of the findings and the challenges that emerged during the study (James & Murnan, 2020). The research sample size for this study was limited to twenty participants. Although not a significant limitation, because rich data was obtained in the study, the low number does restrict the applicability of the findings in terms of general caregiver experiences of caring for CWD. However, to overcome the limitation of a fairly low number of participants, the data was collected from different townships, where participants may have had different experiences in terms of the environment and available resources. The study focused on only one racial group, whereas the inclusion of other racial groups might have added value to the findings. Lastly, the process of the research was affected by the Covid-19 pandemic in South Africa. Instead of conducting in-person interviews, the researcher had to conduct telephonic interviews. This limited interactions, since non-verbal communication could not be engaged in, and the establishment of rapport became a little more difficult, though not impossible.

3.8 Reflexivity

Reflexivity is the process in which a researcher examines their own judgement, practices and beliefs system during the data collection process. The main goal of reflexivity is to allow the researcher to identify any personal beliefs that have the potential of affecting the research study, through questioning their own assumptions (Wilkinson, 2015). According to Braun and Clarke (2019), reflexivity is a means by which a researcher ensures rigour and quality in the study,

helping to ensure that the data is trustworthy. In my experience of working in the field of disability as a social worker, the need for caregivers to share their experiences is very apparent. I have an interest in this field and believe that research in it will enrich my practice as a social worker. From interacting with caregivers and conducting home visits, I learned that the majority of caregivers are unemployed and regard themselves as fulltime caregivers to their children with disabilities. Through my interactions with them, I realised that they have a need to share experiences because of the many challenges they face. I came to realise that there is great shortage of social workers who are able to offer services to families of CWD. My passion for the field has mainly been influenced by the amount of gratitude shown by the caregivers of CWD as I worked with them in the field offering psychosocial support. This was critical in my decision to undertake this study, which could promote intervention and support for caregivers of CWD, improving their lives and that of the children they care for.

3.9 Conclusion

This chapter has discussed the methodology used for this study. It discussed the research design, population and sampling, data collection, research instrument, data analysis and verification, possible limitations, and reflexivity. Each aspect was defined and discussed in terms of its relevance and application to the study.

The following chapter presents the empirical findings of the research based on an analysis of the data.

CHAPTER FOUR

RESEARCH FINDINGS

4.1 Introduction

This chapter presents the research findings to answer the main research question, which is, ‘What are the experiences of caregivers raising children with disabilities?’ To contextualise the findings, participants profiles showing participants’ and CWDs’ biographical and demographic information are presented in Table 4.1. An area profile is included in the discussion to highlight the nature of the living spaces of the participants. Table 4.2 shows the framework for analysis, indicating the four themes that emerged, along with their sub-themes, each of which is presented and discussed in turn. Findings are discussed in light of the literature and in light of the two theories that guide this study, Systems Theory and Object Relations Theory. The presentation of the findings includes direct quotes from participants, to ensure the credibility of the research.

4.2 Participants’ profiles

The participants in this research were all the biological mothers of the CWD. Table 4.2 on the following page presents their profiles, along with details of the children that participants were caring for. This profile provides context to the circumstances and experiences of the participants and helps to create an understanding of the participants themselves.

Table 4.1: Participants' profiles

| Participants | Caregiver | | | Gender of CWD | Age | Child | |
|---------------------|-----------------------|---------------------------|--------------------------|----------------------|------------|---|-------------------------------------|
| | Marital status | Place of residence | Employment status | | | Disability type | Attending day-care or school |
| Participant 1 | Single | Khayelitsha | Unemployed | female | 11 | Cerebral Palsy | Yes |
| Participant 2 | Widow | Gugulethu | Unemployed | male | 7 | Cerebral Palsy | No |
| Participant 3 | Single | Gugulethu | Unemployed | female | 6 | Intellectual disability | Yes |
| Participant 4 | Single | Khayelitsha | Unemployed | male | 8 | Macrocephaly | Yes |
| Participant 5 | Single | Gugulethu | Unemployed | female | 7 | Autism | No |
| Participant 6 | Single | Gugulethu | Employed | female | 4 | Cerebral Palsy | No |
| Participant 7 | Single | Gugulethu | Unemployed | female | 12 | Cerebral Palsy | Yes |
| Participant 8 | Single | Khayelitsha | Unemployed | male | 12 | Cerebral Palsy | No |
| Participant 9 | Married | Khayelitsha | Employed | female | 16 | Intellectual disability | Yes |
| Participant 10 | Single | Khayelitsha | Unemployed | female | 6 | Autism | No |
| Participant 11 | Married | Khayelitsha | Unemployed | female | 6 | Autism | No |
| Participant 12 | Single | Gugulethu | Unemployed | female | 7 | Cerebral Palsy | Yes |
| Participant 13 | Single | Khayelitsha | Unemployed | female | 14 | Cerebral Palsy | Yes |
| Participant 14 | Single | Khayelitsha | Unemployed | female | 16 | Intellectual disability | Yes |
| Participant 15 | Single | Khayelitsha | Unemployed | female | 17 | Intellectual disability and schizophrenia | No |
| Participant 16 | Single | Gugulethu | Unemployed | female | 13 | Cerebral Palsy | Yes |
| Participant 17 | Single | Khayelitsha | Unemployed | male | 8 | Cerebral Palsy | Yes |
| Participant 18 | Single | Gugulethu | Unemployed | male | 10 | Cerebral Palsy | Yes |
| Participant 19 | Single | Khayelitsha | Employed | female | 12 | Intellectual disability | Yes |
| Participant 20 | Widow | Thambo Gugulethu | Pensioner | female | 14 | Intellectual disability and schizophrenia | No |

The participants in this study were all the biological mothers of the CWD. Among the twenty participants, two were married, two were widowed and sixteen were single parents with no relationship to the father of the child. Thus, the majority of the participants were single parents who cared for their child by themselves. The table shows that only three participants were employed, while 17 were fully dependent on the child disability grant they received.

The participants were all from Khayelitsha and Gugulethu townships in Cape Town, which are disadvantaged black communities created during the apartheid era and beset by numerous social problems. Eleven participants were from Khayelitsha, nine from Gugulethu. In Khayelitsha, only one participant lived in a brick house; the rest lived in informal settlements made up of shack dwellings. In Gugulethu, two lived in brick houses subsidised by the government commonly known as RDP houses, four lived in back yards in a small room with their immediate family and three lived in shack dwellings in an informal settlement.

The CWD ranged from six to sixteen years in age, and presented with different disabilities, as shown in Table 4.1 above. Nine had been diagnosed with cerebral palsy (CP). Cerebral palsy is defined by the Oxford Dictionary (2022) as a group of movement disorders that appear in early childhood. The signs and symptoms are said to be different, but common indications are stiff muscles, weak muscles and tremors. One of the common causes of CP is abnormal development or damage to parts of the brain that occurs during pregnancy or shortly after birth.

Six children presented with intellectual disability (ID). According to the WHO (2021), intellectual disability refers to significantly reduced ability to understand new or complex information or challenges with learning and applying new skills. Three children presented with autism. According to Donohue (2019), this is a developmental disorder with symptoms that appear within the first three years of life. Its formal diagnostic name is autism spectrum disorder, with the word spectrum used to indicate that autism appears in different forms with varying levels of severity. That means that each individual with autism experiences their own unique strengths, symptoms and challenges. One child was diagnosed with macrocephaly. According to Gabbey (2018), macrocephaly refers to a condition in which a child has an overly large head. It is a symptom of complications or conditions in the brain. At times macrocephaly is a symptom of other conditions, and it can also be genetic. Of the twenty children, one had hearing loss, also known as deafness. According to Centers for Disease Control and Prevention (CDC, 2021), hearing loss in children has different sign and symptoms. It can appear at any stage of development, when some part of the ear is not working in the normal way. This may

include a malfunction in the outer ear, middle ear, inner ear, acoustic nerve or in the entire auditory system.

The WHO (2021) states that disability is not fully dependent on the child's health condition or impairments; environmental factors are also important to the child's ability to participate in life. In total, 12 of the 20 children were attending some form of schooling, and the rest were not. During discussions with the participants, various reasons were given for the non-attendance of some; these are discussed in the findings section below under themes. Participants explained that the schooling their children received was different from that provided in mainstream schools; these were 'special schools' that catered for children with disabilities. Schooling hours differed, with some children attending a full day of school and some half day, depending on the needs of the parent. The single parents in this study confirmed that the school system was their support system and that most attended school full days.

4.3 Area profile

Khayelitsha is the second biggest black township in South Africa after Soweto in Johannesburg (Smith et al, 1999). A nine-year-old report by Sefali and Staff (2013) states that Khayelitsha comprises at least 22 separate informal settlements that together make up the largest single concentration of informal settlements in the city. The majority are located on land that is unsuitable for housing because of flooding. There is a rapid growth in shack numbers, with approximately 10 000 new people joining the township per annum.

Access to services is poor in the area. According to statistics provided by the City of Cape Town in 2014 (O'Regan & Pikoli, 2014), access to sanitation, water and electricity is one of the biggest challenges in Khayelitsha. Furthermore, there is a high unemployment rate and little economic activity, with many people relying on social services for their income. Access to health services is another challenge, as Khayelitsha has only one hospital (Khayelitsha Day Hospital, also known as KDH) to serve the whole of Khayelitsha. Added to these circumstances are constant land invasions, which in the context of limited land have placed pressure on existing infrastructure (O'Regan & Pikoli, 2014).

Gugulethu shares similar challenges to Khayelitsha, although in terms of resources Gugulethu tends to do a lot better than Khayelitsha. It is one of the oldest townships in Cape Town, and most of it has access to sanitation and water, in both its formal and informal sections. Gugulethu has been described as a combination of vibrant life, poverty, disease and violence with a population of both blacks and coloureds, although the majority are isiXhosa-speaking blacks

(Sikhulasonke, 2001). Motyka (2016) stated that although political violence decreased after apartheid ended, townships like Gugulethu continue to be dangerous places for health and safety, as a result of poverty and unemployment. In total, 40% of the population has a total household monthly income of R3200 or less. High unemployment raises the rate of poverty and crime in this township.

A study conducted by Scheffler et al. (2015) on the impact of healthcare services in the Western Cape showed that people with disabilities who live within 3 km of healthcare facilities had their medications delivered to their homes, while the rest walk to healthcare facilities. Having access to healthcare close to one's home makes an enormous difference for those who are lucky enough to have facilities close by, reducing the burden felt by most. In 2012, three provincial government clinics were built in Khayelitsha and allocated to different sections of the township. There are also a number of small municipal clinics dotted throughout the township. They are recognised as important service as they provide primary healthcare by providing services to children, women, men and youth (Scheffler et al, 2015).

Table 4.2 below presents the themes uncovered during interviews with the participants, which became the framework for analysis of the data. The themes, sub-themes and their characteristics are shown, all of which relate closely to the research objectives. The key findings are discussed below the table, based on this framework of analysis. Each theme with its sub-themes and characteristics is discussed and supported with direct quotes from the interviews that were conducted with the participants.

Table 4.2: Framework of analysis

| Theme | Sub-themes | Characteristics |
|--|--|---|
| 1. Caregivers' understanding of disability | <ul style="list-style-type: none"> • Medical causes • Religious and spiritual causes | <ul style="list-style-type: none"> • Public hospital negligence • Ordained by God as part of personal journey or punishment for past sins. |
| 2. Challenges of caregivers | <ul style="list-style-type: none"> • Balancing social life and parenting • Family challenges | <ul style="list-style-type: none"> • Limited free time to no time to socialise • Family members struggle to adapt and adjust to child with disability • Discrimination from community members. |
| 3. Family functioning | <ul style="list-style-type: none"> • Family and emotional support | <ul style="list-style-type: none"> • Different levels of family support • Religion and spirituality as a coping mechanism |

| | | |
|--|---|---|
| | <ul style="list-style-type: none"> • Religion and spiritual support | |
| 4. Support and services for caregivers of CWD. | <ul style="list-style-type: none"> • Social security • Psychosocial support • Lack of financial security | <ul style="list-style-type: none"> • Poor intervention by DSD social workers. • Longing for parent support groups. • Caregiver unemployment and financial constraints. |

4.4. Themes that emerged from findings

Four themes emerged from the interviews. These are: Caregivers' understanding of disability; challenges of caregivers; family functioning; and support and services for caregivers of CWD.

4.4.1 Theme 1: Caregiver understanding of disability

In describing their understanding of their child's disability, the participants mentioned both medical and religious or spiritual causes of the condition. The main cause of disability appeared to be public hospital negligence during labour. Almost all participants confirmed to have experienced public hospital negligence either during pregnancy or whilst giving birth. From a religious perspective, some saw the disability of their child as a punishment from God and a result of past sins.

Medical causes

All the participants expressed dissatisfaction about their labour experiences in public hospitals. The shared experience of negligence from the nurses in public hospitals was most mentioned as the cause of their child's disability. Most said that they had had long labours which were linked to a loss of oxygen to the child at the time of delivery, resulting in the child's disability. Participant 8 shared that the community clinic that she attended knew her health history, and that when she had been transferred to a public hospital for check-ups during her pregnancy, the hospital did not take her health history into consideration. This, she felt, contributed to the negligence that caused her child's condition.

The one thing I am not happy about or rather was not happy about, the hospital knew my health history as I previously had miscarriage so they were supposed to give me attention for my check-ups. Instead of giving me check-ups on monthly basis, they will wait for the month end and that for me did not make sense. Because one of the reasons the clinic transferred me to hospital is because they knew I am at risk and the hospital should have taken that into consideration. But you know how it is with public hospitals. I mean in this case when they notice that my child did not have enough oxygen, no

action was taken immediately, and I still believe that if they took my situation into consideration, then my child would not be disabled (Participant 8).

Similar experiences were related by Participants 6 and 11. They explained that having experienced a long labour process, they were told soon after delivery that their child had been affected by loss of oxygen.

Mm ... I do not know what I can say, I do not understand her disability. Firstly, I noticed that she has a problem, like during her developmental stages. I noticed that she was not developing according to her age. At six months she was still not able to sit or do anything according to her stage of development, so I took her to the hospital for check-up ... That's only time they ran all the medical tests and scans to check if she was 'normal'. Part of me, I blame the hospital for her disability, and part of me I don't because she was a premature child. For example, why I blame the hospital: After I gave birth, I remember going to the bathroom and coming back - remember she was premature therefore she was supposed to be in an incubator - so I came back, and she was not. That gets to me to think that what if she needed to be in the incubator immediately, yet she was not? On the other hand, I am also thinking that she could have developed this even during pregnancy, so it's a lot to think about. So, I really do not know what could have been the cause of her disability (Participant 6).

When the doctors explained the reason why he lives with autism, is because he has a scar on the brain and that might have happened when I was giving birth, during delivering him, when he did not get enough oxygen (Participant 11).

From the participants' understanding of medical causes of disability, there was plenty of speculation but no certainty on the extent to which hospital neglect was to be blamed. What did seem clear is that hospital staff were sending mothers away with no definitive answers and certainly no admission of guilt. The explanations given seem to have been vague and inconclusive, leaving these mothers more or less in the dark about the cause of their children's conditions. However, from the participants statements, it was evident that they felt that poor hospital services were responsible, mostly in the form of negligence during delivery

Religious and spiritual explanations

The participants grappled with issue of ultimate causes, with many alluding to the spiritual realm to help explain the situation in which they found themselves. It seemed that a spiritual or religious understanding helped these women reach a place of acceptance of their lot. Some

viewed it as a punishment for sin while some accepted their circumstances as a spiritual journey that they had been entrusted with by God.

Participants 1 and 3 viewed their experience as punishment for their sins, while Participants 5 and 6 viewed their experience as a gift given to them by God and chose to embrace this understanding without questioning too much.

You know, Sisi, I am sure God is punishing me for all the bad things I may have done. Like, I do not understand why me, and why he will allow my child to be like this. I am paying for my own sins through this child (Participant 1).

I truly believe that I am chosen to have a child like this because of my past and God is punishing me with him ... [participant starts crying] (Participant 3).

Honestly, I do not have any support; I have accepted that I must raise my child and accept the type of life God has given and not blame him for it, because I believe he knows why he chose me, so I am fine (Participant 6).

For me, I will say it's to understand that nothing is by mistake. God has a plan for everything he does, so even with this, I often told myself that he knows exactly why, and he has reasons for doing what he did, so I am good with it (Participant 5).

4.4.2 Theme 2: Challenges of caregivers

Three main challenges discussed during the interviews were lack of balance between caring for their child and being able to engage in social activities; challenges with family adaptability to living with a CWD in the home; and community attitudes.

Balancing parenting and social life

When participants were asked about their daily functioning as parents with CWDs, all expressed difficulty in raising a CWD, and an inability to find balance between their caregiving, their personal needs and their social needs. Participants shared that they did not have time for themselves, as they always had to attend to the needs of their child. Participant 6, a teenage mother, stated that it was difficult for her to socialise as a working mother, and that her life revolved around work and her child. As a result, she had no free time for social activities. She stated:

I do not take care of myself, I just get up and go to work ... I really do not know what to do anymore, like I do not know what is there, so I do not really take care of myself, honestly (Participant 6).

Other participants also indicated that they did not have a social life as they had to prioritise the needs of their CWD. Participant 16 shared the personal struggle of not being able to allocate time for her other children, as she always had to be present for her CWD. As a result, she often

felt that she was neglecting her other children. In this instance the lack of balance in the family context was evident.

I don't feel so good, as I cannot provide for my other children. For example, I am unable to plan for other things. I also have other children that I need to take care of, but his condition does not allow me to do that (Participant 16).

Family adaptability and adjustment

It was evident that extended families struggled to adapt to the presence of the CWD and that this caused stress and a sense of isolation to the participants, on top of their already high burden of care.

Sisi, you know, I used to get along with my family until I had this child. My family started asking me to leave him behind when I attend family rituals and ceremonies.

Interviewer: *Why do you think this is?*

It can only be one thing they do not want my child around and my child is part of me, so I had to choose my child over them (Participant 3).

So, we are originally from the Eastern Cape. Our family, we will often all go home during December holidays and spend time as a family, so I will take my child with me but I noticed that my family members will ask me to stay in a separate room, especially when these family gatherings ... [cries] ... I mean, Sisi, that is painful for me. I think they are ashamed of my child (Participant 4).

Community challenges

Added to the realities of caring for a child with a disability, the participants shared that they also had to cope with the negative comments and attitudes of their communities. They perceived their communities as unsafe for families of CWDs, as they felt that community members victimise caregivers of CWD, putting their lives at risk. Participant 6 shared that she was robbed and stabbed in front of her children in her home, as the community thought that she had money because she has a child with disability. She explained that community members assumed that any person raising a child with disability has money because of the social grant they receive. She expressed her fear of dying and felt mistreated by people in her community. She explained her traumatic experience:

They make me feel really hurt because people think I have money. They even rob me. For example, I was stabbed inside my house. Gangsters came in whilst I was sleeping

to rob my house, looking for money. They stabbed me in front of my children, so its things like that I am really hurt (Participant 6).

Participant 4 likewise struggled to express the nature of the treatment she received from the community in terms of exclusion, but it was clearly distressing:

The are many experiences I can share, and they are all painful ... I often feel like people take advantage of me because I have a child with disability. There is a funny way ... I am really struggling to describe how people treat me. They often think that I have a lot of money because I get disability grant (Participant 4).

Participant 9 further shared that her daughter was sexually abused by a boy from her community, and that she received no support from community members, so feared leaving the house, as she no longer trusted anyone.

So, one of the boys in the street used to abuse her sexually and emotionally, on the days maybe when we not home, he will come to the house and have sexual intercourse with her and threaten her not to tell. So, this went on until the day he come to our house and we were here. He threatened her not to say anything, she started crying, pointing at her private parts. That's how we knew (Participant 9).

The experiences shared by the caregivers of CWD provide clear evidence of their daily struggle as they raised their CWD. The caregivers spent most of their time attending to the needs of their child. They felt isolated and alone, and shared negative experiences in their communities which affected their trust in the people they lived amongst. They had few social connections. Interestingly, two participants who confirmed that they did not receive any money from their family members shared how fearful they were living in their communities. The perception that they had money clearly contributed to their vulnerability. Their daily functioning was affected by different challenges and stressful circumstances, which made it difficult for them to be at ease whilst parenting a CWD.

4.4.3 Theme 3: How caregivers cope with challenges

When participants were asked about coping skills, the main points came up were family and emotional support, and the importance of spiritual support as a way of coping.

Family and emotional support

Experiences of family support were both positive and negative. Most said that they did not have family support. They spoke of the disappointment they felt in the lack of family support, which seemed to drop markedly after the birth of their child. One participant explained her disappointment, saying that her family wanted money from her when she asked for assistance. Her family, she felt, was trying to use her for financial gain. She explained that after giving birth, she went to Eastern Cape with her child. When the child was about three months old, she left the child in the Eastern Cape with her sister, as she had to return to work.

Sisi, [crying] my family, before I had my child, they use to come to my house and now they do not. This started when my child was staying in Eastern Cape and they were continuously asking me for money. I will send and send, and realised that they were not even using the money for his needs, and that brought a lot of differences, in so much that I ended up taking my child (Participant 8).

Another participant expressed that she was left alone and often felt that she did not even have a family anymore.

I am sure my family cursed me the day I brought this child home. I feel I have always been alone, ever since this child was born. Sometimes I even forget that I have a family (Participant 19).

When the participants were asked about their experiences of family adjustment as an aspect of raising a child with disability, they spoke at length about family exclusion. Some families would take advantage of their situation, using them for money and insisting on payment for any help rendered. In addition, they spoke about families being unable to adjust and being embarrassed about the child.

This was the experience of Participant 1.

I know that my family feels embarrassed to have my child around. At first it used to get to me, but now I made peace. So, they do not invite me to family gatherings and I don't bother to ask them, because I know (Participant 1).

Participants 4 and 6 related similar experiences.

No, Sisi, I do not have any support; I am by myself with my children (Participant 4).

I do not know how I cope. I really do not know how I do it. I have been alone and having to go through everything I went through with her, all alone. Like going to hospitals and

so on ... have made me realise that I am alone and just have to do what I have to do (Participant 6).

In contrast to the negative experiences that formed the majority, two participants had supportive families who even assisted in the practical tasks of caregiving. These were the two married participants, Participants 9 and 11. Family support in this study therefore correlated well with the presence of a nuclear family, in which family members shared one another's burdens. Participants 9 and 11 shared that they received a lot of support from their partners and other children. They further shared that this involvement from the family allowed them to treat their CWD as part of the family, with the CWD able to carry out small household chores and to participate in games with other children. Participant 9 further shared that her mother-in-law was always present and offered support when she needed help. This can be viewed in light of the value of a functioning family, and how, according to Systems Theory, the family hugely affects the individual's outlook and quality of life.

I will not lie, my family has been very supportive. Yes, at the beginning they felt sorry for me, but after seeing how I am taking care of her, they slowly began to be OK and accepting of the situation. Like they will often tell me that they admire the way I handled the situation (Participant 9).

She also stated:

My mother-in-law has always been supportive. Like when I was working, she used to help me by taking care of her, even though when we have a disagreement, she will refuse to assist (Participant 9).

Participant 11 shared similar sentiments:

So, I stay with my extended family in the house. It's my husband, his two siblings and his cousin. So how we do things, I have included her in household chores like others, even though she will not always do it. But she knows that she has household chores. So that is what we practise, and it helps to make her feel included like other children in the house (Participant 11).

She indicated further:

I get help at home by his father, my brother and my niece, so I don't really feel overwhelmed (Participant 11).

Religious and spiritual support

While the participants experienced many challenges with their families and living circumstances, they found ways of coping and accepting their situation. Here religion and

spirituality played an important role, helping the participants adapt and deal with the challenges they faced. In the absence of family support and in the face of many other challenges, religious values and spirituality were an important source of strength for the participants. Most expressed their reliance on God for support. Some viewed their circumstances of having to raise a CWD as a gift from God. Participant 12 shared that she had accepted the life God had given her, while Participant 5 had a similar view, stating that that she understood that God had a reason for choosing her to be a parent to a CWD.

Honestly, I do not have any support; I have accepted that I must raise my child and accept the type of life God has given and not blame him for it, because I believe he knows why he chose me, so I am fine (Participant 6).

For me I will say it's to understand that nothing is by mistake. God has a plan for everything he does, so even with this, I often told myself that he knows exactly why, and he has reasons for doing what he did. so, I am good with it (Participant 5).

Family functioning as a theme for caregivers of CWD was associated with the many challenges participants experienced as a result of not having family support. In these conditions, participants felt that family support was something that they lacked, and that they were forced to cope with their challenges alone. Notwithstanding their circumstances, participants shared positive feelings of accepting their child's disability, without glossing over the challenges that came with it. Most found meaning in religious ideas about God and his plan for their lives, which evidently imparted a sense of peace and acceptance. Their faith gave them a sense that there was something bigger at work in their lives, helping them to see a deeper meaning in their circumstances.

What was remarkable was the positive way in which some participants were able to view their circumstances. Participant 8 went as far as to say that her child had become her 'parent', steering her away from trouble and making her more responsible and self-disciplined. Her child had changed how she viewed life:

The one thing I would say from raising a child like this is that he has thought me discipline and self-respect. Like, I am home most of the time and that has isolated me from a lot of troubles. I was even saying that this morning. To have a child with disability has really helped me. Most of the people I grew up with are no more because they had a lot of free time and used in a bad ways. So, I will say this child is more like a parent to me. He has thought me how to be grounded and to be responsible (Participant 8).

Similarly, Participant 1 viewed her child as a safeguard against getting involved in detrimental social activities. She explained that some of her peers had died as a result of having an intense social life that involved substance abuse. For her, having a CWD removed her from engaging in social activities which she regarded as unsafe. She added that her CWD had changed her life for the better and she could not imagine life without him.

Yes, Sisi, it's not easy to raise a child with a disability but the one thing I have learned, to appreciate my child, as she has changed my life for the better. Like I know I have to be home certain times, so I am excluded from troubles in public (Participant 1).

Interesting, even though all caregivers acknowledged the difficulties of raising a child with disabilities, most expressed a great love and affection for their child and spoke of not being able to live without them. The responses of participants showed that positive aspects prevailed amongst the negative aspects. All affirmed their role as mother, responsible for caring for their child regardless of the challenges they faced. This notion can be seen in the sacrifices mothers were willing to make to for their children. 4.4.4 Theme 4: Support and services for caregivers of CWD

During the interviews, caregivers shared their experiences of accessing social security services, providing insights into the needs of caregivers as they raise CWD. Three experiences were emphasised. These were related to social security support services, the desire for psychosocial support, and lack of financial security.

Social work services

Social security forms a very important part of the lives of caregivers of CWD, as they rely on grants and welfare services to ensure the wellbeing of their CWD. Within this theme, several challenges with public services were shared by caregivers. Caregivers expressed concerns about the low level of assistance provided by social workers from the Department of Social Development. Some expressed disappointment in the way social workers would promise to do assessment visits but never show up. Participant 9 shared that when her child was sexually assaulted, the Department of Social Development promised her that a social worker would be allocated to provide counselling to her and her child, but this never materialised:

Social workers promised to come and never did, so I will say she was never helped, and the perpetrator was released from the prison (Participant 9).

Participant 10 also shared that when she requested counselling as she was struggling to accept the condition of her child, a DSD social worker promised a home visit but never showed up. She stated:

Yhoo, no, we do not have anyone other than ourselves. I will say I counsel myself by accepting her condition daily (Participant 10).

In similar vein, Participant 20 shared that she was let down by a social worker when she was looking for a place of safety for her child. She shared that she was promised a home visit and assistance by the social worker, but when she contacted the office, she was informed that the social worker was no longer employed at that office. She explained:

For me because I am alone, and at that time I was working, I wanted a facility where I will know my child is taken care of and is in a safe place ... but yhoo, Sisi, it was a struggle. I ended up giving up on that option, because the social worker who promised to help me never showed up, and when I called her office I honestly did not get any help as I was told that she is not working there anymore. None of the other social workers were willing to assist me, so I just gave up (Participant 20).

Participant 6 shared that when she was robbed and stabbed by gangsters in her house, she also reported the case to both DSD and the police as she was fearful of a repeat incident. She, too, was promised trauma counselling by DSD, and she waited for a social worker until she gave up.

After the robbery I was so scared, I couldn't sleep at night and my children were also scared. I guess we were all traumatised and worried if they will come back again. I went to report the case to street committees and to DSD, also to police, hoping I will get some form of protection. However, only street committee responded by calling a community meeting to address the matter. However, DSD social workers never came, Sisi (Participant 6).

The desire for psychosocial support

As they reflected on these experiences, the caregivers of CWD shared that they would appreciate more emotional support, because they dealt with many challenges on a day-to-day basis that took their toll emotionally. Some mentioned that they used to benefit from hospital support groups when they attended check-up visits; however, because of Covid-19, the support groups had stopped. Some mentioned that it would be beneficial to hear the experiences of other caregivers who were in similar situations, and that they would value learning how others

coped with the challenges they faced. Two participants were eloquent in their expression of this need. Participant 18 said that she had no one to speak to and sometimes felt lonely and confused, especially when her child was not well.

You know, Sisi, sometimes you just want to be around people who understand what you are going through. I think if I had to be with others parents who have the same challenges, I believe I will be encouraged, you know (Participant 18).

Similar feelings were shared by Participant 16. She explained that she often did not know how to express herself when people were asking her questions, and she believed that by hearing from other mothers she would learn a lot.

For me, Sisi, sometimes I get stuck when people ask me questions about my child. Sometimes I feel so frustrated about explaining to them. So being around other mothers who have disabled children will definitely help me to see that I am not the only one with this problem (Participant 16).

Lack of financial security

Caregivers of CWD spoke about the financial difficulties they experienced since most were unemployed and unable to seek work. Of the 20 participants, only three were employed. All relied on the disability grant, which is not sufficient, especially since the majority of participants were single parents with other children. When asked about their sources of income, the participants noted that they were unemployed for various reasons. The participants were not aware of an additional caregiver's grant that is available for caregivers of persons with disability. When asked about the caregiver's grant, all confirmed that they did not receive the caregiver's grant and seemed not to understand what it was.

Participants of the children with CP indicated that they needed to spend more on their child, as some could eat only soft food and some were still in nappies. Participant 6 shared that her child liked to play outdoors with other children, but could not walk; at the same time, she disliked using a wheelchair. Since she had to crawl, her trousers were always torn and her mother had to spend more money on clothes, as she felt she could not prevent her child from playing.

I am spending a lot, Sisi, like, I have to buy clothes every month because she hates the wheelchair and like I said, she crawls. So, it's like we either have to let her crawl or put her on our lap. It's like she has not accepted her condition, and she's a very strong child with a strong personality. If she wants something, she wants it, and if she does not get it she will throw tantrums and even hit herself on the floor (Participant 6).

Participant 8 likewise shared that her child with severe cerebral palsy could not eat solid food and was still in nappies, so she had to provide both food for the house and for him and ensure that she had enough nappies each week. According to her, he used at least 12 nappies a week in what she described as a good week, which was when there were no tummy reactions.

Yho, Sisi, a disabled child is expensive, I tell you. With him, I am spending more because even though he is 12 years, he's still like a baby, like he still eats soft food like porridge, yogurt and well-cooked veggies. So, I have to make sure he has his food all the time. On top of that he still wears a nappy and nappies for adults are expensive. So, it's just a lot of money, Sisi (Participant 8).

From the interviews, in respect of financial needs, it is evident that more awareness about social welfare grants needed to be shared with caregivers, since none knew of a very basic grant that was available to them on top of the disability grant. They also need to be made aware of free services available to them at local clinics, such as free nappies given out to persons in need. As a social worker who has an experience with working with CWD, the researcher can verify this information, which is also outlined in the WPRPD (2016) policy for person with disabilities.

4.5 Discussion

Caregivers of CWD face many challenges in providing care for their children. These include personal, family and community challenges. The following discussion examines these challenges in light of the findings by other researchers and with reference to the two theories that guided this study, System Theory and Winicott's Object Relations Theory.

According to studies conducted by Aldersey (2012), Aldersey et al (2016) and McKenzie and McConkey (2016) on the views, perceptions, support needed and quality of care provided by caregivers caring for persons with intellectual disabilities in Africa, the majority of caregivers are women. This findings was confirmed in the current study.

The current study further reveals that caregivers received very little support from their family members, communities and agencies tasked with providing support services to caregivers of CWD. This finding aligns with that of the above studies.

Participants in the current study mentioned family adjustment as one of the factors contributing to lack of family support. Different aspects of this lack of adjustment were mentioned; families being embarrassed by CWD during family gatherings, and family members using the caregivers for self-gain, insisting on being paid for any help given. The non-caring and

rejecting attitude of extended family members served to reinforce the burden of care for caregivers. These findings align with the findings in the studies listed above, where caregivers confirmed that they cared for their loved ones with intellectual disability in isolation (Aldersey, 2012; Aldersey et al, 2016; McKenzie & McConkey, 2016).

This lack of family support contributed to the caregivers' increasing sense of isolation from the world, an isolation that was evidently exacerbated during the Covid-9 pandemic. Because their children's needs were almost all-consuming, the participants in the current study spent very little time outside of the home. Some felt that this worked to their advantage, keeping them out of trouble and increasing their sense of responsibility and self-discipline. At the same time, it led to an acute sense of loneliness. The high level of emotions that spilled over in the telephonic interviews reveals the lack of support that these women felt.

Many other studies confirm that caregivers are less likely to participate in social activities than parents of children without disabilities, and have a high chance of experiencing financial difficulties, leading to a poor quality of life (Seltzer et al, 2001; Hirschi et al, 2019; Whiting, 2014). Studies also suggest that disability can have a huge impact on family functioning, affecting various aspects of the family, including the relationship between the child's mother and her husband, with divorce more likely between parents of a CWD than among other parents (Seltzer et al, 2001; Hirschi et al, 2019; Whiting, 2014). In expanding on the difficulties of raising a CWD, Ajuwon and Brown (2012) state that these challenges increased the burden of care, leading to compromises in quality of life for caregivers of disabled persons.

Interestingly, the caregivers shared that while they lacked family support, they were not without inner resources, with most drawing on religion and spirituality as a way of coping with their circumstances. Masuku and Khoza-Shangase (2018) studied spirituality as a coping mechanism among caregivers of persons with aphasia in Tembisa, a disadvantaged community in Gauteng. The study made use of qualitative research and a sample of 14 family caregivers of person with aphasia. When the participants were asked about how they coped, they spoke of being guided by a higher power as they played the role of carer. Some viewed church as their main source of support and encouragement. They spoke of their reliance on prayer as their source of hope, strength and healing power, saying that prayer was their way of communicating with God and/or ancestors.

These findings contrast with the views of Muller-Kluits (2017), who reported a similarly spiritual interpretation of their predicament among caregivers, but of a more negative slant.

The participants in Muller-Kluits' (2017) study expressed guilt and self-blame for the diagnosis, linking it to their belief system in that they felt they were being punished and paying for their sins.

In the current study, religion was used in both ways; some saw their situation as punishment from God, while being able, simultaneously, to draw on religious beliefs to find strength and comfort. A deep sense of acceptance of their situations seemed to be the main benefit of their religious faith.

In systematic reviews conducted Zuurmond et al (2015) examining families impacted by disability in low- and middle-income countries, participants spoke of stigmatisation and discrimination against children with disabilities. This discrimination seemed to affect families' ability to access formal services in health and education. Community participation was also very limited. Similar findings were found in the current study, with participants reporting fear of their communities as result of false perceptions that they had money and were therefore easy prey. All participants spoke of community discrimination and stigma, with two mentioning community violence and sexual assault of the CWD.

Participants raised the issue of being socially excluded, mentioning challenges related to infrastructure, including lack of access to public transport, where they had to pay extra for the wheelchair or where public transport simply did not stop for them, as they were regarded as 'time consuming'. These findings are similar to those of Mkabile and Swartz (2020). Their study was conducted in Khayelitsha on caregivers of children with intellectual disability. The study made use of a qualitative research design using individual interviews. Similar experiences of discrimination and stigma were reported in that study, with CWD even subject to name calling and victimisation by community members. The findings of Mkabile and Swartz (2020) further confirm the challenge of abuse experienced by CWD, both physically and sexually, along with an inability to participate in community activities because of attitudes towards them. The researcher found these findings interesting as they were conducted in one of the areas in which the current study was conducted. Drawing from both these studies, it is evident that caregivers of persons with disability from low-income countries battle with community discrimination and stigma. As result of community discrimination and stigma, they find it difficult to raise their CWD, as they have to continuously find ways of coping with all the social and emotional pressures they experience on a day-to-day basis.

A report written by Dr ZSC Skweyiya, Minister of Social Development, entitled ‘Social relief of distress only for people in dire need’ (DSD, 2009), states that the main challenges that continue to exclude persons with disabilities from mainstream society are community prejudice and social stigma, isolation, and lack of access to support networks. Other challenges include lack of resources for an independent daily existence, lack of access to infrastructure, services, communication, transport, opportunities, resources and education. Access to these basic human rights would allow them independence and promote their sense of dignity, self-sufficiency and responsibility. Women and children are regarded as the most vulnerable to discrimination and abuse, and encounter barriers to participation in society. The results of the current study prove the truth of the report, as this isolation and stigma were reported over and over again in some detail by all 20 participants.

As indicated above, Muller-Kluits (2017) confirmed that some caregivers expressed feelings of guilt, self-blame and of being punished by God for past sins. Thus, their child was seen as an added burden, in the sense that the child was identified as their punishment. These themes were evident in the current study, in relation to how caregivers understood their child’s disabilities. In the study by Mkabile and Swarts (2020), caregivers likewise believed that they were either bewitched or that their ancestors were not happy with something in the family and were punishing them in the form of the CWD. While these studies revealed a sense of self-blame and guilt, the opposite interpretation of spiritual beliefs was also evident; some caregivers showed no indication of feeling guilty for the disability, and instead expressed disappointment at the standard of care that they had received at public hospitals. They saw their situation positively, believing that they had been chosen to take a special road in life and that their CWD was a special gift from God.

In a study conducted by Bowser and Hill (2010), abuse of patients by healthcare staff in maternity settings was referred to as a global challenge both in high- and low-income countries, with negligence being one of the challenges experienced by patients. Added to this, the World Health Organisation stated in 2014 that the problem of disrespect and abuse of women during facility-based childbirth is a global phenomenon requiring urgent attention. Looking at the information shared by the participants during interviews, it is evident that the public hospitals act as contributing factors to the conditions of CWD. When it came to causes, many believed that it was negligence at hospital that caused their child’s condition.

Looking at the challenges of services for caregivers of CWD, it is clear that a lack of social services was the main challenge. Participants shared their great disappointment at the lack of

social work intervention, particularly from the Department of Social Development which failed to deliver the expected and promised services to them as caregivers of CWD.

These findings draw attention to the statement made in South African White Paper on the Rights of Persons with Disability (WPRPD, 2015). The White Paper calls for government, civil society and the private sector to work together to ensure the socio-economic inclusion of persons with disabilities. According to WPRPD (2015), the government seeks to create a caring and inclusive society that develops and protects the human potential of its children, creating a society where persons with disability, including children, enjoy their rights as fellow citizens, and where all citizens and institutions share equal responsibility for building a just and prosperous society.

While the WPRPD (2015) mentions the challenges and recognises the need to address them, caregivers of CWD continue to live with the burden of limited services from government departments. Most of the recommendations of the WPRPD remain a pipe dream to them. A research study conducted by Mdlankomo et al (2017) showed that there were several serious constraints in providing services for people living with disabilities, which included inadequate knowledge and skills on how to take care of people living with disabilities, and inadequate funds to support them. However, Govender (2015) argued that the role of social workers in the Department of Social Development is under-estimated, as the mandated functions are a huge responsibility. Most social workers do not have the expertise to execute supervision and assessments, because of minimal resources and a lack of expert training (Ross&Ncube2018). In examining both the findings of this study and the literature, it becomes evident that the tasks of social workers in disability are constrained by multiple challenges, and hence the experience of disappointment and lack of support mentioned by caregivers of CWD in this study. In view of this, the World Health Organisation (WHO, 2014) recommends that community services be established and expanded as a way of providing support to families of children with disabilities, in order to enhance family members' health and wellbeing. Overall, the above insights highlight the experiences of caregivers and the circumstances that needs to be addressed for change to be affected in their lives.

Systems Theory provides a framework for understanding the experiences of the participants in the context of their family, community and larger society, including the welfare system. Systems Theory views relationships and interactions in a family as parts of a whole, in which the whole is more than the sum of its parts (Robbins, Chatterjee & Canda, 2006). The findings

suggest that positive family relationships support caregivers with CWD, while a lack of family support negatively affects them. Participants who said that they had the support of their extended families expressed a sense of satisfaction with their situation. They were far better off emotionally than those who lacked this family support. They confirmed that family support and religious faith were their two most important strategies for coping.

Most participants felt disappointed in their families, whose perceived neglect and callousness exacerbated their sense of distress. Family support allows the parents of a child with disability to ‘find themselves’ in their role as caregivers. Family support serves as a community-based service, giving caregivers of CWD the strength to be attentive to the needs of the CWD. This naturally has a positive effect on the care that the CWD receives. A study conducted by Adithyan et al (2017) on children with intellectual disabilities also found that family services were the most integral component of the wellbeing of the child with intellectual disability.

Furthermore, participants who lack family support have been shown in this study to be at risk in their communities, partly because of the perception that they have money. As most were single mothers without family support, they were targets of violence and abuse in the community. These circumstances are complicated by the social environment in which the participants live. According to Tigere and Makhubela (2019), parents who are raising children with disabilities fight many battles while raising their children. Caregivers of children with disability lack support structures (Tigere & Makhubela, 2019). In addition, the social welfare system was found wanting in terms of the provision of support to caregivers. Grants were limited and social workers displayed poor if not unethical conduct to caregivers as clients. It is evident that coping with a CWD has many ramifications, and that the mothers bear the brunt of all the difficulties.

Anderson et al (1999) state that Systems Theory allows one to understand the components and dynamics of family systems, yielding an understanding of family functioning in relation to a problem and helping one see problems as an outcome of a malfunctioning system. Furthermore, Systems Theory helps one to introduce balanced interventions that address the entire system and not just one component of it, with the goal of enhancing the ‘goodness of fit’ between individuals and their environments.

With this in mind, it is evident that caregivers of CWD lack family support as their families struggled to develop strategies of coping with CWD, thus forcing the caregiver to raise the CWD in isolation. Systems Theory further points out the importance of systems operating

together to increase functionality within the system. In this study, the lack of synergy between the various systems in the lives of caregivers of CWD negatively affected them.

When considering the finding in terms of Winnicott's Object Relations Theory, a broad link in this regard may be made with the caregiver's acknowledgment of their difficulties while also affirming their love for their CWD (Anderson et al, 1999). This finding supports Winnicott's description of the maternal experience. It is evident that the participants, as biological mothers of CWD, developed attachments to their children; they moved beyond the challenges of raising the child with a disability, and expressed love and even a sense of divine purpose in their role as mothers to CWD. Thus, they fulfilled the role of 'the good enough mother'.

One of the caregivers shared that she did not trust other people to take good care of her child, and therefore she sacrificed working to look after her child. According to Winnicott, a mother is the one who creates a safe environment for herself and her child by being attuned to the needs of the child. Through this safe environment, the child begins to trust the world around them. On the basis of this theory, it is evident that the caregivers as biological mothers of the CWD had created the safest, most secure environment for their children that they could in the circumstances in which they lived. The fact that many expressed enjoyment in their role as caregivers supported Winnicott's Object Relations Theory, since they went beyond just accepted their maternal role and actually relished it.

4.6 Conclusion

This chapter has presented the research findings of the study. It provided a profile of the participants in tabular form and described the areas where they lived. It further provided a table showing the framework of the study, showing four themes, each with sub-themes, which were subsequently discussed in detail, using verbatim quotes to substantiate the findings. This was followed by a discussion of the findings in relation to the literature and the theoretical frameworks of analyses. The following chapter presents the conclusions of the study and makes recommendations relevant to caregivers with CWD.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter concludes this dissertation. It presents the conclusions of the study in relation to the research objectives and provides recommendations, including recommendations for further research.

The aim of the study was to explore the experiences of caregivers raising children with disabilities. To achieve the aim, the study explored the challenges experienced by caregivers while caring for a child with disability (CWD) and the effects of this full-time care on family functioning. The study also examined the nature of support received by caregivers caring for a CWD and assessed the services available to them.

The study was conducted in two townships, Gugulethu and Khayelitsha, based in the Western Cape. The participants were primary caregivers of the child with disability. The participants were selected using purposive sampling and the study was conducted using a qualitative research method. It made use of a phenomenological approach to explore the commonality of lived experiences of caregivers of CWD. This approach was best suited to the study as it allowed participants to share their lived experiences in their own words (Cresswell & Poth, 2018).

5.2 Summary of findings

The findings of the study are summarised according to objectives of the research.

Objective 1: To explore caregivers' understanding of the disability of their child

Caregivers perceived hospital negligence as being one of the main causes of their child's condition. Many had experienced long labours and difficult births, while not receiving the necessary level of care. In addition, at least one felt that her infant had not been properly incubated after birth. More than one referred to lack of oxygen available to the child during labour. Added to this, a few participants alluded to a lack of attention during routine antenatal check-ups, despite, in one case, the presence of a pre-existing condition which hospital staff

seemed unaware of. Caregivers who had this experience further expressed that they had not been given much information about the causes of their child's condition. Many showed little understanding of their child's diagnosis.

In addition to a basic understanding of the physical causes of their child's condition, many adopted a spiritual explanation, which helped give them a sense of the 'why' of their situation. Participants believed that one of the reasons for their child's condition was that the child and his or her condition were divinely ordained as part of their personal journey in life. One or two saw this as punishment, but most adopted a positive view in light of their sense of God's involvement in the situation. Because of this understanding, these participants made a conscious decision to accept the CWD and to embrace their circumstances as part of their own personal growth. They perceived their CWD to be a gift from God, since they were not like other children.

In sum, public hospital negligence was seen as the immediate cause, and divine ordination was seen as the deeper cause, or reason, for their having a CWD. Their framing of the situation as ultimately spiritual in nature imparted a sense of acceptance and peace, even enjoyment, about their situations.

Based on the findings about the participants' understanding of their CWD, it can be concluded that participants understood their circumstances as being due to poor medical services and neglect at public hospitals, as well as to religious and spiritual reasons which they accepted, regardless of whether they saw the matter as punishment or as a gift from God. This suggests that participants understood their circumstances as being beyond their control, and accepted the situation. The first objective of this study has therefore been met

Objective 2: To explore the challenges experienced by caregivers caring for CWD

Participants shared their daily challenges of raising a CWD. A prominent theme was the daily struggle of being in the sole caregiver which required focus and constant availability. They need to be extra vigilant as the children depended on them and had limited independent functioning. Owing to their children's extreme dependence, they struggled with balance in their personal lives and found social activities almost impossible to engage in. Most said they had no social life as they rarely left their homes. Since they had to be constantly present to their CWD, they did not have any free time for other engagements including romantic relationships

– a situation mentioned by many of the single mothers. On the other hand, participants who were married shared slightly different experience related to relationships. They said that they felt more supported and better able to meet the needs of their other children, and even to enjoy their relationship with their partners and friends.

Another challenge caregivers experienced was family adjustment to their circumstances and their CWD. Some of the participants indicated that extended family members did not accept their child and could not relate to the CWD. They experienced exclusion when it came to family gatherings and found themselves no longer invited to traditional events. Some spoke quite pitifully of their exclusion and the pain this caused them. They felt that their families were ashamed of the CWD and discriminated against them as result of having a CWD. However, caregivers who were married had a more positive experience of family adjustment. They experienced family adaptability as one of the things that made the parenting journey enjoyable. They confirmed that family support also helped the CWD to explore the world with a positive attitude and to feel more like other children.

Caregivers shared that physical vulnerability was a particular concern, as single parents raising a CWD. Their perceived lack of safety was one of their most pressings concerns. They spoke of being raided in their homes, of being stabbed in one instance, and of the constant sense of being discriminated against and disrespected in their communities. They were often discriminated against and ill-treated for having a CWD, a treatment linked to the stereotype that poorly educated people tend to hold of CWD. Community attitudes showed a lack of understanding and of compassion. Participants shared a sense of being in danger of violent attack and of not being safe in their own communities. These feelings were expressed both by single mothers and mothers in nuclear families. Community members perceived them as being unlucky to a certain extent and judged them harshly for giving birth to a CWD. Because of the discrimination, they felt unsafe and fearful of the people around them and felt that they did not have anyone to turn to when they were being mistreated by community members. This lack of understanding and active discrimination by community members exacerbated their sense of isolation and the burden of caring for their CWD.

Findings reflect that caregiver also found it financially challenging to raise a child with disability. Most were unemployed and received a grant. However, this was not sufficient to provide for the practical and material needs of a CWD, making care a daily struggle.

In respect of the challenges, it can be concluded that caregivers experienced multiple challenges, including personal, social and financial challenges, all of which affected their wellbeing and their child's wellbeing. Caregivers had limited support and faced community circumstances that created risks to their lives, including being exposed to violence. They lived in fear on a daily basis and felt unsafe in their communities. In addition, their lives were restricted to the care role, leading to a lack of balance between caring for the CWD and healthy social engagements. It is possible that the treatment of the community is linked to the perception that caregivers of CWD deliberately isolate themselves and want to be alone, which creates a sense of suspicion. However, the reality is that these women have to be available to their children almost all of the time and moving about the community with their CWD is difficult both practically and emotionally, in view of the stares and comments.

Objective 3: To examine how caring for a CWD affect caregivers' family life

This study revealed that lack of family support is one of the biggest problems facing caregivers of CWD and certainly a big contributing factor to their sense of isolation and burden. The impact of not having family support led to caregivers living in isolation and having limited time to partake in social and community life. The findings further revealed that caregivers who are also biological mothers of CWD mostly raise their children alone, without the help of fathers. Although the findings did not clearly state the reasons for a lack of commitment from fathers, abandonment and lack of care may be inferred from the findings, as none of the single parents mentioned support from the father of their child. Shame and discrimination were shown to be one of drivers of lack of family support. Looking at the findings, it is also evident that some families exclude caregivers of CWD from family functions and gatherings because of feelings of discomfort, embarrassment or shame associated with having a CWD in the family.

Given these conditions, the study concludes that caregivers have limited family support which affects them and their CWD negatively. There is a lack of understanding of the caregivers' circumstances and of disability in general that affects their intra-family relationships, especially in the case of single parents. In cases where participants were married, there seemed to be better family support from extended family, as they had a larger network of family that they could rely on.

Objective 4: To examine what support caregivers receive while carrying for CWD

This finding related to the objective of assessing welfare services available to caregivers of CWD. The findings show that the caregivers received very poor services from DSD social workers. Social workers are not able to deliver on their promises to caregivers of CWD and leave them hanging after the initial meeting, with promises of home visits never fulfilled. In addition, caregivers expressed a need for support groups, which they felt would be beneficial for their emotional support as they faced many challenges every day. Thus, having a space to share their experiences would be of benefit to them. Caregivers of CWD confirmed that they were unemployed and financially dependent on their children's disability grants as sources of income. Information on the caregiver's grant remained unclear, but it appeared that none of the caregivers were receiving this specific grant. Caregivers reported that taking care of a CWD was financially demanding, as some required special food, extra clothing because of their crawling rather than walking, or a constant supply of nappies, which are expensive. Financial constraints were therefore one of challenges experienced by caregivers of CWD. Many of the caregivers were dependent on the disability grant and had no extra income as they were unemployed and mostly living as the head of a single parent household.

It is evident from the findings that in addition to limited family support and community understanding of their circumstances, caregivers face further challenges related to the social welfare system. It may be concluded that current social work services in the areas of this study are not effective in supporting caregivers and their CWD. Caregivers are also unaware of some of the basic services available to them, besides the grant their child already received. There is a need, therefore, for greater awareness and education on disability and improvement in the services provided to caregivers and CWD.

5.3 Recommendations

Based on the empirical findings and the conclusions of the research, the following recommendations are made in respect of social welfare services, social work intervention, and future research.

While social welfare services are mandated by the government, they seem to be lacking when it comes to implementation, especially in the case of families caring for children with disabilities. The procedures and protocols for professional social workers were apparently not followed in the case of these caregivers, who lacked knowledge, support and adequate services.

Ensuring implementation of social welfare services by the government for families raising CWD would assist these families to access proper services. Added to the recommendations, training should be provided to all social workers of the Department of Social Development (DSD) and non-governmental organisations on matters relating to disability, and in particular, the needs of caregivers. Social workers should have the necessary skills on how to work with families of CWD. Through training, social workers would be better equipped on suitable interventions for the families of CWD. While student social workers are required to complete field practice as part of their curriculum, there is very little emphasis on equipping them to work with disability. Universities should include disability as part of the social work curriculum to prepare student social workers while they are still studying.

In South Africa, procedures and guidelines exist on paper; however, implementation of these is very limited. The government should consider procedural guidelines and a national plan to implement social work interventions for families of CWD. Non-government organisations should at the very least offer to organise and facilitate support groups for caregivers, and if possible, clinics and hospitals should be equipped with disability facilities, including day-care, for CWD. They would need to ensure that these services are known and promoted to the families of CWD, as caregivers need the services but are fairly cut off from normal social communication channels. They lack information. Community outreach programmes could also educate community members about the physical causes of disability and encourage the adoption of compassionate and respectful attitudes to CWD and their caregivers. The government could work closely with the NGOs in disability sector to facilitate these programmes and educate community members.

The study acknowledges that the sample used in this study was small and thus recommends that further studies with the more focus on caregivers of child with disability, be conducted with larger samples and in other areas.

5.4 Conclusion

This study aimed to explore the experiences of caregivers raising children with disabilities. The study was a comprehensive exploration of these experiences, examining all aspects of caring for a CWD, including its effect on family structures. The researcher spent time exploring the experiences of caregivers of CWD in Khayelitsha and Gugulethu townships in the Western

Cape. The study made use of qualitative research methods which were deemed best for eliciting the kind of in-depth, qualitative data that was sought. After the researcher had conducted interviews, data was analysed using thematic data analysis, and thereafter findings of the interviews were arranged in themes, presented and discussed. All four objectives of the study were met. The researcher acknowledges the disadvantages of a small sample, but nevertheless believes this sample was large enough to yield relevant and valuable data on the lived experiences of women caring for CWD. If the recommendations of this study were implemented, they would go some way to alleviating the hardships that carers of CWD experience in Cape Town's impoverished townships.

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APPENDIX A

Response letter of informed consent

Semi-structure interview question

Researcher: Busisiwe Hazel Kokolo

Cell: 0610420059

Email: busikokolo@gmail.com

Participant's name.....Date.....

INFORMED CONSENT

Title of the study: Exploring the experiences of caregivers raising a child with disability

1. Purpose of the study: The purpose of the study is to explore the experiences of caregivers raising a child with disability.
2. Procedures: Due to Covid-19, all the interviews will be done telephonically and the best time suitable to participants. The semi-structured interviews will focus on the questions related to experiences of caregivers and will take approximately one hour.
3. Risk and discomforts: This study is an investigation, not treatment, therefore there are no known anticipated risks or discomfort to be gained from my participation. If I or any participant experience fatigue or stress during the interview, I will be given as many breaks as may be required during the session.
4. Benefits: I understand that there are no known direct benefits for participating in this study. I am also made aware that the results of the study may help the researcher to gain better understanding of experiences of caregivers raising a child with disability.
5. Participant's rights: I am given right to withdraw from participating in the study at any time.
6. Financial compensation: Participation is voluntary. I will receive no financial compensation from the researcher for my participation in this study.
7. Confidentiality: I am being warned by the researcher of a tape recorder that will be used to record accurately all the information shared during the session. I am being assured that my response will be anonymous, my name and my child's name will not be used

or mentioned. The tape will be listened to only by the above-named researcher and authorized members of the research team. I understand that the obtained data will be kept confidential.

8. If I have any questions or concerns, I can call Busisiwe Kokolo at 061 462 7059 at any time during the day.

I understand my rights as a participant in this study and I voluntarily consent to participate in this study. I understand what the study is about, how, and why it is being done. I am aware that the data will be stored for fifteen years.

I will receive a signed copy of this consent for.

Signature of respondent

Signature of researcher

Date signed -----

APPENDIX B

Semi-structure interview questions

The goal of this study can be formulated as follows: **Exploring the experiences of caregivers raising children with disability in Gugulethu and Khayelitsha, Cape Town**

A) Demographic

- Name and surname
- Age of the child.....
- Type of disability
- Area living in.....
- Is the child attending ECD (YES/NO)? if so, where
- Are you receiving child disability grant

B) Caregivers understanding of the disability of the child they are carrying for

- Are you the biological parent of the child or primary caregiver?
- Can you tell me about your interaction with the child?
- What is your understanding of the disability of your child?
- Can you tell me about the cause of your child's disability?
- Is there anything you do not understand about disability your child has? If so what do you think will assist you to understand your child's disability better?
- Perception of caregivers on emotional and practical challenges experience
- What are some of the emotional challenges you have experienced / are experiencing in raising your child?
- What are some of the practical challenges you have experienced / are experiencing in raising your child?
- How do you cope with the challenges you are experiencing?
- What could help you to cope better with these challenges?

Caregivers perception on effects of family functioning of child with disability

- How could you describe your current family functioning?
- Does caring for a CWD, if at all, affect family functioning?
- What are the family challenges you experience? Are there any positive aspects from raising a child with disability, if so can you kindly share them?

Experiences of support system of caregivers CWD

- What type of support, if any, do you have whilst caring for your child?
- How has this support helped you to cope?
- How are you taking care of yourself, to ensure you can function daily?
- What do you consider your support system?
- How has this support system contributed to the wellbeing of you and your child?
- What is it like to live in your area while caring for a child with disabilities?

Services and resources available to caregivers of child with disability

- What services, if any, are available to caregivers of CWD?
- Is your child taking any chronic medication, if so, how do you receive medical assistance for your child?

APPENDIX C

Ethics approval letter

The study of this nature has been of benefit to this community as it provided the caregivers with an opportunity to share their experiences of caring for CWD, the participants during the interviews shared their gratitude of partaking in this study as it allowed them opportunity to speak to someone about their experiences.

Findings of this study will add value to future researcher who may be interested in disability. It will also add value to social work curriculum in higher academic institutions as tool they can use to enhance their skill, for social workers who have an interest in working with CWDs and their families.

The lack of relationships with their children's father adds on the burden of having to carry the challenges experienced in the community alone. Looking at the age of CWD presented on the table the youngest child being 6 years and the oldest being 16 years of age, where there is high need for attention of caregiver and relying on them for emotional support. Whilst the development stages for CWD may not be aligned with their development resulting from the disabilities living with, however caregivers are in position of providing intensive care. As many of them have communicated to be full time mothers for various reasons, some not having trust towards other people taking care of their CWD and others being unemployed and not affording to pay for day-care.

Data was obtained through telephonic semi-structured interviews; the method of data collection took into consideration pandemic (COVID-19) by avoiding face-to-face interaction. Participants' consents were maintained telephonically, and copies of consent forms made available to participants.