An exploration of the barriers and enablers that NGO service providers experienced in delivering community-based rehabilitation services to children with cerebral palsy in the Bitou local municipality, South Africa.

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A mini-thesis submitted in partial fulfilment of the requirements for the degree of Master of Public Health at the School of Public Health, Faculty of Community and Health Sciences, University of the Western Cape

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Keywords

- Barriers
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- Children
- Rehabilitation service delivery providers
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- Rural
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ABSTRACT

Presently, two main modalities of service delivery with regards to cerebral palsy rehabilitation exist in South Africa: institution-based and community-based rehabilitation. The Framework and Strategy on Disability and Rehabilitation that was published by the South African Department of Health in 2016 included Community-based Rehabilitation (CBR) as a key concept in future rehabilitation strategies. Yet, there is little documented evidence of the implementation of CBR projects and programme within South Africa. Members of the disability and rehabilitation community (working in both the public health service and NGO sectors) have insufficient insight and evidence as to what the obstacles and challenges are in providing CBR. This qualitative, explorative study seeks to explore the barriers and enablers that NPO service providers experienced in delivering community-based rehabilitation services to children with cerebral palsy in the Bitou Local Municipality, South Africa.

A sample of 12 service providers, namely 11 fieldworkers and 1 occupational therapist, out of the 20 community-based rehabilitation workers who are employed by the NGO, was obtained through purposive sampling. Semi-structured, in-person interviews were conducted with the participants and thematic coding analysis was utilised in the data analysis process. The University of the Western Cape's Biomedical Research and Ethics Committee reviewed the procedures of the proposed study and ethical clearance was obtained. Approval was granted by the organisation, where the research was conducted.

The researcher was guided by ethical principles throughout the research process, ensuring that participants were able to make informed decisions with regards to their voluntary participation in the study and that their anonymity and confidentiality was ensured. Participants were informed of their free will to halt participation in the study with no adverse effects to themselves, their colleagues or their employment. Any potential risks that involvement in the study would incur was also communicated to the participants. Safeguarding of all data collected throughout the study was ensured and implemented through electronic information and transcripts being kept on the researcher's own biometric access-controlled computer and any hard copies of transcripts and notes taken during the interviews, being kept in a locked cabinet that could only be accessed by the researcher. Both electronic and hard copy data will be stored for 5 years before being carefully disposed of.

On enquiry of the CBR workers understanding of CBR, it was found that they believed this strategy was defined by support for the communities that they worked in through provision of co-operation, empowerment and problem solving. It was believed that this was achieved through the development of a trusting relationship between themselves and the caregivers of children with cerebral palsy. The study revealed a number of barriers and enablers which community-based rehabilitation workers experienced whilst providing community-based rehabilitation services in local communities for a 5-month period in 2020. Some logistical challenges were described by the CBR workers as barriers to service provision specifically within a rural setting. It was not possible to develop a definitive list of what participants felt were the enablers to CBR or the barriers to CBR as the difficulties expressed by one CBR worker were sometimes noted by another to be an enabler that assisted them in providing CBR.

The recommendations that emerge from the study are intended to assist in formal training of CBR workers as well as to strengthen disability-awareness programmes. Further recommendations were made for the development of implementation guidelines for the conceptualisation and formalisation of CBR strategies in order to provide support for the country's 2030 national rehabilitation goals to be met.

DECLARATION

I declare that "An exploration of the barriers and enablers that NGO service providers experienced in delivering community-based rehabilitation services to children with cerebral palsy in the Bitou Local Municipality, South Africa." is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources of information and data I have used or quoted have been duly indicated and acknowledged by complete references.

Full Name: Leslie Ester Labuschagne

Signed:

Date: 10 November 2022

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ABREVIATIONS

CBR	Community-based rehabilitation
IBR	Institution-based rehabilitation
CBRW	Community-based rehabilitation worker
NGO	Non-governmental organisation
CP	Cerebral palsy
WHO	World health organisation

DEFINITION OF KEY TERMS

Community-based rehabilitation

This term refers to rehabilitation services that are provided by therapists[1] and assistants[2] to persons with disabilities within their communities, either at their home or within a community centre such as a community hall or mobile clinic (Dambi & Jelsma, 2014).

Institution-based rehabilitation

This term refers to the modality of health care service delivery where patients are required to visit district, provincial or tertiary health care facilities (Dambi & Jelsma, 2014).

Community-based rehabilitation worker

This term refers to rehabilitation personnel who are positioned within the home or communities that do not hold a bachelors degree, but render non-institution-based services which includes development within communities, under the guidance of rehabilitation professionals (Ned et al., 2020).

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

Childhood disabilities is the umbrella term used to describe certain conditions that affect neurological function, musculoskeletal components, genetic aspects as well as cognitive, behavioural and language disorders in children below the age of 18 years (Mathye & Eksteen, 2016). One such condition is known as cerebral palsy, being the most common paediatric neurological condition (Dambi & Jelsma, 2014). Cerebral palsy can be defined as "a group of disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain" (Dambi & Jelsma, 2014: 1471). Moderate to severe disability in children with cerebral palsy requires long term and costly medical and rehabilitative intervention due to the conditions chronic nature (Gorgon, 2018). Cerebral palsy has varied aetiologies, including intrapartum hypoxia, birth asphyxia, low birth weight, infections and neonatal seizures (Gladstone, 2010; Cooper, 2015) and pathologies such as HIV/Aids and malaria have been associated with a higher prevalence of cerebral palsy (Gladstone, 2010).

Cerebral palsy has a global prevalence of 2 to 2.5 per 1000 live births (Gladstone, 2010) and is estimated in South Africa to be between 2 to 10 per 1000 live births (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014) with a prevalence reported in rural Kwa-Zulu Natal to be as high as 10 in 1000 live births (Couper, 2002). The higher prevalence of Cerebral palsy in Africa - in comparison to high-income countries – has been documented by researchers such as Gladstone (2010) and Donald et al., (2014). In addition, a higher prevalence of more severe cerebral palsy has been documented in Africa (Kakooza-Mwesige et al., 2015). The latter has been thought to be the case due to poor access to health care and varied health care systems that result in children with milder forms of cerebral palsy either not accessing health care or not being documented correctly by personnel that are insufficiently trained in cerebral palsy identification and management (Kakooza-Mwesige et al., 2015; Donald et al., 2015).

Presently, two main modalities of service delivery with regards to cerebral palsy rehabilitation[3] exist in South Africa: institution-based (IB) and community-based rehabilitation (CBR) (Dambi & Jelsma, 2014). CBR refers to rehabilitation services that are provided by therapists[4] and assistants[5] to persons with disabilities within their communities, either at their home or within a community centre such as a community hall or mobile clinic (Dambi & Jelsma, 2014). CBR was founded upon the principles of the Declaration of Alma-Ata (Dambi & Jelsma, 2014) and later became an integral part of the formation of the global primary health care strategy by the World Health Organization (Dambi & Jelsma, 2014). It was conceptualized and integrated into public health strategies more than 30 years ago, yet remains a relatively under-researched modality of service delivery globally (Dambi & Jelsma, 2014). Even though CBR was included in the National Rehabilitation Policy of South Africa in 2000 (Department of Health, 2000) as an approach to re-orientate service delivery strategies, the preferred method of rehabilitation for children with cerebral palsy within the South African public health sector still remains institution-based.

Institution-based rehabilitation (IB) refers to the modality of health care service delivery where patients are required to visit district, provincial or tertiary health care facilities (Dambi & Jelsma, 2014). This institutional approach and the related treatment guidelines for children with cerebral palsy, having originated from high-income countries, have often proven to be inappropriate within the African context given the barriers some patients face (especially those living in remote settlements) in accessing health care institutions (Donald et al., 2015).

Importantly, some institutions, for example some district hospitals and non-governmental organisations (NGO), have implemented hybrid service delivery methods in South Africa, utilizing both IB and CBR in an effort to make rehabilitation more accessible (Finkenflügel et al., 2005).

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[3] Rehabilitation refers to the process where individuals with disabilities are enabled to reach their optimal level of functioning. In South Africa these services are provided in both the public and private health sector through physiotherapists, occupational therapists as well as speech and language pathologists.

[4] The term therapist in this content refers to Physiotherapists, Occupational therapists and Speech and Language pathologists.

[5] The term assistant in this context refers to individuals that assist physiotherapists, occupational therapists and speech and language pathologists in implementing therapy but have not received any formal training or have a professional qualification. Assistants are usually individuals who have previously been carers of people with disabilities within institutions or are community health care workers.

In South Africa, the COVID-19 pandemic, like elsewhere in the world, had a significant impact on the health services that could be provided to those living with disabilities, thus increasing the burden of disease (Ebrahim et al., 2020). In March 2020 a national state of disaster was declared in South Africa and over the next two years the country experienced a series of "lockdown" levels (1 – 5), which placed restrictions on, for example, those who could and could not work, the number of individuals allowed per m^2 within a building at any one time, as well as the mandatory wearing of face masks and social distancing between individuals. Understandably, those individuals working in the essential services, such as health professionals, were able to work during the higher levels of lockdown (e.g., levels 5 and 4) – when many others could not.

In mid-2020, when the country was in lockdown level 5 (May 2020 - September 2020) – a local NGO seeking to address barriers to inclusivity of children with disabilities within the Bitou Local Municipality and concerned about the COVID-19 health risks facing patients seeking rehabilitation-related care within facilities), acknowledging the CBR theoretical framework and working towards a shift from institution-based to home-based services, not necessarily fulfilling the 'gold standard' of CBR as embodying a community development strategy that is embedded within the community . This was sustained throughout level 4 of lockdown, but with easing of restrictions and children being allowed to return to school or similar institutions, the NGO reverted to a hybrid model of therapy, having both institution-based as well as community-based rehabilitation, which is still ongoing. Table 1. provides a description of the NGO's shift in service delivery.

Table: 1 The organisations shift in service provision towards embodying CBR practice.

Prior to 27th March 2020	**27th March – 30th April 2020 (Lockdown level 5)**	**May – September 2020**	**September 2020 – currently**
Provision of mostly institution-based rehabilitation with 1 x monthly home visit (a CBR strategy) for home programme implementation and	No service provision due to Covid-19 lockdown level 5	1 x weekly home visit implementation for individual therapy sessions, education and empowerment of caregivers.	Revert to mostly institution-based rehabilitation with 1x monthly home visit implementation.

BOX 1: A description of the local NGO that provided CBR and is a part of this study

The NGO being studied provides services to the Bitou Local Municipality, which includes the towns Plettenberg Bay, Keurboomstrand, Krantshoek, Kurland, Kwanokuthula, Nature's Valley and Wittedrift (Municipalities of South Africa, 2018). The NGO mainly serves the smaller/rural settlements within the municipal district namely Kwanokuthula, Krantshoek, Kurland, New Horizons and Bossiesgif. The NGO was established in 2004 and receives funding through both state funded enterprises such as the National Lottery Fund as well as private donations, fundraising and sponsorships.

The NGO, working from a base institution within New Horizons, serves children within the area and surrounds that have various disabilities, a large portion of these are children with cerebral palsy, and strives to promote inclusion within the education sector and society. The NGO employs 3 occupational therapists, 1 physiotherapist, 1 speech and language pathologist, 1 manager for the community-based rehabilitation workers, 15 classroom assistants and caregivers that together form the community-based rehabilitation workers team, all in varied capacities from part time to full time employment.

The NGO has, on average, 158 children that are being reached, with ages ranging from infant to18 years, with approximately 60 of these being children with cerebral palsy. These children are referred to the NGO by health care professionals within the surrounding communities, as well as community members such as teachers or parents.

The NGO sees the rehabilitation services that they provide to children with cerebral palsy as complementary and supplementary to what the public health service provides within the Bitou Local Municipality. This municipality is the smallest of seven municipalities that make up the Garden Route District Municipality within the Western Cape Province, South Africa. Bitou Local Municipality has a population size of 59 157 individuals that reside within the 8 towns included within its boundaries (Municipalities of South Africa, 2018). It is within this setting that this study was conducted.

1.2 Problem Statement

'The Framework and Strategy on Disability and Rehabilitation' that was published by the South African Department of Health in 2016 (Rule et al., 2019) included CBR as a key concept in the country's proposed rehabilitation strategies. However, there is little documented evidence of the implementation of CBR projects and programmes within South Africa (Rule et al., 2019).

The NGO mentioned previously (Box 1) is the only such institution to have provided community-based rehabilitation services within the Bitou Local Municipality. It did this for a five-month period in mid-2020 but soon reverted to providing predominantly institution-based rehabilitation services as the strictest COVID-19 restrictions were lifted.

Whilst aspects of their CBR approach still exist within the NGO practice today, (for example, every child client of theirs receives 1 CBR session per month) their experiences in part of the COVID-19 lockdown period, of implementing a more comprehensive CBR service delivery approach, provided a valuable opportunity for this researcher to explore what some of the obstacles and challenges were in providing CBR in the South African context – something which has been identified, as highlighted previously, as an information gap existing in South Africa. It is unclear why the organisation has reverted to predominant institution-based rehabilitation methods of service delivery.

1.3 Purpose of the Research

Using the NGO's practice of delivering CBR over a 5-month period (May 2020 - September 2020) in lockdown this study aims to explore what the implementing therapists and their assistants perceive to be as barriers and enablers in providing CBR to children with CP in a rural district. It is hoped that the results from this study will assist stakeholders working in the rehabilitation field within the Garden Route District Municipality, and districts like it in South Africa, with some insights as to how they can re-orientate rehabilitation services to incorporate more CBR strategies in the delivery of health services at a community-based level.

CHAPTER 2: LITERATURE REVIEW

This chapter will include a review of literature that is pertinent to the study topic. Literature on the impact of cerebral palsy within the South African context will be discussed, as well the priority care needs of children living with cerebral palsy, and the implications for service delivery and service providers within South Africa. Existing findings of service delivery methods - namely institution-based and community-based rehabilitation will be compared with further discussion on the challenges and enablers for the provision of community-based rehabilitation that have been noted in other studies.

2.1 Cerebral palsy in Sub Saharan Africa: the burden of disease

As described in the introductory chapter, cerebral palsy is the most common neurological condition amongst children not only resulting in movement disturbances but potential communication and perceptual fallouts, just to name a few (Saloojee & Bezuidenhout, 2020). Cerebral palsy can result in moderate to severe disability that has a significant impact on not only the child with cerebral palsy but also the families, requiring long term medical care and rehabilitation (Gorgon, 2018).

In 2019 the global prevalence of cerebral palsy was between 2 and 2,5 per 1000 live births (Gladstone, 2010) with the estimated 'years lived with disability' (YLD's) being 265.1 per 100 000 children under 5 years of age or 1,8 million YLDs (Olusanya et al., 2022). In low- and middle-income countries, such as many African countries, the prevalence of cerebral palsy is higher i.e. between 2.6 and 3.4 per 1000 live births (Saloojee & Bezuidenhout, 2020) with resultant higher YDLs of 353.3 per 100 000 children under 5 years of age or 586 762 YLDs. In 2017 the prevalence of children with cerebral palsy in South Africa was estimated to be close to 59 000 children (Saloojee & Bezuidenhout, 2020).

Interestingly, a review of literature on cerebral palsy in Africa indicated that the estimated prevalence of the condition was generally higher in Africa than other studies conducted in the United States or Europe (Donald et al., 2014). It was postulated that this could be due to the term cerebral palsy regularly being used in Africa to refer to all motor disability syndromes with postnatal insults being included up to the age of 5 in contrast to internationally accepted consensus of up to the age of 2 years with exclusion of some motor disabilities from the internationally accepted definition (Donald et al., 2014). Varying definitions and exclusion and inclusion criteria for the condition have also resulted in the findings of publications on cerebral palsy being difficult to compare (Gladstone, 2010);(Donald et al., 2015). Some research also suggests that the term ‘neurological disability’ has been more widely used in literature as it is easier to define, yet this encompasses a greater number of conditions other than just cerebral palsy (Gladstone, 2010). Even though such disparities in reported rates occur, cerebral palsy is still a significant concern for low to middle-income countries (Gladstone, 2010).

2.2 The range of priority care needs of children living with Cerebral palsy

Due to cerebral palsy referring to a group of neurological disorders that could present with numerous fallouts such as with movement, posture, speech and language, oral-motor function, as well as sensory and perceptual fallouts, there are copious related medical and rehabilitation needs (Dambi & Jelsma, 2014). Due to these varied fallouts, cerebral palsy is first diagnosed and then classified by a medical professional, usually a doctor, according to the type of movement disorder observed (National Institute of Neurological Disorders and Stroke [NINDS], 2013). There are four varied forms of cerebral palsy, namely Spastic Cerebral Palsy which is characterised by stiff or spastic muscle groups, secondly Dyskinetic Cerebral Palsy - with characteristic writhing and uncontrolled movements, thirdly Ataxic Cerebral Palsy where children will be observed as having slow, uncoordinated movements and lastly Mixed Type Cerebral Palsy where some children may experience stiffness in some muscle groups but laxity and incoordination in others (NINDS, 2013).

Children with cerebral palsy may present with other associated conditions such as feeding difficulties, hearing and visual impairments, intellectual impairments and spinal deformities with resultant respiratory complications to name a few (NINDS, 2013). These further complicate treatment strategies and rehabilitation for children with cerebral palsy, placing an increased burden on the health care system, the caregivers and general economy (Saloojee & Bezuidenhout, 2019).

With the complex nature of cerebral palsy, it can be extrapolated that the treatment and priority care needs for children with cerebral palsy are also intricate and complex with no standard therapy interventions. Cerebral palsy cannot be cured, so medical and therapeutic interventions aim at improving lifespan, ensuring quality participation and improvement of the child's capabilities (NINDS, 2013).

With regards to medical intervention, children with cerebral palsy can be treated with oral medications such as Baclofen that relax stiff muscles or Botulinum toxin injections for overactive muscles (Buizer et al., 2019). Some surgical interventions can also be undertaken to relax contractures and potentially improve mobility or Selective Dorsal Rhizotomies can be used to target specific nerves and reduce pain (Gough et al., 2007).

The educational needs of children with cerebral palsy are varied, dependent on the child's capabilities. In children that only have motor or movement fallouts, an assistive device that assists with this may suffice in order to ensure inclusivity within the educational system (NINDS, 2013). Such a device may be an adapted and suitable wheelchair or a K-walker for assistance in ambulation. More complex education needs may include augmentative and alternative communication devices utilised in cases where children have difficulty with language and verbal communication (Davies et al., 2010). Such devices are costly and exclusive to privately funded health care options within the South African context. Further educational assistance can be in the form of a classroom assistant that accompanies the child in a mainstream schooling system. There are also schools and institutions that are exclusively dedicated to children with physical or intellectual challenges and cater for their priority needs.

The rehabilitation needs of children with cerebral palsy may include treatment from a physical therapist, an occupational therapist, a speech and language pathologist as well as mid-level workers or therapy assistants, dependent on their individual needs (NINDS, 2013). These therapies assist with maximising the child's independence and participation in life through improving mobility, preventing regression and potential muscle contractures, facilitating inclusion within society and their communities, issuing of assistive devices as necessary, such as wheelchairs, aids for eating or other activities of daily living, play facilitation and language and communication facilitation just to name a few (NINDS, 2013).

The social and emotional needs related to children with cerebral palsy are often times overlooked. The burden of care on the primary caregiver and families and communities of children with cerebral palsy is large. In a study conducted by Akpinar, (2021), it was found that anxiety levels in caregivers of children with cerebral palsy were high, further exacerbated by the COVID-19 pandemic and related medical stressors.

Many of the needs described above have been noted in literature and profession specific training within medical guidelines and protocols are available. These guidelines have however been noted as being inadequate and irrelevant within the African context (Donald et al., 2014). Protocols specific to cerebral palsy from a rehabilitation and educational perspective within the South African context are necessary, with professionals and individuals working within these fields having to develop their capacity through post graduate short courses such as the Practical Course on Cerebral palsy for Therapists or Paediatric Bobath Neurodevelopmental Trainings, which are facilitated by Malamulele Onwards and Dare Consult respectively.

2.3 Implications for cerebral palsy - related services and service providers in South Africa

According to the Sustainable Developmental Goals, set out by the United Nations, the ratio of health care workers should be 4,45 per 1000 population globally by 2030 in order to ensure universal health coverage (WHO, 2016). The estimated supply of health care workers in Africa in 2013 was found by the WHO to be represented by 2,2 health care workers per 1000 population (WHO, 2016). In South Africa the most recent figures suggest one health care worker per 1000 population (WHO, 2022) which is significantly under the Sustainable Developmental Goals, placing a large burden of care on the health care system and related services in South Africa.

In relation to the management of cerebral palsy, with an estimated 59 000 children currently living in South Africa with this diagnosis (Saloojee & Bezuidenhout, 2020), this can be extrapolated to one health care worker per 454,5 children with cerebral palsy, grossly under the Sustainable Developmental Goals, placing a large burden of care on the health care system and related services in South Africa.

Some of the basic health care components that are required for effective cerebral palsy interventions are also not readily available in many African contexts. These include access to regular therapy - with few tertiary institutions being able to provide allied health services other than physiotherapy (Donald et al., 2015); enough health care workers and rehabilitation staff that are specialized in the field of cerebral palsy; as well as contextually relevant resources, such as culturally relevant assessment tools and equipment (Donald et al., 2014).

The African Child Neurology Association has also reported that guiding policies on cerebral palsy services are lacking within the African continent (Donald et al., 2015). A treatment gap for children with Cerebral palsy exists within the African continent and could be attributed to a lack of resources such as wheelchairs and ambulatory aids that assist in accessing treatment services, and in order for cerebral palsy to be effectively targeted and managed, future research needs to be directed at multicenter collaboration, both institution-based and community-based rehabilitation, on the prevalence, risk factors and treatment modalities (Donald et al., 2015)

With increased cerebral palsy prevalence, there is also increased cerebral palsy litigation, all stakeholders therefore need to concentrate efforts on the effective and efficient treatment of cerebral palsy. As there is an increased demand and load on cerebral palsy services, which currently are institution-based service delivery methods, we need to rethink and re-align cerebral palsy service provision.

2.4 Comparison of institution-based (IB) vs community-based rehabilitation (CBR) service delivery modalities

The African Child Neurology Association reviewed existing guidelines, from high-resource settings, due to the lack of local and contextually relevant guidelines, for the treatment of children with cerebral palsy. These were deemed as ineffective and inaccessible and suggestions were made for home-based or community approaches such as CBR, that have been described in literature as well suited to a low-income-resource settings as compared to IB models of intervention that require increased infrastructure and resources (Donald et al., 2015).

Community-based rehabilitation is an intricate concept that has presented with complex and often varying definitions, but largely aims at the provision of primary health care and rehabilitation services within the individuals' communities (Dambi & Jelsma, 2014). Institution-based modalities of health care and rehabilitation refers to individuals having to access health care and rehabilitation services at a centralised location, such as a hospital or equivalent centre (Dambi & Jelsma, 2014).

Some comparison between IB and CBR as modalities of intervention have been reported on in allied health literature (Gorgon, 2018);(Wuang et al., 2013);(Chadd et al., 2021) (Dambi & Jelsma, 2014). Two studies highlighted the use of home programmes - a CBR strategy - as modalities, through increased reliance on caregivers, with significant improvement in outcomes obtained (Wuang et al., 2013); (Gorgon, 2018). One study (Dambi and Jelsma, 2014) noted a 6% improvement in function in a group of children with cerebral palsy who received CBR – in comparison to the control group that received IB. In a study by Chadd et al. (2021), a change from usual IB modalities to CBR modalities was noted in response to the COVID-19 pandemic with a 63.1% increase of utilization of CBR service delivery methods (Chadd et al., 2021). Even though disadvantages in relation to CBR were highlighted in these reviews (for example, social isolation and a lack of access to technology and appropriate equipment within the home environment), the general consensus was that CBR could form a potential alternative in response to calls for cost-effective and easy access interventions (Gorgon, 2018; Wuang et al., 2013;(Chadd et al., 2021).

Interestingly, authors have noted that the most effect rehabilitation model for service delivery in low to middle income settings has yet to be determined due to the limited number and quality of publications on CBR and CBR vs IB rehabilitation (Dambi & Jelsma, 2014;Finkenflügel et al., 2005). Similarly, Donald et al. (2014) noted that the effectiveness of using community health care workers, parent support groups and outreach programmes as a mode to manage cerebral palsy in Africa has yet to be evaluated thoroughly (Donald et al., 2014).

Thus, even though the benefits of CBR and caregiver-provided assistance have been noted, many authors (Gorgon, 2018; Finkenflügel et al., 2005; Donald et al., 2015; Dambi & Jelsma, 2014), note the urgent need to further explore community-based services delivery methods with empirical evidence in order to inform restructuring of rehabilitation services and guide rehabilitation policy development in the future, across the African continent.

2.5 The challenges of implementing CBR

A number of barriers which are considered to impede the effective implementation of CBR have been identified, drawing from international literature from low- to middle-income countries as well as literature specific to the Sub-Saharan and South African context. These include, for example,

- the vague and broad definition of CBR which has negatively influenced the practical implementation of the related strategies (Fiorati et al., 2018; Rule et al., 2019);
- poor communication and a lack of teamwork between the various CBR stakeholders has led to fragmented and ineffective planning, goal setting and CBR implementation (Cayetano and Elkins, 2016; Fiorati et al., 2018);
- a lack of trained individuals in the field of CBR – and specifically those that were able to think beyond the use of the biomedical model (Fiorati et al., 2018);
- poor accommodation to CBR workers and programmes due to social dynamics brought about by individual and collective attitudes towards disability (Lorenzo et al., 2015).

Lastly, and in many authors opinion the most important barrier to CBR implementation, was the well-intended policy development across low- to middle-income countries with CBR at their core, yet the lack of practical implementation of such strategies in a visible manner (Cayetano and Elkins, 2016; Doig et al., 2008; Fiorati et al., 2018; Rule et al., 2019).

Despite the many barriers to implementation, CBR continues to grow, based largely on the experience-led accounts of its success (Finkenflügel et al., 2005), and its appealing principles of making rehabilitation services more accessible to those who are particularly vulnerable and in need of specialized care.

2.6 The enablers of CBR implementation

In a study conducted by Wuang et al. (2013) of the effects of an occupational therapy home programme, the results indicated that there was a significant increase in satisfaction with the childrens' overall performance among caregivers of children with disability who participated in the study (Wuang et al., 2013). The same study also indicated that there was a high compliance rate of caregivers and programme implementation, owing to the programme being embedded in the family routine and taking into consideration the family dynamics, values, prioritisation and furthermore creating a collaborative goal-setting approach (Wuang et al., 2013). For the successful implementation of CBR strategies, some areas were highlighted throughout literature to be imperative. These include, for example:

- collaborative partnerships between all stakeholders (Doig et al., 2008) with good channels of communication and goal setting (Wuang et al., 2013);
- specific and situational feedback within the patient’s known context, creating a more relaxed environment with increased therapy and caregiver contact (Cayetano and Elkins, 2016);
- teamwork and a sense of shared ownership over rehabilitation outcomes, assisting with inclusion and functionality (Cayetano and Elkins, 2016);
- competencies and positive characteristics of CBR worker's implementation of programmes within communities, such as good communication skills, openness, and transparency as well as good interpersonal skills (Lorenzo et al., 2015).

Barriers to the implementation of CBR strategies in Brazil have been reported on even though standardised indicators for CBR implementation and evaluations were available in the setting. Fragmented communication, lack of co-ordination and disconnectedness between acute and community-based rehabilitation has been attributed to the challenges of implementing CBR (Fiorati et al., 2018).

In order to understand the root causes of sub-optimal implementation of CBR strategies within rural Brazil, health care workers were asked to provide their insight on barriers to optimal CBR implementation One important aspect that the above study mentioned was that CBR was a well-intended policy within the country but that due to the lack of understanding and the broad definition of CBR, the practical implementation was still not being achieved (Fiorati et al., 2018).

The World Health Organisation has taken various steps on an international platform to assist with the conceptualisation and implementation of CBR strategies, through the publication of the CBR guidelines and matrix (WHO, 2010). On review of literature post 2010, unanimous results have indicated sub-optimal utilisation of CBR strategies within low- to middle-income countries, including South Africa (Cayetano and Elkins, 2016; Doig et al., 2008; Fiorati et al., 2018; Rule et al., 2019).

2.7 The role of teamwork across all stakeholders in CBR

One of the recurring themes in the literature which has explored the successful implementation and sustainability of CBR strategies, is the importance of collaboration between all stakeholders involved (Fiorati et al., 2018; Rule et al., 2019). Stakeholders are defined in this literature as CBR programme developers and managers, healthcare workers[6], monitoring and evaluation personnel, persons with disabilities as well as community members (Fiorati et al., 2018; Rule et al., 2019).

Doig et.al. (2008) noted that collective involvement and leadership across all stakeholders could reverse the power differentials often experienced within communities. Some areas of collaboration needed between therapists and caregivers of children with disabilities have been highlighted in systemic reviews. These areas include management of expectations and shared decision-making throughout the rehabilitative process (Gorgon, 2018). Certain barriers that affect caregivers' compliance and access to rehabilitation services were noted by various authors and include economic and financial factors, such as travel costs, cultural reasons, expectations placed on the caregiver by other family members with regards to household duties and medical reasons, such as the child or other family members becoming ill (McConachie et al., 2001;,Donald et al., 2015;,Mahesh et al., 2018). These factors affected the caregivers' abilities to provide basic needs for their children. Further strain was felt through the financial implication of attending centers for medical care, rehabilitation, assistive devices and transportation. This stresses how shared decision-making and negotiating with caregivers with regards to the mode and content of service delivery is of utmost importance (McConachie et al., 2001).

The importance of establishing a therapeutic alliance with the primary caregiver has been noted in literature as an integral part of successful intervention focusing on children with developmental delays and disabilities (Potterton et al., 2009). A greater understanding of the complexities of establishing a therapeutic alliance with primary caregivers of children with neuro-disabilities is needed in order to create and deliver more specific and effective rehabilitative interventions for these children (Gladstone et al., 2014).

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[6] Healthcare workers includes doctors, nursing staff, therapists and community health care workers.

Another pertinent theme that was highlighted in literature was contextual difficulties, specifically with regards to the co-ordination between stakeholders and sectors. It was noted that planning, goal-setting and implementation was often fragmented and ineffective due to poor communication and a lack of teamwork between stakeholders responsible for CBR implementation, resulting in systemic constraints (Cayetano and Elkins, 2016; Fiorati et al., 2018).

CBR strategies were included in the Framework and Strategy for Disability and Rehabilitation Services (FSDR) in 2015, emphasising the importance of these strategies being comprehensively incorporated at each level of care (National Department of Health, 2015). This has yet to be realised within many provinces of South Africa as provincial implementation guidelines are lacking. The South African Health Review ‘Towards Rehab 2030' (Philpott, McLaren & Rule, 2020) has urged the collaboration between multi-sectoral stakeholders in regard to CBR implementation through sharing of resources, expertise and findings in order to achieve rehabilitation goals set out for 2030.

It is clear from this review of literature on the implementation of CBR, both within the South African context as well as internationally, that further research needs to be conducted in order to increase and strengthen its optimal implementation. The aim of this study is to provide further insights into how such a therapeutic strategy was implemented within the South African context. The following chapter will describe the study methodology and the process that was undertaken in preparing for and conducting the field work.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

The methodology used in this qualitative research study is described in this chapter, together with the aims and objectives. The study setting, study design, study population, sampling, data collection and analysis are also outlined in this chapter. The chapter also describes how rigor and ethics have been considered in the research process.

3.2 Study Setting

The study was carried out at a local Non-Governmental Organisation (NGO) that provides rehabilitation services to children with cerebral palsy within the Bitou Local municipality in the Western Cape Province in South Africa. The study was initiated in November 2021, when the researcher introduced the study to the NGO, and then proceeded to gather data over a three-month period in the study site between February – April 2022.

It is important to note that the researcher lives and works in this same municipal district and is employed as an occupational therapist in a similar NGO in the same district. She works closely with the occupational therapists at the NGO being studied.

3.3 Study Aim and Objectives

The aim of the study was to explore the barriers and enablers experienced by NGO service providers in delivering community-based rehabilitation services to children with Cerebral palsy in the Bitou Local Municipality, South Africa.

The study objectives were:

1. To explore what the NGO service provider’s understanding is of the concept of CBR.

2. To describe the range of physical spaces and settings in which the NGO service providers provided CBR to children with CP in the Bitou Local Municipality.
3. To explore what the NGO service providers perceive and experienced as barriers to their implementation of CBR to children with CP in the Bitou Local Municipality.
4. To explore what the NGO service providers perceive and experienced as the enablers of the provision of CBR to children with CP in the Bitou Local Municipality.
5. To explore the extent to which NGO service providers believe their implementation of CBR in Bitou Local Municipality could be utilised in the broader implementation of CBR strategies in the Garden Route District Municipality.

3.4 Study Design

An exploratory study was done using a qualitative research approach as this approach gave a greater insight into the experiences and viewpoints of the NGO service providers, thus allowing, as Malterud (2001) notes, the researcher to gain deeper insight into the unique contextual experiences of these individuals. A qualitative approach allowed the researcher to contribute to a greater understanding of the issue, as Sargeant (2012) suggested, in an unstudied setting – which in this case was the Bitou Local Municipality, South Africa. Unstudied settings refer to those geographical areas where research findings are thin, the Bitou Local Municipality being one of these. The amount of literature available on caregiver perspectives of CBR is also sparce, further re-iterating the unstudied setting of this research. Semi-structured interviews were utilised as this aligns with an inductive approach (Pope and Mays, 1995). An inductive approach is whereby the researcher moves continuously throughout the period of data collection, between raw data and the conceptualisation of the findings and then thereafter develops a hypothesis in order to pay due homage to the meanings and experiences of all those they interviewed. This approach was beneficial for the study as it provided the researcher with the time and tools to uncover the concepts and social phenomena in question (i.e. summarize what this social phenomenon in question is), and to try and truly express and represent the views of the study participants.

3.5 Study Population

The study population consisted of all the individuals either employed on a full- or part-time basis for the NGO and who worked between 6 hours and 40 hours per week. The study population was made up of two distinctive staff categories:

1. The 5 service providers who are health professionals, namely: 1 physiotherapist, 3 occupational therapists (1 who only worked within a managerial capacity) and 1 Speech and Language pathologist, and
2. The service providers who are referred to as therapy assistants who support the work of the health professionals and are the equivalent of a community-based rehabilitation worker. 15 therapy assistants worked for the NGO in the Bitou Local Municipality.

The first category will from here on be referred to as health professionals and the second category referred to as the community-based rehabilitation workers (CBRWs). The total study population for the study was 20 employees of the NGO.

3.6 Sampling procedures and sample size

As Sargeant (2012) outlines, the individuals selected for a qualitative study need to meet a set of criteria that is predetermined by the researcher. For both the professional health workers and the therapy assistants, the following criteria were applied:

- They ought to have been a member of the NGO team that exclusively delivered CBR services to children with CP within the Bitou Local Municipality region at any point between May 2020 to September 2020.
- They ought to have at least three months experience of being part of the NGO CBR team during the above period.
- They ought to be 18 years and older.

According to Sargeant (2012), it is difficult to pre-determine the sample size in qualitative research as the number of participants is determined by the extent to which a point of data saturation has being reached. Data saturation refers to the process that occurs within data collection, where with the addition of data from new interviews does not result in the researcher identifying new information, ideas or themes (Sargeant; 2012). In this instance, data was continuously analysed throughout the data collection process, allowing the researcher to document themes identified from the interview scripts. After completing 12 interviews the researcher became aware that very little new information was being introduced, but that similar themes were being repeated. It was therefore decided that data saturation had been reached.

In terms of selecting the study sample, purposive sampling was used so as to deliberately choose participants who would both meet the pre-requisite criteria as well as potentially provide the richest information for the study (Moser & Korstjen, 2018). Purposive sampling involves selecting participants who would assist in answering the research question through the provision of the richest and most comprehensive data (Sargeant; 2012). According to Richie et al. (2003), having varied individual experiences and people would enable the study to develop central themes around the phenomena in question.

In developing the purposive sample, the researcher created a list of all 20 employees in both of the two categories (i.e. health professionals and community-based rehabilitation workers) in terms of their involvement in the CBR team that delivered CBR services between May 2020 and September 2020, a minimum duration of 3 months of provision of CBR services and the length of time they had been working for the NGO.

With regards to the health professionals, one physiotherapist was on maternity leave during the duration of data collection, and the speech and language pathologist did not meet the criteria with regards to provision of CBR services for a minimum of 3 months. One occupational therapist worked in a managerial capacity and did not provide CBR services during the May 2020 to September 2020 period. This resulted in the 2 remaining occupational therapists being included as candidates for participation in the study as both had formed part of the CBR team between May 2020 and September 2020 and both had a minimum duration of 3 months of provision of CBR service. An interview with one of the two occupational therapists was conducted. The interview with the other occupational therapist did not take place for logistical reasons.

The community-based rehabilitation workers (CBRWs) all met the inclusion criteria as they all had formed part of the CBR team between May 2020 and September 2020 and they all had a minimum duration of 3 months provision of CBR services during this period. All of the CBRWs were proficient in either English or Afrikaans as well as all being 18 years of age or older. They were then purposely sampled from the longest duration of experience as a community-based rehabilitation worker to the shortest, with those with the longest duration of work experience interviewed first, till data saturation occurred. This was done in order to ensure that rich data could be collected from those CBRWs with more work experience.

Many CBRWs had a number of years' experience where they provided both institution-based rehabilitation as well as community-based rehabilitation previous to the exclusive provision of community-based rehabilitation from May 2020 to September 2021, and it was thought that this would enable more detailed answers during the interview. In total 11 of the 15 community-based rehabilitation workers were interviewed in person until data saturation was reached.

3.7 Data Collection Instruments and Procedures

Once approval by the University of the Western Cape's Biomedical Research Ethics Committee had been received, the researcher sent a letter of request (Appendix A) to the NGO Board and Managing Director which introduced the study and requested permission for the study to commence within the organisation. Once approval was granted from the organisation, the researcher made the necessary arrangements to introduce the study to all the service providers that formed part of the NGO's CBR team (i.e., the 20 employees which were described in Section 3.5). This was done by an in-person consultation with the 3 occupational therapists, after which one occupational therapist then introduced the study to the 15 therapy assistants at their weekly team meeting. She also supplied them with the participant information sheets in English and Afrikaans (Appendix B & C).

The 15 CBR workers and 2 occupational therapists who fitted the selection criteria, and expressed an interest in participating in the study, were asked to make contact with the overseeing occupational therapist, who then arranged a date and time that was suitable for each one of them to participate in an individual interview with the researcher. This was done in an in-person individual interview, were all the necessary COVID-19 protocols were adhered to (such as physical distancing of 1.5 meters and wearing of a mask that covered both the nose and mouth) in order to ensure the safety of the researcher and research participants. Prior to each interview, participants were provided with a hard copy of the consent forms in either English or Afrikaans (Appendix D & E). The researcher then discussed both documents at the start of the interview and then obtained the participants signed consent form. The interviews were conducted at the NGO in a private room that had been made available for that specific purpose and were conducted in February, March and April 2022.

Given the familiarity of the researcher with the district and members of the NGO team, it was assumed by the researcher that all participants would be comfortable if the interviews were conducted in either English or Afrikaans – as these are the two languages that are used predominantly in all of the NGO meetings and consultations with clients, as well as the researcher being fluent in both of these languages. The length of the interviews was between 38 and 60 minutes each. At the start of the interview, the participants were asked which language they preferred, resulting in 11 interviews being conducted in English and one in Afrikaans. The researcher made use of a semi-structured interview guide (Appendix E), with open-ended questions. As Moser & Korstjens (2018) note this assists the researcher to gain a more comprehensive understanding about the phenomenon in question.

Essentially, the interview guide focused on the main research question: *"What are the barriers and enablers experienced by NGO service providers in delivering community-based rehabilitation services to children with cerebral palsy?"* and explored this, based on their experiences, of working within the Bitou Local Municipality.

All of the interviews were conducted by the researcher. They were also all audio recorded on the researcher's phone making use of an application called Otter.ai which made audio recordings of the interviews and then once uploaded, made transcripts of the interviews. Whilst conducting the interviews, the researcher also made use of note taking. (Moser & Korstjens, 2018), noted that making use of both of these methods (the audio recording and note taking) ensured that the researcher was able to extract as much data as possible from both the transcriptions as well as their own visual and auditory observations. The researcher then checked all of the electronic transcripts whilst listening to the audio recordings and checking the notes taken to ensure that the electronic transcripts were accurate, due to varied pronunciations of words. The one Afrikaans interview was manually transcribed by the researcher as the Otter.ai application did not make allowance for this language. This transcription was translated into English by the researcher as the researcher is fluent in both languages.

3.8 Data Analysis

In order for the researcher to gain a deeper understanding of the NGO service providers' experiences and opinions, an interpretive analysis approach was used throughout analysis of the data. The process of data analysis was iterative whereby the researcher was involved in the process of data collection and data analysis simultaneously (Petty, Thomson and Stew, 2012). The researcher started transcribing, reading and re-reading these transcriptions whilst listening to the audio recordings in an effort to become fully immersed within the data, whilst still being within the data collection process. This enabled the researcher to become sensitive to the point where data saturation had occurred and data collection could cease, as well as to familiarise herself with the data and become aware of new aspects that would arise with re-reading of the transcripts. This process assisted in developing detailed descriptions that 'emerged' from the data and enabled a greater understanding of the individual's experience that might not have previously been considered by the researcher (Moser and Korstjens, 2018).

Thematic analysis, as identified by Petty et al., (2012), was used for data analysis by the researcher whereby the participants responses were analysed and codes were assigned. This process of coding refers to the allocation of labels to words, phrases, events and actions that were seen by the researcher to be repetitive, both within that transcript but also across other transcripts. Sargeant (2012) describes the above process as the first step in the data analysis process and terms it the deconstruction stage.

Secondly, the researcher then compared these codes that emerged within and across the data transcripts, searching for codes that were found to be similar within and across transcripts as well as any differences found. The researcher then found that many of these codes or labels could be grouped together in larger, more comprehensive phrases or sentences, and thus potential themes and sub-themes were identified. A process of analysing and re-analysing the data and potential themes occurred, as described by Sargeant (2012) as the second step in data analysis, termed 'Interpretation', with the researcher then sending these potential themes to the supervisor for additional peer review. On feedback received, it was identified that some of the potential themes, instead of being separated into enablers and barriers to CBR, could rather be collapsed into one area of enquiry in order to reduce repetition and redundancy of data findings. An example of this was with the initial theme of 'Lack of team-work, accommodation and buy-in from the caregiver', that was perceived as a barrier to CBR services, and 'A sense of connectedness and team work with caregivers' which was included as an enabler to CBR service provision. Both of these themes were speaking to similar topics and addressing similar points of views and were each initially within their own area of enquiry. After peer review, it was suggested that these two be collapsed into one, where both the positive and negative experiences as identified in the data are discussed. The specific phrases that were initially assigned to the themes by the researcher, were also changed following the peer review by the supervisor, to include longer and more explanatory phrases in order to reduce any potential confusion.

Finally, the researcher could then reconstruct the data findings according to the themes and subthemes analysed and re-analysed by both herself and her supervisor, into a logical format that adequately represented the findings of the study. This was described by Sargeant (2012) as the third and final step in the data analysis process.

3.9 Ensuring rigour throughout the research process

A number of processes were used to ensure that a level of trustworthiness was obtained through the study – all of which Sargeant (2012) notes relate to the quality of the data analysis process.

Firstly, in terms of **credibility:** in order for the researcher to have maintained the original intent of the study and to present a set of findings that were a true representation of the phenomena in question, the following methods were employed:

- *Researcher reflexivity* refers to the process whereby the researcher identifies their own preconceptions, beliefs and assumptions and analyses these (Korstjens and Moser, 2018). This can then be documented throughout the research process and potential influences on the study findings highlighted (Malterud, 2001). This was utilised by the researcher throughout the study through making use of a reflection journal in order to document particular biases and how these could have influenced decision making throughout the research process. On reflection, the researcher noted that she had become more confident towards to end of the data collection process and that she required the use of the interview guide less and less and could lead the discussion more organically. It was also noted that the interview with the health professional, an occupational therapist, resonated more with the researcher as she herself was also an occupational therapist, and that she felt this interview was more data rich. These findings were documented as potentially making subtle differences to the data collected.

- *Prolonged Engagement* refers to the familiarisation of the researcher with the study setting and population in order to develop rapport and assist in establishing a trust relationship to ensure openness during data collection and potentially reflect the population's experiences accurately (Shenton, 2004). The researcher is an occupational therapist employed at a similar NGO also within the Bitou Local Municipality. The researcher was thus familiar with the study setting and some of the study population due to previous and continued engagement with the NGO in a formal work capacity, such as referrals between NGO's and discussion of children who were being seen for various therapies by both organisations. Prior to data collection, the researcher also consulted some relevant documentation used by the NGO, such as a form that CBR workers are required to fill in during every home-visit (a CBR strategy) they perform. This was done in order for the researcher to be immersed in the NGO context and develop further understanding of processes surrounding the NGO and CBR service provision.

Secondly, **transferability** was considered. This refers to the collection of comprehensive, descriptive data (Petty, Thomson & Stew, 2012). Through provision of rich description, readers are provided with the opportunity of reaching their own convictions regarding the transferability of the study to other settings (Shenton, 2004), which can also provoke a reaction and connectedness between the reader and participant (Creswell and Miller, 2000). An example of this within the study was that one of the objectives was to describe the setting where CBR services were delivered, in order to ensure a sufficient rich contextual description of the study. Questions relevant to this objective were asked in the interviews, where the participants described the typical environment where they conducted CBR services, this later being translated into a number of themes being developed, such as ‘The lack of space and privacy in which to provide CBR’ and ‘Logistical challenges of working in a rural site’. Through the inclusion of these themes, the reader is able to reach their own conclusion with regards to the transferability of this study to their own or known contexts.

Thirdly, **dependability** was taken into account. This refers to the process whereby the researcher documents all processes and procedures utilised during the research process, in order for the reader to ascertain if the findings of the study would be congruent if replicated in a similar setting, taking inevitable variabilities in cognisance (Petty, Thomson & Stew, 2012). A research journal was used throughout the research process to ensure thorough documentation of the procedures utilised in a clear and systematic manner to enable auditability. The researcher also documented her reflections during the research process in order to have an audit trail of her reasoning processes that guided the research process. According to Shenton (2004), this would also assist in creating dependability of the study with the reader.

Fourthly**, confirmability -** the extent to which the experiences and perceptions ascertained within the study findings are in fact those of the participants (Petty, Thomson & Stew, 2012 -, was created through the researcher disclosing (within the research journal previously mentioned) her presumptions and assumptions, as well as her personal beliefs about the study being researched. An example of this was the assumption the researcher had, before conducting the study, that methods of CBR service delivery were the only methods beneficial for all stakeholders involved and would be the preferred method of rehabilitation service delivery. This assumption was reflected deeply upon by the researcher within the research journal and subsequently discussed with various individuals, such as her study leader as well as other health professionals with whom she works. This was done to seek confirmation or disconfirmation of these assumptions in the study findings, whilst constantly being mindful of this assumption and potential blind spot during the research process. During the interview process, the researcher also made use of reflexive listening, often repeating what the participant had said in order to ensure that the researcher had documented what was a true reflection of the participants' opinions.

3.10 Ethical Considerations

Ethics approval for commencement of the study was obtained from the University’s Biomedical Research and Ethics Committee and thereafter the Senate Research Committee of the University of the Western Cape in November 2021 (Appendix G). After UWC ethics approval was obtained, a request to conduct the study was submitted to the relevant NGO (Appendix A), along with the relevant ethical approval documentation and information about the proposed research (Appendix G). Participation in the study was entirely on a voluntary basis and on the basis of informed consent, and all the board members and relevant staff members (service providers) of the NGO were informed of this when the study was introduced to the organisation. All study participants were provided with a Participant Information Sheet (Appendix B & C) which described the aim and process of the study. The informed consent document (Appendix D & E) also included the aim of the study and assured participants of their confidentiality as well as that they were free to leave the study at any time with no adverse effects with regards to their work or the services that they provided to the NGO. The researcher took appropriate measures to protect all participants' identities and contributions towards the study. Participants' names were not included in the interview transcripts or other data collected, but rather a code was assigned to each participant which was utilised throughout the research process and final write up of the research findings.

Safeguarding of all data collected throughout the study was also ensured and implemented through electronic information and transcripts being kept on the researchers own biometric access-controlled computer. Any hard copies of transcripts and notes taken during the interviews were kept in a secure drawer within a study at the researcher's home that was only accessed by the researcher. Both electronic and hard copy data will be stored for 5 years before being disposed of. In the researcher's opinion the study would not prove to be invasive or detrimental to any of the participants, but if any participants were distressed and in need of further support, arrangements were made for counselling to be provided to by the Family Association South Africa (FAMSA) situated within the local municipality.

The next chapter will present a description of the study participants and the results of the interviews.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter describes the study participants and what they perceived as the barriers and enablers experienced in delivering community-based rehabilitation services. These study results, as mentioned previously, were drawn from semi-structured, in-person interviews conducted with each of the 12 study participants.

4.2 Description of study participants

The study sample consisted of 12 participants who were all NGO service providers. All 12 study participants were female, reflecting the gender composition of the NGO staff. There is only one male member of staff: the transport driver. The sample consisted of 11 field workers, who will be referred to as community-based rehabilitation workers, and one occupational therapist, who at times played a supervisory role over the community-based rehabilitation workers. Most (i.e. 7 of the 12) participants were between 30 and 40 years of age. As described in Chapter 3, the service providers were chosen to have some experience with delivering community-based rehabilitation, with the inclusion criteria requiring a minimum of 3 months experience. All of the participants had in fact between 2 – 10 years of experience in the CBR field, as can be seen in the table below:

Table 2: Years of community-based rehabilitation experience held by participants

Years of CBR Experience	Number of Participants
< 2 years	0
2 - 5 years	6
6 - 10 years	6

As can be seen from Table 2 below, the 12 participants were between the ages of 20 and 69 years of age with the majority i.e. 58% of the participants being between the ages of 30 and 39 years of age.

Table 3: Age breakdown of participants

Age Category of Participants	**Number of Participants**
20 - 29 years	2
30 - 39 years	7
40 - 49 years	2
50 - 59 years	0
60 - 69 years	1

A number of themes emerged from the analysis of the data from the 12 interviews. The table below illustrates the study objectives and the researcher's exploration of these and how, through this, a series of themes emerged in relation to each.

Table 4: The study objectives and themes emerging from the data

Areas of Enquiry / Study objectives	**Themes**
Service provider's understanding of the concept of CBR.	CBR as a form of community support provided through co-operation, shared problem-solving and empowerment
	Building trusting relationships between the CBR workers, the communities and caregivers
The physical space and settings in which CBR was delivered.	The lack of space and privacy in which CBR was provided
	Logistical challenges of working in a disadvantaged and rural area
	Social issues within the household and

	impact on the provision of CBR
	A lack of organisational resources for CBR
Perceived and experienced barriers and enablers to implementing CBR	Considerations related to time
	Receptivity of caregivers to CBR
	Lack of accommodation and buy-in from the caregivers of CBR
	Establishing an atmosphere of reciprocal learning
	Organisational support and mentorship
	A sense of connectedness and teamwork with caregivers
	Communication, transparency and trust between the CBR workers and the caregivers
CBR worker characteristics and traits	Observations on the characteristics and traits of the CBR workers
Perceived extent of broader implementation of CBR strategies	Organisational support and mentorship
	Community awareness of disability and therapy

4.3 Service provider's understanding of the concept of CBR

Service providers were asked to elaborate on their understanding of the therapeutic services that they were providing within communities. The discussions around this concept were concise, but interesting and informative themes arose, with similar threads being picked up throughout the rest of the study findings, reiterating that the service providers' worldview and understanding of the foundations of their work influenced the way they perceived the barriers and enablers of their service provision.

4.3.1 CBR as a form of community support provided through co-operation, shared problem-solving and empowerment

Five of the 12 study participants articulated that they understood community-based rehabilitation - the services that they were providing - as a form of provision of support for the community and caregivers. The following CBR worker noted on being asked what her perception of CBR was, that she saw this as support of the community through encouragement of the caregivers:

> *"I would say, definitely uplifting the community, encouraging them."* (CBRW 3)
>
> *"I'm doing mainly empowerment."* (CBRW 8)

The above study participant interpreted her understanding of CBR strategies as ones that involved encouragement of community members which led to their empowerment.

Further understanding that CBR is about support of the community was reiterated by the following study participant, noting that she saw CBR strategies as a form of outreach into the community, where problems faced by those in the community could be brainstormed, and solutions found together:

> *"...it's a way of reaching out to the community... I am there so that we can share in finding the solution."* (CBRW 4)

This community support was attributed to co-operation between the caregiver and the CBR service provider. The study participant below communicated her understanding of CBR strategies to this co-operation aspect.

> *"...[it] is the co-operation between the fieldworker and the parent."* (CBRW 10)

4.3.2 Building trusting relationships between the CBR workers, the communities and caregivers

The biggest theme that emerged from data on enquiry of the service provider's understanding of CBR was that it was grounded on building relationships with the caregivers, basing this on mutual trust. One CBR worker articulated it well, describing this relationship as real and a place where stakeholders could be vulnerable.

> *"...working within the community? Face to face, hand to hand, heart to heart, ja, like that...They must trust you."* (CBRW 9)

She described how her understanding of CBR service provision was the development of a relationship between her and the caregiver, which was nurtured through vulnerability which in turn fostered trust. Another study participant concurred with this finding, communicating that CBR service provision to her meant building a relationship with the caregivers, where they were seen as equals. This study participant described CBR as being a therapeutic strategy where:

> *"...you get to know them of their level...it's more inclusion [inclusive]."* (CBRW 9)

One CBR worker noted that her perception of CBR strategies was provision of a sense of security through developing a trusting relationship. She noted that this sense of security stemmed from developing a foundational relationship with caregivers and through this their experience would be that they were not going to go through their struggles alone.

> *"...yes, it is building more of a relationship [with the caregivers], to give the parents that sense of security, that there is someone else [the CBR worker] ...who is going through this with them."* (CBRW 5)

4.4 The physical space and settings in which CBR was delivered

In relation to the physical context in which CBR was being delivered by the NGO, study participants highlighted some important logistical and practical issues associated with their therapeutic practice.

4.4.1 The lack of space and privacy in which CBR was provided

Almost all of the community-based rehabilitation workers commented on the lack of space for therapy within the homes that they visited and how this negatively impacted on their sessions. This is described by two participants as follows:

> *"Sometimes you will find that it's not home, it's not a home appropriate, because you will see that it's one room. The, the bed is here, cooking places here, and they are not [gestured sign 'okay']. And then in, because of those situations, we decide when it's raining, we're not going for home visits, because we can't...so when it's raining, they are all in the house. You can't tell them go wait outside because I need to see the child and the mom. So, it is sometimes, it has, that's why we started, when we doing the home visit, when it's raining, we are usually not going, because they all live in one, one room and they are a lot."* (CBRW 1)

> *"Sometimes it this homes that has a lot of people, and then you go there…there is a lot of family inside and then these houses is so small, you are just sitting in the couch. And then there is some of them passed out here, they walking up and down. And some*

> *of them, they watch TV and they chat... it's not nice, because there is no space".* (CBRW 7)

As can be seen from these two quotes the CBR workers describe the homes that they provide CBR services in as usually being small, one to two bedrooms, with little space provided to perform rehabilitation and no privacy. There are continuously other family members either in the space or moving through the space that they are providing therapy in, making the CBR workers potentially feel uncomfortable as that they cannot provide the service that they would like to due to the lack of space and other individuals continually being in the space that they are using.

Only two of the 11 CBR workers stated that even though space was limited, the families were so accommodating that they were still able to work comfortably and effectively. The health care worker described this as follows:

> *"So, I recently did a home visit, which went really, really well...so we went to the house and this mommy's amazing, she's got like a special carpet for her boy and, ja, so we worked in the lounge and she basically went and got, rolled the carpet out, put him down on the carpet...so they actually have quite a small house...so we had a really lovely session."* (HCW 1)

4.4.2 The logistical challenges of working in a disadvantaged and rural area

Another aspect mentioned in relation to the context in which the study participants were delivering CBR was the difficulty they experienced in actually accessing the homes of their clients and this was highlighted by many of the participants as a hindrance to the initiation and progress of therapy.

Many of the homes were termed as 'difficult to access' due to poor road infrastructure and weather creating further inaccessibility. As two study participants described:

> *"Sometimes access, accessing like transport, the bad roads to go to that house...".* (CBRW 11)
>
> *"So, I think like physical barriers, so like travelling to the community...but then also you know people are working during the day. It's a huge barrier. So you get there and they're not there, they're working."* (HCW 1)

Another logistical difficulty described by a number of CBR workers was the difficulties they encountered in not being able to speak to and liaise directly with the parent or the guardian of the child as they were often not the child's immediate caregiver during the day.

A breakdown in communication – something which was often attributed to the lack of access to parents and/or guardians had to a reliable means of communication, was also highlighted. Many of the community-based rehab workers spoke about their difficulties in reaching the parents or guardians via telephone or in person. This made collecting the appropriate information about the child difficult as well as presenting challenges in making and maintaining the scheduled appointments.

> *"Access is challenging. Some of [those] that I'm working [with]..., [they are] inaccessible, and ....so now [I have] to make...lots of arrangements to get [a hold of] this person, because in that household there's not a single person who has a telephone.*" (CBRW 10)

> *"I was at that home, Sunday, I did my visit, I was supposed to be there on Tuesday. But the parents doesn't have a cell phone, that is a challenge, and she's staying far from me. So, I have to walk and then most of the time when I get there, she's not there."* (CBRW 4)

> *"And in the community, if a piece job comes up, that person is going to do it. If it means that they are missing a therapy appointment for themselves or for their child, they're going to do this piece job because it's so important. So very often…the parents are unable to communicate with us that they have to cancel the appointment, for example. So that is lack of communication."* (HCW 1)

Throughout the interviews the study participants shared how, despite being frustrating, they understood why there was a breakdown in communication and that they understood that owing to the financial constraints and the social issues experienced by the caregivers, they were not always able to keep the therapy appointments.

4.4.3 Social issues within the household that impacted on the provision of CBR

A number of social issues were raised by 8 of the 11 community-rehab workers as being another barrier to delivering effect services to the community. The most common social issues that were raised were the significant poverty of the household, child neglect and alcohol abuse. As one of the CBR workers describes:

> *"The environment is not nice for these children. They are not nice at all. Step number one, the house is not clean. No matter I live in a shack with one room, that it can be at least clean for this child. We will find our children ,... dirty. You will be heartbroken because you can't do anything with the child, the child (isn't) appropriate to work with. The child is dirty, the child has been lying in that bed for the whole morning, the child haven't being eaten yet. There's the carer, the one who's supposed to look after him is not, nowhere to be found. So sometimes you feel like it's not appropriate for this children to be at home, in their homes, because they're not taking care of them like they supposed to.* "(CBRW 1)

Neglect of the children within households was raised by another CBR worker as a major hindrance to the provision of services within the home environment.

> *"You know in our community, there's lots of stuff going on...sometimes the parents is maybe under the influence ,... or there's nobody at home, the kid is alone in the street. That happens a lot of times in our community where I stay in, where I work with the kids... in my own personal opinion, it's most of the neglect that is going on."* (CBRW 9)

In explaining the situation above, the CBR worker shared how the lack of hygiene and care for the children in this context was a factor of concern for them. On arrival at a home, finding that the child was not clean or had a dirty nappy that needed to be changed or hadn't been fed yet, was often very disheartening for the CBR workers. They would then have to wait for the caregiver to provide such basic care for the child (such as feeding and cleaning) or reschedule the appointment given that rehabilitation strategies cannot be provided under such conditions.

The community-based rehab workers showed deep insight into the social issues raised, identifying and validating the difficulties surrounding disability and community integration.

> *"They are good people, they are not working, they are suffering financially, and also, because most of them are working with disabled kids, so there are a lot of stress. There are a lot of drinking, sometimes when you do a home visit you find some parents, they are drunk. Not because they want to but there are a lot of stress."* (CBRW 4)

One interviewee further elaborated on how she would use an uncomfortable situation to rather address these social issues and create an atmosphere of trust and team-work with the caregivers:

> *"Because sometimes ,... in the home visit reports, you will ask some difficult questions, like "do you have something to eat?" And then you can see they want to tell you there is nothing, but they will say "no, we fine". So, then I will say "you can be honest, I know it's a difficult time." And that's where they can see, and they can tell me "No, we need something to eat."* (CBRW 9)

4.4.4 A lack of organisational resources for CBR

Inaccessibility of resources was noted by 3 study participants as negatively impacting on their service delivery. This included either not having access to the necessary resources and equipment (where they would have been easily accessible within the centre), or not having sufficient space to properly utilise these resources within the homes.

> *"Only one challenge that would have been a challenge in that time ,...when you need it, maybe a specific resource, or a piece of equipment that moment, and you didn't,...have it with you."* (CBRW 3)

> *"So yeah, I have found it's a valuable method of therapy. But I also think that not everything is possible on a home visit, so there's, there's many things that you can do better in a central place. For example, when you're doing splinting, wheelchairs or things that sort of take time and require specialised equipment. And it's really difficult and time consuming to do that on home visits."* (HCW 1)

The two study participants quoted above note the difficulties experienced whilst working in the community and not having a resource that they need - such as a side-lyer or wedge - in order to position a child. The lack of this equipment could very well have been due to the CBR worker having to perform a session within the community that was unplanned, or a particular piece of equipment being inadvertently left behind at the NGO office. Without the ease of readily available transport for CBR workers, they cannot quickly return to the NGO office to access something that is required or has been forgotten. The NGO only has two vehicles available and the CBR workers are dropped off in a community earlier on in the day and only collected later - if the community is not the community that the CBR worker herself resides in.

Another CBR worker commented on the lack of space frequently found within a home for assistive devices or other therapy equipment. Therapy equipment can often times be large and irregularly shaped, such as a standing frame or side-lyer, making these pieces of equipment difficult to transport to and from the children's homes for therapy or have caregivers willing to store within their homes. The CBR worker quoted below articulated that she would want to make use of such equipment within a therapy session with a child at their home but would not be able to transport the equipment or store it at the child's home due to its size and shape.

> *"There is not enough space for our resources sometimes."* (CBRW 2)

The following health care worker made note of her viewpoint that CBR should work in conjunction with other methods of service delivery in order to holistically address the child's rehabilitation needs. She however noted that CBR service delivery methods were essential in order to be made aware of the home environment and available space. This was articulated as necessary in order to issue space-appropriate therapy equipment and assistive devices that could be kept within the home and used by the caregivers.

> *"I've done a home visit to pretty much every child in our organisation that has CP because when it comes to issuing equipment you have to know what the home looks like and you have to actually do it there with the equipment that they have. Otherwise, it's very difficult for them to translate it out of the therapy room to the house. So yeah, I think there is a benefit and it's really important to do home visits. But that potentially, it's difficult to do everything home visit based."* (HCW 1)

4.5 Perceived and experienced barriers and enablers to implementing CBR

In line with the study's objectives, a number of themes emerged from the interviews that were highlighted by participants as either ***enabling*** CBR delivery or ***hindering*** therapeutic services. Often, however, a single theme could be interpreted in a positive light by some of the interviewees and in a negative light by others, depending on the context and the perception of the interviewee. Thus, a single theme (such as time or communication) was often seen by some as an enabler and by others as a barrier. These themes – whether they were enablers or hindrances or both are discussed below.

4.5.1 Considerations related to time

The issue of time was highlighted as both a factor that could positively influence the CBR workers' service provision or negatively impact their service provision. For example, for some, the time taken to travel to a community to provide CBR and/or time ‘wasted’ because a patient was not available, was seen in a negative light by some in comparison to having scheduled therapy appointments in a central area. The health care worker noted that time for her was a commodity that she felt was not utilised effectively by doing home visits - a CBR strategy -resulting in a lot of ‘wasted’ time, and in conjunction, time was utilised in a more effective manner with Institution-based rehabilitation.

> “*...it's difficult to do …home visits because there's travel time in between, plus there's always like the navigating the social introduction, which takes time and because you have to prepare the space and make sure that only the relevant people are there, and you have to work with what the family has. So that's also like time consuming and often like more effective if you can just have patient after patient after patient at a central spot. So I think that there's an expense to doing home visits.”* (HCW 1)

Most of the study participants noted the challenge they faced in caregivers not being at home at the time scheduled for the CBR session, and the decreased efficiency in service provision given they had to then re-schedule appointments. The following health care worker noted that:

> *“I've had quite a lot of home visits where you know, you inform the parents about the visits and then you arrive and they're not there, for the visit. And now you've spent like a lot of money and time going to the community.”* (HCW 1)

In contrast, one CBR worker noted the freedom she experienced with being able to manage her own time within the community and subsequent CBR sessions provided her with increased job satisfaction and feelings of efficacy. This CBR worker noted that when she was able to manage her own time, she could utilise it to build therapeutic relationships with caregivers of children with cerebral palsy which would essentially improve the outcomes of her therapy session.

> *“And one thing about me, I'm not going to make an appointment to see you if I only have 5 minutes. I am going to sit with you and make myself comfortable, [drink] some coffee or some tea, because we are now so comfortable [with each other]. Sometimes*

> *they don't even want me to leave, or they even walk with me to the corner [of the street], so this is the relationship that we have built by now."* (CBRW 5)

The sense of considerations related to time being perceived as a positive experience was observed as being a minority opinion in contrast to many CBR workers noting the difficulties they experienced with time related considerations and provision of services within the community.

4.5.2 Receptivity of caregivers to CBR

Being accommodated by the caregivers and families was seen by the community-based rehab workers as highly important in determining the success of their visit. This accommodation was seen as the attitudes that caregivers of children with cerebral palsy as well the surrounding communities had towards CBR service provision and the related CBR workers. These attitudes were often times relayed through how welcome the CBR were within the caregivers' homes and how these caregivers' answered questions or how they eager they were to work together with the CBR workers. Throughout the interviews, this was either an enabler or barrier, being situation and person specific. This specific CBR worker experienced the caregivers lack of receptivity through not being welcome within the home and noted how this negatively affected her perception of the CBR service delivery.

> *"Sometimes people didn't want us there...Sometimes[we] were not welcome. They got tired of us coming there, every second day or every third day...Sometimes they would lie and say no, somebody's sick...When you come to [the] house and you,... have a plan for the day, that today I want to do this for the child, and then the family isn't accepting of your being there. So that was one of the things that was not nice for me."* (CBRW 3)

A few of the community-based rehab workers shared their interpretation of why they thought some individuals and families were less accommodating of their visits, suggesting that it might be due to their lower level of income and various social issues within the household:

> *"And then some of the people were like, "no, it's fine, you can come, I have nothing to hide." But the most interesting thing for me is the way the people approach you when you come to their houses. It was like some of the people are friendly. Some of them were like, "no, you don't come into my house". Some of them are a little bit shy about their houses. Maybe some of them were embarrassed."* (CBRW 9)

The CBR worker above suggested that some of the households she visited were hesitant to welcome her in due to their feelings of shame about their impoverished homes. The health care worker also noted that she experienced a lack of receptivity by some community members and attributed this to individuals within the community opposing change (such as a change in delivering therapeutic services from children with cerebral palsy from institution-based to community-based rehabilitation).

> *"And, yeah, those kinds of barriers are huge. And I think also just the attitudes of the community. And we find that there's some communities who are less receptive... And they have been doing things in a certain way for many years, and are not really wanting to change. Also, a lot of people don't really want anyone in the house. That is also an understandable area, but a barrier."* (HCW 1)

This lack of receptivity of caregivers to CBR and the CBR workers was mentioned in the majority of the interviews and came across as being a very significant barrier for the CBR workers. It was often shared in the interviews that the CBR workers often felt uncomfortable and that their presence was not felt to be welcomed within the homes. Understandably this was seen as a barrier to service provision and the creation of a trusting and reciprocal relationship between important stakeholders, the caregiver and CBR worker.

In contrast to the above experiences, one CBR worker mentioned that she felt welcome in the households that she delivered CBR services and that this increased receptivity towards her, assisted her in gaining insight and information into their situation:

> *"Whereas in the welcoming environment I got a lot of information."* (CBRW 4)

Similarly, another community-based rehab worker shared how her experience of caregivers in their own home was a positive influence on her service provision as she perceived the caregivers were more comfortable with her in their home and would display greater levels of engagement with the session.

> *"I think that the positive thing is that you will have to be there, on..., their own comfort, because they tend to be more comfortable in their own space."* (CBRW 11)

The power of this reciprocal relationship that was created between this caregiver and the CBR worker highlighting how such a welcoming and receptive environment was a pinnacle in the provision of a service that the CBR worker was pleased with and that she deemed would benefit the child the most.

The receptivity of caregivers to CBR and CBR workers was seen across the interviews with the CBR workers as a contributing factor towards their experience of success or failure within service provision in the community. Most of the instances named mentioned the lack of caregiver receptivity and the negative impact this had.

4.5.3 Lack of Accommodation of and buy-in from the caregivers of CBR

This was the most commonly raised theme across all the community-based rehab workers' interviews. All of them noted the increased difficulty and service delivery issues due to some caregivers' not accommodating them on their visits. This lack of accommodation was displayed through unwelcome environments created, the caregivers not availing themselves throughout the session and decreased buy-in and co-operation within the therapy process.

> *"...some of the parents, they don't care. you talk to them, ...You come back and it's like, they don't want [you],...they are not involved, they are not participating."* (CBRW 11)

> *"...they've been given tasks to do, then you would find out that you need to keep on reminding or doing follow ups, otherwise what we're expecting from them, it won't be done."* (CBRW 8)

As seen from the above two study participants that lack of reciprocal participation from the caregivers and their assistance with the rehabilitation process and performing home programmes with their child was a barrier for therapeutic service delivery. They felt that the information that they gave the caregivers with regards to a home programme that the caregiver needed to perform with the child, was not implemented, and that they would see the evidence of this at their next visit and would have to relay the same information again.

The lack of accommodation and buy-in from the caregivers in the therapy process was often times disheartening for community-based rehab workers, decreasing their levels of job satisfaction, as noted by the following CBR worker:

> *"Like I said, challenges [were] like when you show the parent what to do the rest of the week and you come back and the parents didn't do it. And you find the child very stiff than before. You felt like, I'm the last person that touched this child in this manner."* (CBRW 1)

This CBR worker's sentiments of feeling like she was working in isolation with little reciprocity from the caregivers and continuity of care were also noted by others. The general tone of these conversations were melancholic and the sense that the CBR workers were disheartened was palpable.

4.5.4 Establishing an atmosphere of reciprocal learning

One of the key enablers identified by 7 of the 11 community-based rehab workers was their own ability to create an environment where the caregivers not only learnt rehabilitation strategies and home programmes from them, but that they, as the community-based rehabilitation workers, were also open to learning and exploring with and from the caregiver. This was termed reciprocal learning by the researcher, describing where they could both learn from each other. The following health care worker saw this benefit of reciprocal learning within some of her service delivery sessions, how together with the caregivers, they could reach solutions quicker and easier.

> *"...there're parents that are like taking initiative and prioritizing...and they are happy for you to come into their house, because they realise the value of you being able to actually see how they live and also parents that are able to problem solve for you,... or together with you."* (HCW 1)

> *"[It's] enjoyable at [their] home,...to see how they do it. And maybe to,... improve that by sharing what we know, or what we can show [them]. Or,... what we can get from them, what we can learn."* (CBRW 3)

The benefit of learning and teaching going both ways between the caregiver and the CBR worker was further re-iterated by the above study participant.

One of the community-based rehab workers took the reciprocal learning theme broader than just between the CBR worker and the caregiver and explored this theme within the greater community. She mentioned how family members of the child with cerebral palsy could further take what they had learned from a CBR worker and share this knowledge within the broader community, potentially aiding someone else who has a similar situation, as stated below:

> *"...the whole family gets to be included in that, they get to see and they get to learn. Which they can also again take and share with other people in the community who are facing similar situations."* (CBRW 3)

Further learning was identified by some within the organisational system, amongst the CBR workers. This CBR worker noted below how a safe, reciprocal learning environment existed between her and the occupational therapists which enabled her provision of therapeutic services.

> *"So I'll run to the OT's to give me... some ideas, which....toy I can give, or which exercise is right for this child,... am I doing....stretches [right]?. Is it fine? Sometimes, we take videos, if I'm in the house, and then send it [to the OTs] and then I asked if it's right. Or can I add something? Yes, so they are helping us..."* (CBRW 2)

The theme of reciprocal learning was also identified within the support group system that the organisation holds for all parents and caregivers to attend once a month. Here reciprocal learning was noted to happen amongst the parents and caregivers within a safe and supportive environment that was created within the support group. The following CBR worker recounts an instance that occurred during the support group, where one caregiver shared what she was struggling with, and another caregiver supported her and gave her advice.

> *"There was one lady who really poured her heart out and then there was another parent to support her and tell what to do and tell her everything is going to be okay. And all of us here inside, is going through the situation that you're going through, we've been there."* (CBRW 9)

4.5.5 Organisational support and mentorship

Nine of the study participants highlighted organisational support and mentorship as a key enabler for effective delivery of rehab services within the community. The first form of support identified was support from the organisation to the community-based rehab workers, in the form of training, workshops and mentorship. The following CBR worker noted on the mentoring relationship that she has with her direct manager and how she has learned good communication and people skills from her.

> *"Sometimes when,... I didn't know what to do or what to tell the people,...I would always go to [CBR worker manager] because she is very good. And that's where I*

> *learn how to work with people. She will always give me some good answers, [like] what to say, when I don't know what to say."* (CBRW 9)

> *"...our job is very stressful, so sometimes they give us sessions, or trainings and also a session to debrief [with a psychology student volunteer], because there's a lot of pressure."* (CBRW 4)

This CBR worker above noted how the NGO prioritised the CBR workers' wellbeing through acknowledging how the work that she provided would be emotionally taxing and how she felt supported and seen by the organisation through their provision of psychological support. A sub-theme that arose within the interviews was also the support and mentorship that the organisation provided for the caregivers and parents of the children with disabilities. The following CBR worker noted the support that the organisation arranged once a month for the caregivers together with some of the CBR workers, creating a space and atmosphere for the caregivers to share their concerns and troubles as well as create an environment for support and community between the caregivers.

> *"... according to the situation you, you decide like, okay, I'm gonna invite this parent for the support group. And they come to the support group and then we make lots of advising on how to help [them] out..."* (CBRW 10)

> *"And then [the organisation] has everything, the resources... You get everything at one place...[they] even provide transport....There's lots of services they offer."* (CBRW 10)

The above interview mentioned that the organisation provided assistance with transport of the children from the community to the organisation as well as transport of the parents to the support groups showing how invested the organisation was. Other resources were also mentioned by some, such as food package distribution within the community during COVID-19 lockdown periods. Not only did the organisation assist the children and families with rehabilitation related issues, but they also encompassed complete support and guidance, providing a sense of caring wholeheartedness, as noted by the following study participant:

> *"They care a lot and they follow a story,... they follow your,... problem with your child, they follow it...[till] there's a solution... They follow any kind of problem that the parent [has]... with the child...they [are]...very good for them. They start a child from zero up... Stories turned out to be successful."* (CBRW 1)

> *“...and... what they're doing,...make[ing] a difference to other people's lives. I think that that's what keeps us going. And the fact that...management is also working alongside... staff,... they [are] encouraging...the staff to ensure that...service delivery that we're rendering to the community's, [is] of good value.”* (CBRW 8)

The above CBR worker once again made note of the support they felt they had received from the NGO and displayed their understanding that the NGO knew it was only as strong and effective as the sum of all its parts, e.g., the CBR workers. It was noted during numerous interviews that the giving nature of the organisation created a receptiveness within the community and the caregivers between them and the CBR workers and how this was an enabler for more effective service delivery. The excerpt below from one of the CBR workers noted the willingness of the organisation to assist the caregivers with social and managerial aspects around having a child with a disability. She mentioned that the organisation would assist the children and caregivers in applying for necessary documentation such as birth certificates, that the organisation knew would be essential for the caregiver to apply for a care-dependency grant (i.e., a disability grant for children).

> *“Because [the organisation],... is helping,...giving information. Because some people...don't know these things,...the government is not going to the people to give this information. But [the organisation], give[s] the information, we give the information that "no? The child doesn't have the birth certificate? [okay], let's try this, let's try that. Let's approach home affairs".”* (CBRW 11)

4.5.6 A sense of connectedness and teamwork

Teamwork and connectedness emerged from the interviews as an integral part in ensuring the success of community-based rehabilitation. Some caregivers and parents displayed a sense of ownership over home programmes and tasks given to them, as well taking responsibility for appointments arranged and creating an environment suited to the appointment. Many CBR workers viewed this as pinnacle to a successful visit. The following CBR worker noted that she felt a sense of teamwork with the caregiver when the visit was arranged in time and she could see that the caregiver was prepared for her.

> *“What make it [CBR] successful is the co-operation between the fieldworker [CBR worker] and the parent. If you organise [the home visit] in time,... then when you get there the parent will be,...organised.”* (CBRW 10)

The following study participant noted that her therapeutic services were enabled through team-work she experienced when the caregivers did the children's homework with them or the home program given them. She noted that this displayed interest from the caregivers part in the therapeutic process as well as a sense of ownership.

> *"And every time we come the child [has] already done the homework...the parent will also involve themselves in the activity for the children,... And then they [are] willing for us to come... They interested [in what you are doing with the child] if you've got questions [for them]...they [are]willing to answer."* (CBRW 2)

This sense of teamwork between the CBR worker and the parent, working towards a common goal and having buy-in within the rehabilitation process was noted by the majority of CBR workers as essential in the CBR worker determining if a CBR session would be successful or not. The theme of teamwork was further explored within the larger context of the organisation having heard some of the CBR workers comment on the teamwork they felt existed between them and organisation. This specific CBR worker had taken cognisance of the fact that she felt that there had been clear communication of the goal of the organisation which had contributed towards them all working towards the same common goal, having created unity amongst all stakeholders and ensured the success of the CBR intervention.

> *"And then [the organisation] has everything, the resources... You get everything at one place...[they] even provide transport....There's lots of services they offer. And characteristics of the people...You've got...staff that understands the job and the goal of the organisation. So I think [that's] the other thing that makes us successful, because we are all working towards the same [goal]...so unity,...and the same goal in mind."* (CBRW 10)

Connectedness and the feelings of satisfaction and efficacy due to this connectedness between them and the caregivers and families of children with Cerebral palsy, was touched on by many CBR workers. The importance of relationship building, mutual understanding and engagement was noted as being an enabler to creating this connectedness to further success within the therapy process. The following CBR worker communicated that this connectedness was created through engaging and communicating with the families, incorporating them into the therapeutic process.

> *"So we are always engaging with the families. I think that's,...why we are successful."* (CBRW 10)

The study participant below noted that by doing *rehabilitation* together, this connectedness and team-work was built.

> *"...doing it [rehabilitation] at home, we get to do it together."* (CBRW 3)

The following CBR worker mentioned how a sense of friendship between her and the caregiver made her job easier, alleviating the burden that such social care and support can often times have on a CBR worker.

> *"So we are,...the field worker,... for the whole family. And then you find out the parent has no one to talk to...It makes our job peaceful, because now you are the friend that they don't have,...and then you make it better...and they know that they can,...talk to you anytime....So that,...also makes our job easier."* (CBRW 11)

Teamwork and connectedness were noted during the interview process as an active engagement between the CBR worker and the caregiver, often requiring the CBR worker to put in a lot of effort and using her own initiative in building and maintaining these relationships. This wasn't something that always spontaneously occurred but required sacrifice and intentionality from the CBR worker, as noted from two of the CBR workers below:

> *"Through doing home visits, it is... a building of relationships. to give the parents that sense of security that there is this person,...I can go through this [difficult] thing with them."* (CBRW 5)

> *"Like,...most parent[s] that I'm working with, it's like, [they are] part of my family now... I know their birthdays, like if it's Mother's day, [I] send [them] a message. Like they're part of my family."* (CBRW 4)

The following CBR worker noted that her being aware of the difficulty that some of the caregivers were going through with having a child with a disability, as well as her acting upon this, showing empathy and trying to share the responsibility and being kind, not only enabled her to feel success during the CBR session but further fostered this teamwork and connectedness. She communicated that she often did half of the therapy session with the caregiver and then gave them space to do other tasks within the home or rest, and in so doing, share some responsibility in taking care of the child.

> *"So for me if, if I was able to go out for one hour, with one child, it meant something to me. It was a little bit of weight off of that parents shoulders. For one hour she could...I would let the parents sit in for half an hour and half an hour I would do on my own. So that gives them like a breather where they can go out and do something without having to watch the child."* (CBRW 3)

After hearing the below remark during an interview with a CBR worker, a foundational change occurred in the researcher and her perception of the data collected thus far, resulting in the realisation of the importance of all stakeholders feeling and fostering this connectedness. For this CBR worker, provision of services within the community gave her a deep sense of seeing others as well as being seen.

> *"Oh...[what] was it like working with the community? Face to face, hand to hand, heart to heart. Like that, Ja."* (CBRW 9)

A sense of teamwork was mentioned not only between the CBR worker and the caregiver, but also between the community-based rehab workers themselves, indicating that the success of the team as a whole was important to all involved, as mentioned by the study participant below:

> *"I ask the teachers to assist me and even [the occupational therapist].I asked them,..."I started with this [activity], how can I do [this activity]? Because I am trying all the angles in order to get this child [to participate]. And I also asked the OTs, they also give me help."* (CBRW 6)

4.5.7 Communication, transparency and trust between the CBR workers and the caregivers

This theme emerged throughout the interview process as both an enabler as well as a barrier - if communication and transparency were not present. The importance of good open and transparent communication between the caregiver and the CBR worker was noted, and how this then further enabled transparency and trust which would further enable a more effective and efficient therapy session. The following CBR worker noted that, in time, and with good communication and engagement, the caregivers of children with cerebral palsy got to trust her and communicate effectively back.

> *"You notice the second time you come for the visit...you get to engage with the parents, you get to communicate,...And then you eventually get the answers...[from]the parents, without you asking sometimes."* (CBRW 10)

This study participant noted the lengths that she would go to in order to ensure adequate communication, making note of its importance within the therapeutic process.

> *"I want to go back, if there is something that I need to follow up on, then I want to go back and give the parents feedback. Then we work from there. So for me, it's about how much you communicate [with the parents]."* (CBRW 5)

One CBR worker noted the non-verbal aspects of communication that were necessary in order to create a CBR session that she deemed as being effective. These aspects included reading individuals' body language as well as the 'atmosphere' within the home and being respectful of these. She displayed insight into having to communicate these and ask the parents if the CBR session was convenient for them or if they should re-schedule. This seemed to display mutual respect and create transparency. She also noted her own responsibility in having to create this atmosphere in which the most could be done for the child and how to win over the caregivers.

> *"You should be able to read the atmosphere, how the people feel that day. Then you should ask 'is now the right time for a visit?'. Sometimes you get to people and you think to yourself 'what is going on here', but they aren't going to tell you they don't feel well, unless you ask. So I always ask 'is today a good time to chat or should we rather chat another time?' So a person always needs to create that atmosphere....so that we can communicate that to each other and understand each other well."* (CBRW 5)

An important aspect of this theme was the CBR workers ability to create an environment of trust. Showing the caregivers that they could trust them with their children, their needs and their information, and that trust was earned. Both accounts below demonstrate how the CBR workers noted that through visiting and communicating with the caregivers in their own homes, a relationship of trust was built. This made the caregivers more comfortable with the CBR workers and this acted as an enabler for communicating difficult things.

> *"And to find out what the parents need most, because some of the parents,...you call them maybe for [a] meeting [at the school], they're not willing to share [at the*

> *meeting]. So as you go... one by one [to their] house, you get information about what they want, what they need, or the condition of the child...Sometimes they're not sharing [this]... at school. They [are] very shy, not comfortable to give all the information. So they willing to trust you, as you are coming [to their home] one by one."* (CBRW 2)

> *"But me, I don't have, ...the right to,... dig, but I just make the parent...see that she is welcome to share."* (CBRW 6)

The above account from a study participant showed that she understood that this trusting relationship takes time to build and is often developed through non-verbal communication and being non-judgemental.

The importance of this trust and communication being a two-way path was noted by the following two study participants. It was of some of the CBR workers' opinions that in order for some caregivers to communicate and trust, they had to do it first, they had to show that they would be transparent and trusting.

> *"They [are] very open,...I trust them, they trust me...They were easy,...they ask questions. They want to learn more, and also the way they were talking about education, what is going on at home, everything."* (CBRW 4)

> *"First thing, you must let the people trust you...Sometimes they will talk [about] everything with you, because they trust you."* (CBRW 9)

4.6 CBR worker characteristics and traits

This theme was not overtly expressed by the community-based rehab workers themselves, but is drawn from the observations and reflections that the researcher made during the course of conducting the interviews with the CBR workers. It was clear that certain characteristics of the CBR workers - that were either learnt or innate, assisted the community-based rehab workers in delivering a service within their communities as well as knowing how to approach all individuals involved.

4.6.1 Observations on the characteristics and traits of the CBR workers

Knowing how to navigate the social interactions with caregivers and how to approach them in order to create an environment of receptivity was the main trait that most community-based rehab workers mentioned, as noted by the CBR worker below:

> "*...and that person's house,... it was quite small,...and I can see in their faces, they're... embarrassed. Because outside you don't even know that they are living in that situation...So I try my best to say 'no, it's fine. I will come again' and 'you can tell me if I can come in or not, but it's fine, we can speak outside.'... I would say it's my personality. I know it's work, but I will try my best not to make it like work, I won't let them see [it's work]. I will come with my papers into their house but I won't let them see I'm sitting like this [filling in forms],...Because I know my people feel very,... uncomfortable when people come with papers and pens and are very serious and then they will almost like shut down. So it's a way of approaching them...That's how I'm doing it, an approach,...to do with their community or certain families. And some of the mothers are very,...shy. [they] don't want to talk. Some of them are embarrassed. Some of them are very private people. So you must do,... everything just to get them comfortable...Yes, it's our approach, all of our ladies [CBR workers], we treat the families, the people,...like family...We don't treat them like we are the field worker so you must,...just listen to me. We treat them like family."* (CBRW 9)

Another characteristic that was noted was the flexibility of the community-based rehabilitation workers to set aside formal plans in the interests of their client and context in which they were working. They weren't rigid in sticking to therapy plans or job descriptions, and just as the organisation's vision was to help individuals in whichever way possible, the same willingness from the CBR workers to assist and help with all things was also a strong sub-theme that came through in their interviews. The following study participant articulated that she would enable CBR service delivery by being flexible, helping the caregiver with whatever she could.

> *"You know, some of these parents...are going through difficulties or challenges,...[you] can help them with that...[you] cannot just say to the parent 'no, that's not in my field, [I] can't help you with that.' You will have to provide them with alternatives...Instead of shutting the person [down] and saying 'no, that's not my job, I'm not here for that'....they won't be able to ask you or tell you anything else.*

> *Because now she's afraid of the answer,...so it's all about having the right approach."* (CBRW 10)

A few of the CBR workers showed how accepting of other people and their differences they were – and how non-judgemental they were; accepting others' lifestyles, cultures and ways of life and seeing this as an enabler to moving towards working together for the good of the child. The following CBR worker noted the importance she placed on not judging the caregivers and how this enabled her in her service provision.

> *"It's not to judge. When you are there, you don't have to judge...you are there to assist and facilitate. So that helps a lot."* (CBRW 11)

In the course of the interviews, many of the community-based rehab workers displayed excellent work ethic, dedication to the cause and a passion and love for the children and their communities. This was often noted as absolutely necessary for the success of such a programme within another community. When asked what the CBR workers thought would be necessary for other CBR workers to carry out similar services in other communities, characteristics such as love, generosity, dedication and having a passion for working with children with special needs were highlighted as necessary. Some of their suggestions for other CBR workers were as follows:

> *"I think their [CBR workers] must have good hearts. You want to give back to the community...when you've got something, you don't want to hold it to yourself,...so for them to share that love around...You give not to expect to something back. You give with a good heart,... with a clean heart*." (CBRW 4)

> *"I would feel like there must be somebody who,... loves what they are doing. They must be really interested, and love what they are doing, and love people and love children....That person must really have a passion to work with [children with special needs]...like the [NGO's name]."* (CBRW 9)

Many study participants also commented on the positive re-enforcement that they received after seeing the impact that they had made with a child, family and community, and how that further motivated and enabled them to remain persistent with community-based rehabilitation. They would see the child improve and build relationships with the caregivers, and this would make them feel good, and inspire them to keep on going. It was as if the positive feedback they received in seeing how their sessions had contributed to a positive change with the client, further enabled them to keep on doing CBR sessions with others. As two CBR workers shared:

> *"...[the CBR session felt] very nice, I felt like I am doing something...[for] that child. I [am] making that child's day. I felt very excited. It was my best year [just utilising CBR strategies]. I like working like that...it was very exciting for me, I was loving it.*" (CBRW 1)

> *"Just a sense of knowing that I am concentrating on this child now. And the feedback that I was getting from the parent...the feedback that I got from the child...It feels good to know that she's enjoying this. This is helping her here...[and] there."* (CBRW 1)

4.7 Perceived extent of broader implementation of CBR strategies

4.7.1 Organisational support and mentorship

Although this theme has been discussed as an enabler for community-based rehabilitation, it continued to emerge as a theme for the success of broader implementation of CBR within other communities. The following CBR worker noted the importance she placed on being trained by the organisation in order to work within communities with caregivers of children with rehabilitation needs and the continued support that they deemed as necessary for the success of such programmes. The health care worker noted the importance of a central office or 'base' as she put it, where all staff (CBR workers included) could meet, re-group as well as learn and be trained at this central organisation or office.

> *"I think it's very translatable into any context. I think that they will need a base. I definitely think that a base, where all the field workers come together, and receive training and receive mentorship is very important."* (HCW 1)

> *"And they will need lot and lots of experience,...experience like trainings. First training...[and then] more trainings. So that once you start, [you] won't just fall apart."* (CBRW 1)

The above CBR worker noted that she placed so much emphasis on support from the organisation through the provision of training, that without it, any CBR endeavour would not last.

It was also noted by the health care worker how the lack of adequate support, training and mentorship of CBR workers could have a major negative impact on the implementation of CBR strategies within other communities. The health care worker also noted that this process of training and support takes time and effort.

> *"And I think a big barrier is also education and finding people that are properly qualified for the job, because to be a field worker and like a community rehab worker,...we just realise more and more how much training they need...And so, you know, field workers need basic counselling skills, field workers need experience working with children with disabilities in our context. They need to understand disability. They have to understand the parents' perspective. They have to be able to navigate those social situations. And they also have to be the right kind of person, and we, we are realising more and more that not everybody is cut out for that."* (HCW 1)

Organisational support for the community also became a strong theme for the success of broader implementation of CBR within other communities. This strongly linked with a previous theme of teamwork, connectedness and buy-in where some of the CBR workers noted that shared responsibility and ownership between the organisation and the caregivers contributed to the success of CBR strategies within the community. The following two CBR workers made note of the support that they saw the organisation provided the caregivers and community, and how they deemed this as something that created trust, awareness and reciprocity from the community towards the organisation.

> *"They [the organisation] are assisting them [the community] with a lot of things,...to[be] aware that as a parent to... child[ren], [that] are disabled. They are...[creating]awareness,... and support group[s] and then the parent[s]...come...[to the] support group. Then each and every parent...talks about...[their] problems and then...they...[have] insight, and then the others [parents]...support that person...[yes], they support each other.*" (CBRW 7)

> *"And that's where the people and the parents open up to [the organisation], because they see it's not only 'come to the centre, come for therapy.' We help them also."* (CBRW 9)

4.7.2 Community awareness of disability and therapy

Importantly, many community-based rehabilitation workers noted the lack of community awareness of children with disability and how this was a barrier that they needed to overcome in order to deliver a service to the community. The following study participant communicated below how the organisation assisted in creating disability awareness within the community, teaching caregivers and other how to relate to these children.

> *"And they assist them a lot,...the parent, to know how to relate to...children with disabilities. They mustn't lock [the children] inside the house...the parent[s], have that knowledge to open the[their] mind that this is my child."* (CBRW 7)

The following CBR worker when asked what she deemed important in order to ensure the success of CBR strategies in a similar environment, made note of the importance she placed on creating awareness within the community. She was of the opinion that due to decreased awareness of disability, many parents or caregivers kept their children indoors, not sending them to school or for rehabilitation, as well as keeping them from their surrounding communities. This CBR worker saw that as a major barrier in her delivering an effective service and noted below:

> *"Okay, the difficulties I see,...the parent didn't come out with their child, so that I [that I need to] do awareness, awareness, awareness... So that the parents can see what I would want to do in this community. So...I think I could do,... maybe awareness and support groups."* (CBRW 7)

It was highlighted that receptiveness to community-based rehabilitation was low due to the community not being aware of disability and the role and value that community-based rehabilitation would have, and that increased awareness and information, would assist in caregiver teamwork and buy-in. The following CBR worker noted that with increased disability awareness, the communities and caregivers would understand her job and the necessity of service provision within the communities, further enabling her.

> *"Understanding people, they understand...why are we doing the home visit? We are doing it to support the parents that are in need, that have,... special need kids."* (CBRW 4)

The study participant below articulated that through lack of disability awareness within the community and provision of information, communities and caregivers would react badly to CBR intervention strategies.

> *"Like doing awareness. Like go to school, talk[ing] about it, go to clinic, like make the people aware. Like there's an organisation like this,...[they]are reacting badly, because they don't have information."* (CBRW 4)

The following CBR worker went so far as to say disability awareness has the potential to enhance the child's quality of life.

> *"Educating the community. In this case, particularly about children or people,...with disability, to educate. To enhance their quality of life."* (CBRW 3)

The results of the study were reviewed within this chapter and the study participants understanding of the concept of CBR was explored as well as the physical spaces and settings that CBR was provided. Further exploration was done of the enablers and barriers that were perceived by the service providers , as well as CBR worker characteristics and traits and their perception of broader implementation of CBR strategies.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This research study sought to explore the experiences of an NGO providing community-based rehabilitation in a rural area over a 5-month period and what they deemed were the enablers as well as barriers to the provision of such services in this community. The study aimed to describe the NGO's experiences so that other organisations that were considering the transition to community-based rehabilitation could potentially learn from the experiences of this NGO. This chapter will consider the findings of this study and relate them to what is already known about community-based rehabilitation enablers and barriers within the literature. The implications of the study findings will also be reflected on for practitioners working in the field and how this could potentially influence rehabilitation strategies implemented for children with cerebral palsy as well as the potential impact of the findings on community-based rehabilitation services going forward.

Few studies, to date, have remarked on community-based rehabilitation workers' experience of delivering these services within low- and middle-income settings (Dambi & Jelsma, 2014; Finkenflügel et al, 2005). This study aims to provide new information that could contribute to the evidence base of community-based rehabilitation and, by implication, guide policy development and provide further support for the restructuring of rehabilitation to become more community-based.

5.2 Logistical challenges and the physical setting of working in a rural site were barriers to CBR

One of the sub-themes that emerged through the interviews was the physical barriers the community-based rehab workers felt whilst performing their service in the community. One of the first issues raised in relation to this was the decrease in physical access that CBR workers experienced in relation to their clients and their homes due to poor road infrastructure or weather conditions. Research suggests that community-based rehabilitation programmes are better suited to low- and middle-income settings due to difficulties caregivers experienced in accessing institution-based modalities of rehabilitation (Donald et al., 2015) as a result of transport difficulties, financial constraints and poor weather conditions (Cayetano & Elkins, 2016). The results of this research study suggested that just as clients experience difficulties in leaving their homes to access services, the service providers experience the same in trying to bring community-based rehabilitation to the homes of their clients. It is thus identified that all stakeholders (both CBR workers and caregivers) experience access as a barrier to receiving or giving therapy. The question was raised by the researcher, as to which stakeholder would be able to more effectively address and manage this lack of access in order to ensure that service delivery still occurs, be it within the community or at an institution. Saloojee & Bezuidenhout (2020), in a review of experiences of community-based peer supporters within two training programmes in South Africa, suggested that the travel and access barrier could be overcome when individuals within the communities are trained as peer supporters for individuals with disabilities within their own communities. This concept of community-based peer support could be carried through to training of CBR workers and allocation of their work areas that are in the CBR workers' communities.

Another issue related to logistical challenges was not being able to access certain resources that would be kept at the organisation and that were potentially forgotten or unplanned for and required in a session. The lack of access to appropriate equipment and resources is reflected in the literature and has been noted as a well-known barrier (Gorgon, 2018; Chadd et al., 2021; Rule et al., 2019) of CBR service delivery. This was further supported by Wuang, et al. (2013), who raised the caregiver perspective of children with disabilities, acknowledging that they lacked sufficient resources and felt that they couldn't provide a sufficiently well-equipped environments for adequate therapy to be provided in their homes. In contrast to this perspective, one service provider interviewed (HCW 1) commented that even though she experienced resource constraints and that she didn't believe all therapy could occur through CBR, she was encouraged by the caregiver's resourcefulness and eagerness to use objects in the home to achieve similar outcomes to those that the facility-based resources could achieve.

Doig, Fleming & Kuipers (2008), drew on the enablement factor that the physical setting of CBR would have, such as providing increased contact time with the caregivers and the family. Through the provision of CBR services, the CBR worker would be able to spend more time engaging and communicating with the primary caregiver of the child with cerebral palsy. This was noted during some of the interviews, with one CBR worker (CBRW 5) reflecting how this increased contact time was essential for her to feel she had delivered an effective therapeutic service. One CBR worker (CBRW 6) noted that the relevant caregiver (i.e. the primary caregiver) was often not at home, with a family or community member caring for the child and that this increased contact time was then had with a pertinent individual.

Another enablement factor was being able to provide more situationally-contextual feedback during therapy sessions within the physical setting of CBR (Doig, Fleming & Kuipers, 2008). This finding was found to resonate with many study participants, with one (HCW 1) noting that the issuing of contextually relevant assistive devices was only possible through provision of CBR services. The provision of such therapeutic services allowed the CBR worker to get to know the child's home and make recommendations with home programmes and assistive devices that were contextually relevant, thus ensuring sustainability and relevance that could potentially be difficult to achieve with primary provision of institution-based rehabilitation.

A further enablement factor that was created through CBR's physical setting was creating a relaxed atmosphere between the service provider and the caregiver (Doig, Fleming & Kuipers, 2008). This perspective was reflected on by one of the service provider’s experience (CBRW 9) of the increased levels of comfort for the caregiver and the CBR worker that she had experienced throughout the therapeutic process which further created a relationship of trust and shared decision-making.

In contrast, this enablement factor as noted by Doig, Fleming & Kuipers (2008) was noted by many throughout the study findings to be a massive barrier to their provision of effective CBR services. Many CBR workers noted that CBR's physical setting was a negative influencing factor on their CBR service delivery attributed to caregiver's unwelcoming attitudes and being unreceptive of them within their homes. One CBR worker (CBRW 9) noted that caregivers sometimes experienced shame around poor living conditions and social issues within the household, creating an atmosphere which was difficult for CBR workers to create trusting relationships in. Within literature, the importance of establishing a therapeutic relationship between CBR worker and caregiver has been noted (Potterton et al., 2009) with a call to a deeper understanding of the complexities of such a relationship (Gladstone et al., 2014). The service providers experiences as described above with regards to understanding the physical setting of CBR service delivery, navigating this and how it can both negatively and positively influence therapeutic services can play an important role in informing a deeper understanding of the fostering of a healthy therapeutic alliance.

5.3 Difficulties faced by caregivers and their impact on CBR workers and subsequent CBR service delivery

Various issues came up during the course of the interviews that highlighted difficulties that caregivers may be facing, both personally and within their communities. Many CBR workers made note of these difficulties and the impact that these had on them as individuals as well as with regards to the therapeutic process of CBR service delivery. It was noted that the CBR workers approached these with sensitivity and fostered a sense of understanding around some of these difficult themes, yet still acknowledged the impact that they had on therapeutic services.

One of the themes that emerged that the CBR workers noted that they had struggled with was witnessing the social issues that they observed the caregivers facing. These social issues included abject poverty, child neglect and alcohol abuse. Alcohol abuse had been noted by some CBR workers (CBRW 1; CBRW 4; CBRW 9) during the study process, as a social evil that often resulted in child neglect, exacerbated poverty and caused a potential breakdown in communication and development of a distrusting relationship between the CBR worker and the caregiver. This was seen as a major stressor and developed into a barrier for the study participants as they expressed the negative impact this difficulty that caregivers experienced with alcohol misuse had on their delivering an effective service. A measure of understanding from the CBR workers experiencing these barriers also emerged and alcohol misuse/abuse was seen as an implication of the caregiver's stressful environments surrounding financial constraints and caring for children with disabilities. McConachie et al. (2000) commented on the negative association between health care usage and parental stress levels showing some resonance with the findings of this study.

Both the literature and the findings of this study confirm the negative effect that a lack of resources and financial stability - or living in abject poverty - has on children’s access to therapeutic care. Financial barriers experienced by caregivers were noted to have a negative impact on CBR strategies in low- and middle-income countries within the Asia-Pacific Region (Cayetano & Elkins, 2016). This study noted that in order to continue provision of CBR programmes, recognising and anticipating these financial constraints could enable the feasibility of these programmes (Cayetano & Elkins, 2016). Poverty was noted by Donald et al. (2014) to significantly impact the caregiver’s ability to provide for their children with a disability. This was re-iterated by some CBR workers as being displayed in the care or lack thereof that the children had received from their caregivers and how this was a barrier to CBR service delivery. The financial implications around seeking medical care and rehabilitation at institutions were also seen as far too great a barrier (Donald et al., 2014). Within the study the participants did not make mention of their concern regarding the financial implications of seeking medical care and rehabilitation for caregivers of children with cerebral palsy but rather noted that they deemed the assistance from the organisation, such as food parcels and transport, that could be translated as financial assistance, was a positive influence and enabler for CBR strategies.

Another barrier raised in this study was the lack of teamwork between the CBR worker and the caregiver. This resonates with Cayetano & Elkins (2016) who suggests that "major barriers to a successful CBR implementation are lack of teamwork and co-operation". This lack of teamwork and co-operation was identified by many of the CBR workers in the study findings and were presented in various ways. These were observed by the CBR workers as decreased co-operation from the caregivers with home programme implementation. One CBR worker (CBRW 1) noted that she felt she was the last person that had "touched" the child in a therapeutic manner.

The CBR workers further mentioned that poor attitudes and decreased motivation towards them and their therapeutic sessions were a barrier they experienced in CBR service delivery. This was communicated by one CBR worker (CBRW 3) as her interpretation of not feeling welcomed and being received within the home, which she noted had negatively impacted the development of an important trust relationship between her and the caregivers. Literature has suggested that this lack of receptivity and poor attitude towards CBR stems from a misunderstanding of CBR strategies as well as decreased awareness of the same (Cayetano & Elkins, 2016). Ebrahim et al, (2020), in an effort to re-imagine rehabilitation outcomes in South Africa, suggest that individual attitudes towards disability and rehabilitation strategies breed from social and organisational belief systems and that a concerted effort needs to be made to combat these negative attitudes. It is proposed that if potential power imbalances between stakeholders, such as the CBR workers and caregivers, are rectified through "nurturing participation and collaboration between all stakeholders", these barriers and negative attitudes can be overcome (Fiorati et al, 2018). This is reiterated by Saloojee & Bezuidenhout (2020), who suggest that if caregivers perceive CBR workers as peers, there is greater potential for them to learn more and participate in therapeutic sessions.

Interestingly, Mayo (1981), suggests that the implementation of home visits (a CBR strategy implemented by the CBR workers), promotes increased parental involvement. The CBR workers throughout the study had noted that lack of parental involvement or teamwork was perceived as a barrier for them, currently. This could potentially, with time, as Mayo suggests, transform into an enabler through increased parental involvement due to rectified power imbalances and a change of poor attitudes towards CBR interventions.

5.4 Organisational support as an enabler for CBR strategies

The theme of organisational support remained continuous throughout the research process with both support from the organisation towards the CBR workers and from the organisation towards the caregivers being strongly noted as an integral part of the success of CBR strategies. Many CBR workers commented on the support and mentorship that they had received from the organisation with specific regard to being upskilled, goal setting support as well as mentorship and socio-emotional support. This support was deemed by all of the CBR workers who mentioned it, as a facilitator to provision of CBR services, as well as a necessity for similar CBR service provision within another context.

Fiorati et al (2018), noted that a barrier to CBR service delivery was the lack of training provided to CBR workers. To date, there is little formal training of CBR workers provided within the South African context (Philpott, McLaren & Rule, 2020), with CBR workers having to rely on the organisations and institutions that they are employed by, to provide informal training and upskilling, such as the organisation studied. A lack of planning and goal setting in CBR strategies were also attributed as a barrier to therapeutic service provision (Cayetano & Elkins, 2016), with the foundations of these being good communication and teamwork between stakeholders. No mention in literature has been found on the benefit or barrier that CBR workers experience through mentorship and socio-emotional support. The organisation in question has displayed attributes opposite to the scenarios mentioned within literature, with the majority of CBR workers interviewed noting the strong theme of support from the organisation and the benefits for service implementation thereof.

The findings of the study showed the organisation's support of the surrounding communities and individuals within them. Many of the CBR workers made note of this, not only with regards to support for the children through receiving therapy, but financial and social support for the communities as well. One CBR worker (CBRW 7) articulated the support that the organisation in question provided through parent support group, food parcels, information and disability awareness and travel assistance for medical care. These measures of support were mentioned to have created a receptiveness within the communities that positively impacted CBR strategy outcomes. In Dambi & Jelsma's (2014) study, the importance of caregiver support was noted and the beneficial outcomes on therapy that the children received, quantified. The positive correlation between patient and caregiver satisfaction with compliance to treatment modalities and outcomes, was also seen within the study.

According to Cayetano & Elkins (2016) as well as Fiorati et al (2018), one additional major barrier to the success of CBR implementation strategies was a lack of intersectoral work, creating isolation and poor sharing of responsibilities between all stakeholders. Through noting the high prevalence of childhood disability within rural South Africa, Couper (2002), mentions the implications of this on service delivery for these cases. Collaboration through all sectors was pleaded for in order to more effectively deal with these disparities. The findings of this study make note of the all-encompassing service provision that the organisation delivers, through collaboration and intersectoral work with various sectors. There were many mentions that the organisation was "caring" in nature and would provide complete support. Their continual collaboration with the Education sector and Department of Social Development was mentioned by one study participant (CBRW 10), in the form of assisting with birth certificate and care-dependency grant applications, through providing transport, information and communicating between the caregiver and official at the relevant department all in order to ensure that the children are accommodated as far as possible.

5.5 Enablement of CBR strategies through community awareness of disability and CBR

Throughout the interview process, the theme of community awareness of disability arose as almost being essential to the success of CBR strategies and having a major impact on some of the other themes that were deemed as enablers for service delivery.

According to Heyman et al.(2020), individuals with disabilities in the South African context are often excluded from interacting within society which is further exacerbated and exclusion re-iterated by shame and stigma. This was confirmed in many of the interviews conducted, which note the tendency of some caregivers to keep their children with disabilities "locked up" within their homes, not integrating them within their surrounding communities. It was alluded to that this was due to shame the caregivers felt with regards to having a child with a disability. The researcher, with her own experience in working with individuals and families with disabilities, has often witnessed this shame and stigma that a community places on individuals with disabilities, with resultant sense that these individuals and their families do not feel welcome and wanted. Interestingly, Heyman et al., (2020) suggest that the construct of disability is rather created by society and communities rather than any lack of physical ability on the individuals' part. It is noted that both the physical and attitudinal unaccommodating nature, by the surrounding communities, creates a sense of an individual feeling like they have a disability (Heyman et al, 2020). Both the physical and attitudinal nature or receptivity of the communities and caregivers to CBR have been themes that have repeatedly come up as barriers to CBR service delivery.

One solution to this would be disability-awareness programmes, as suggested by many of the CBR workers participating within this research study. Heyman et al., (2020:3), further expands on the far-reaching effect of such programmes:

> *Disability-awareness programmes have the capacity to augment disability knowledge, awareness, attitudes and acceptance.*

This resonated with some of the findings from this study as some of the CBR workers mentioned that lack of information, or as termed above "disability knowledge", within the communities negatively impacted the provision of CBR services due to poor receptivity within the communities, attributed to this lack of information.

The receptivity of caregivers to CBR services was another theme that emerged numerous times throughout the research process – also as an enabler to CBR service provision. A number of CBR workers noted in their interviews that they believed that the caregiver's receptivity to CBR could be increased had there been more information and disability awareness within the community. Heyman et al., (2020) terms this receptiveness "attitudes and acceptance" and suggests that disability-awareness programmes would facilitate more inclusive attitudes towards disability. One CBR worker (CBRW 4) noted this awareness around disability as a measure of understanding rehabilitation strategies - namely community-based rehabilitation. She thought that this increased level of understanding on the caregivers' part would facilitate receptivity and build a trusting relationship based on mutual understanding. It was many of the CBR workers' opinions that if there was this attitudinal change within communities and caregivers, the role and value of community-based rehabilitation would be better understood and appreciated, fostering a more responsive and receptive environment for CBR services and the related strategies.

5.6 Implications

5.6.1 Implications for CBR worker training

Training in CBR strategies and service delivery was a theme of importance that emerged throughout the research study. Even though the CBR workers interviewed had only received informal training from the organisation in question, this continually came up as an enabler for the CBR workers and was deemed by the study participants to be a necessity for the success of future CBR endeavours by their own and other organisations.

Forms of informal training and mentorship provided by the organisation included training in various pathologies including cerebral palsy, therapeutic and rehabilitation facilitation through participatory workshops as well as support and debriefing sessions for socio-emotional difficulties the CBR workers could face. Even though the CBR workers mentioned that they were enabled through this training provided, the healthcare worker acknowledged that their lack of formal training was problematic. The health care worker noted that due to the lack of easily accessible formal training opportunities in South Africa, employing a CBR worker with adequate experience and training was difficult, placing an increased burden on the organisation to provide such training – at the start of their employment and during the course of their employment – so that they were suitably equipped to go out into the communities. The healthcare worker noted that adequate training in counselling skills, contextually appropriate rehabilitation strategies, understanding disability and the parents' perspective around disability as well as being able to navigate socially difficult situations, was key.

This need for formal training of CBR workers in South Africa was articulated by Tiwari, Ned & Chikte (2020: 53), with a call for:

> *"formalised training of community-based rehabilitation workers done collaboratively by departments of health, social development and education."*

Access to rehabilitation services within South Africa was mentioned by Tiwari, Ned & Chikte (2020) to continue to be problematic, with 50% of individuals with disabilities not having their rehabilitation needs met, having then mentioned that this could be addressed through formal training strategies in order to increase the number of community-based rehabilitation workers who would then be able to meet this need. In a study conducted by Philpott, McLaren & Rule (2020), it was noted that in order to achieve the Rehab 2030 (Philpott, McLaren & Rule, 2020) vision in South Africa, that community-based rehabilitation workers need to be trained in aspects of clinical understanding of specific pathologies, social and communication skills as well as culturally and contextually relevant rehabilitation strategies. Such formalised training programmes of CBR workers in South Africa are not widespread. For example, the Division of Disability Studies at the University of Cape Town, initiated a community-based rehabilitation and inclusion course that commenced in 2012 (Lorenzo et al., 2020). This provided the opportunity for individuals to become accredited CBR workers after completion of this one-year course (Lorenzo et al., 2020). The lack of similar training courses across South Africa across more accessible platforms needs to be addressed.

5.6.2 Implications on disability-awareness programmes

Many CBR workers noted throughout the study the importance that they placed on disability-awareness within the communities that they were working in. They mentioned that many barriers for CBR implementation would be overcome if the communities and caregivers had a greater measure of awareness around disability and rehabilitation. The barriers they mentioned were negative attitudes and receptivity towards CBR strategies and CBR workers, that they believed would be positively influenced if the communities and caregivers had received more information around their children with a disability, and this would also foster teamwork and connectedness, making their work easier. CBR workers noted that future CBR endeavours could be facilitated by disability-awareness programmes within the communities in which CBR was implemented, and that these programmes needed to incorporate aspects of information and knowledge around disability and the importance of rehabilitation and rehabilitation strategies.

Heyman et al (2020) noted that disability-awareness programmes have the ability to combine information and knowledge around disability and create awareness which influences receptivity to rehabilitation strategies. It was further noted in this study, that true impact in communities through disability-awareness programmes could only be made through the inclusion and self-advocacy of persons with disabilities within their communities (Heyman et al, 2020). A recommendation was made by Heyman et al. (2020) for organisations such as the NGO which is part of this study, to develop and implement disability-awareness programmes lead by persons with disabilities. This could prove difficult for individuals with cerebral palsy due to the nature of the condition and potential cognitive and language difficulties. In another study conducted by Saloojee & Bezuidenhout (2020), there was a review of a nationally implemented programme specifically designed for cerebral palsy in the South African context, namely Malamulele Onwards. This programme is not overtly a disability-awareness programme but focuses on enablement of caregivers of children with cerebral palsy and incorporates aspects of disability-awareness through some of the modules focusing on information about cerebral palsy and rehabilitation strategies as well as facilitation of inclusion within their communities (Saloojee & Bezuidenhout, 2020). This programme concentrated on the enablement of caregivers and on review of the caregiver's experiences, in which they mentioned that they felt empowered due to their deeper understanding of cerebral palsy and a greater understanding of how to care for their own child (Saloojee & Bezuidenhout, 2020). It was further noted by Saloojee & Bezuidenhout (2020: 94) that:

> *"Caregivers felt empowered and ready to explain CP [Cerebral palsy] to family members and neighbours.... This has to be liberating for parents in rural settings where ignorance and negative attitudes abound."*

It seemed that that caregivers who were part of this intervention were becoming change-agents within their own communities, often acting as peer supporters and advocates with their own form of disability-awareness programmes. It has been highlighted by Heyman et al (2020) that this is integral to disability-awareness programmes, as learning within communities is more effective and more efficient if power imbalances are rectified and information sharing occurs amongst peers. As seen in the Malamulele Onwards programme, other organisations, such as the one that was part of this study, should explore training ventures of caregivers of children with cerebral palsy as drivers of disability-awareness programmes within their communities.

5.7 Limitations

Given that this was a study that formed part of a mini-thesis its scope was informed by the limitations of resource constraints and scope of a mini-thesis. The study was a relatively small one - with study participants all working for a single organisation. The insights gained were thus representative of this particular group – all of whom were working within a specific geographical setting - the Bitou Local Municipality. Given the nature of qualitative research, the findings of this study do not have an automatic generalisability to other similar, rural settings (Robson & McCartan, 2017) within the Western Cape where community-based rehabilitation workers provide similar services within similar communities, and contexts in other provinces. However the study does intend to provide some insights (Robson & McCartan, 2017). Thus, whilst the study revealed some important insights into the perceived enablers and barriers of CBR service delivery within this specific study setting, the results must be considered in this light. The most important insights were the importance that the study participants placed on the support that they received from the organisation. Also important was their training, even though informal training was implemented, and included aspects such as CBR strategies and other relevant areas. Further important insight was the significant impact that CBR workers deemed disability-awareness programmes within their communities would have as an enabler to their provision of CBR services.

Another limitation of this study was that it was conducted when various COVID-19 related restrictions and safety protocols were in place. It was noted by another UWC MPH student, when conducting her mini-thesis research amongst clinicians in a hospital in the Western Cape, that their clinical practice had changed during the COVID-19 pandemic (Parbhoo, 2020). This was evident in this research study as the CBR practice of the NGO prior to COVID-19 was a hybrid service delivery method, combined with institution-based methods. However, during the COVID-19 pandemic, specifically level 5 lockdown where schools and institutions for children were not open for attendance, such as was the case with the NGO being studied, the NGO employed comprehensive CBR service delivery methods within the Bitou Local Municipality. This comprehensive CBR service delivery actually became the subject studied within this mini-thesis. The provision of CBR services within the community was implemented out of necessity, due to the base-site of the organisation being closed. The results of this study may reflect that CBR implementation within the organisation was born out of necessity rather than deliberate, whole-hearted conviction of the benefits of such CBR programme implementation.

Another factor to consider whilst carrying out this study during the COVID-19 pandemic, was the social distancing and mandatory wearing of masks that could have reduced the personal nature of the interviews and hampered the building of a relationship of trust between the researcher and participant. A study conducted by Dondé et al. (2022) noted that the wearing of face masks during interviews hampered the interviewer in being able to accurately read non-verbal cues. This might have resulted in a loss of richness and depth of data as noting non-verbal cues of participants whilst sharing some of their personal and professional experiences could be difficult (Dondé et al., 2022).

The researcher previously disclosed that she is also a health practitioner, and occupational therapist, at a similar NGO within the Bitou Local Municipality. The NGO being studied as well as the NGO that the researcher works for, often liaise between one another with regards to children who are being seen for therapy by both NGOs. This is done in order to support the need and case load within the community. Through these liaisons, relationships have been formed between the health professionals employed by the NGO studied and the researcher. This could have potentially influenced the content of what the participants might have shared with the researcher during the data collection process. For example, they might have felt hesitant to share some of the challenges they experienced with their NGO as this might have seen it as a betrayal of their allegiance to their employer.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This research study sought to explore the barriers and enablers that the health workers in one rural NGO service provider in the Western Cape Province, South Africa experienced whilst providing community-based rehabilitation services in local communities between May and September 2020.

The term community-based rehabilitation still lacks a definitive understanding within the health sector but upon exploration of the findings of this study with regards to the CBR workers' understanding of the term community-based rehabilitation – a common understanding of the term was seen among the study participants. The CBR workers believed that CBR was providing support for the communities in which they worked, through co-operation, empowerment and problem-solving, and through the development of trusting relationships between themselves and the caregivers of children with cerebral palsy. It was further noted that the CBR workers' understanding of the concept was informed and affected by their perceived barriers and enablers of service provision. This was often seen through noting the findings of their understanding of CBR and then observing these sentiments mirrored in their articulated barriers and enablers of service provision.

In the exploration of the physical contexts where the CBR workers delivered their therapeutic services, a number of logistical challenges were identified, such as difficulties travelling to and from their client's homes, not having the necessary equipment on hand for their sessions, as well as having to navigate difficult social situations within the households.

It was not possible to develop a definitive list of what study participants felt were the enablers to CBR or the barriers to CBR as the difficulties expressed by one CBR worker were sometimes noted by another to be an enabler that assisted them in providing CBR. For example, some CBR workers raised as a difficulty the fact that caregivers were not always able to keep to or honour the time of their scheduled appointments. Another CBR worker felt that working within the community, in a more informal manner, allowed her to manage her own time more effectively and allowed her to foster more trusting relationships with the caregivers and the household. CBR workers also had very different experiences within the communities, for example, some CBR workers noted that a negative attitude and unwelcoming environment created by certain caregivers was a barrier for them in being able to provide therapy whilst other CBR workers noted that their work was enabled by a welcoming and receptive caregiver and a supportive home environment. Thus, whilst the enablers and barriers to CBR were often experienced differently by the different caregivers, the interviews did bring to the surface some potential facilitators and challenges that other organisations working in a similar environment might find useful to bear in mind when implementing CBR within a community.

A sense of teamwork and connectedness with the caregivers of the children with cerebral palsy was also communicated by the majority of CBR workers as essential in the provision of good quality home-based services, which some expressed this as really enabling their practice. This sense of teamwork (that was experienced within a household) was linked to what many CBR workers experienced and valued within their organisation as a whole - where they felt supported and part of a larger team.

One of the themes that was not explicitly discussed by the participants themselves, but that was noted by the researcher, were the characteristics or traits that were observed in the course of the interviews and their accounts of their practice. Some of these traits included the CBR workers ability to "read" a situation and then determine the right approach with the caregivers of children with cerebral palsy. There were many instances in the accounts of their CBR practice that the researcher believed showed how sensitively the CBR workers were able to engage with the caregivers, be sensitive to their privacy and the challenges within their homes and were very likely to be a key determinant in a successful intervention session. Other characteristics that emerged were how sensitive the CBR workers could be, not passing judgement on the tenuous situations within the households and accepting the caregivers, their homes and their inputs by placing value on them and their opinions.

6.2 Recommendations

The following four recommendations are made, based on the findings from this study:

1. More accessible formalised training opportunities for CBR workers is of the utmost importance and could be facilitated through a collaboration between the Departments of Health and Social Development and non-governmental organisations working in the field. Programmes such as the year-long training programme implemented by the Division of

Disability Studies at the University of Cape Town could be implemented across broader studying programmes (such as Unisa or local colleges) across South Africa, making it accessible to all. This should be considered critical in response to the large rehabilitation need within South Africa, in order to empower CBR workers with a specialised skills set to address comprehensive rehabilitation needs. A succeeding issue would be one where jobs and opportunities to absorb there post-trained CBR workers needs to be addressed and collaboration between stakeholders for inter-sectoral budgeting and planning needs to be mobilised (Ned et al., 2020).

2. CBR strategies in South Africa have been incorporated in the National Framework and Strategy for Disability and Rehabilitation Services (National Department of Health, 2015), but have yet to be incorporated and realised within provincial rehabilitation strategies. Implementation guidelines need to be conceptualised and formalised in order to provide support for the 2030 national rehabilitation goals to be met.

3. Further empirical research on the practice and impact of CBR strategies in a South African context need to be conducted in order to shift CBR from being seen for the most part as a theoretical concept, to being practically implemented on a larger scale in South Africa. Identifying the various barriers that are hindering the more wide-scale CBR service provision and providing evidence-based solutions for these barriers would be of great benefit.

4. The creation and optimisation of disability-awareness programmes, especially within resource-constrained settings in South Africa, needs to occur much more extensively. The exploration of caregivers of children with cerebral palsy as paid peer-educators within their own communities needs to be a priority, as this could assist with eradicating some of the stigma associated with disability and increase the community-level understanding of the needs and experiences of those living with cerebral palsy and other disabilities.

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APPENDICES

Appendix A: Permission letter for carrying out research at the NGO

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

<u>Re: Letter of request to conduct research at your institution</u>

<u>For Attention:</u>

NGO Managing Director & Board

[Date]

Dear Sir/Madam

I am writing to request your permission to perform research at your facility. My name is Leslie Labuschagne and I am a student at the University of the Western Cape currently completing my Masters in Public Health. I am required to write up a mini-thesis in order to complete my qualification. As part of the mini-thesis aspect of my training I am required to perform research and present this to our faculty. The title of my research project is ***"An exploration of the barriers and enablers that NGO service providers experienced in delivering community-based rehabilitation services to children with Cerebral Palsy in the Bitou Local Municipality, South Africa."***

The research will involve my interviewing the therapists and assistants that provide rehabilitation service delivery, at a time that is convenient for them and that does not interfere with their responsibilities of functioning in your facility. The research aims to explore the therapists' and assistants' experience of providing community-based rehabilitation services as well as their perceived barriers or enablers to the continuation of provision of these services. Ultimately the research may guide further implementation of community-based rehabilitation services within the Bitou region as well as other similar regions.

The research is purely explorative with no experiments or client - rehabilitation planned to be affected. The research proposal has been granted ethical approval from the University of the Western Cape with reference number: (BM21/10/4)

The results of the study will be available in 2022 and I would like to share them with your facility when they are.

I trust this provides enough information for you to consider granting permission but if any other information is required then please do contact me with the details below.

Yours sincerely

Leslie Labuschagne
Occupational Therapist
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Paradise
Knysna

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083 391 1695

Appendix B: English participant information sheet

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
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PARTICIPANT INFORMATION SHEET

Project Title An exploration of the barriers and enablers that NGO service providers experienced in delivering community-based rehabilitation services to children with Cerebral Palsy in the Bitou Local Municipality, South Africa.

What is this study about?

This is a research project being conducted by Leslie Labuschagne, a Master in Public Health student at the University of the Western Cape. I am inviting you to participate in this research project as a therapist or as an assistant that has provided community-based rehabilitation services to children with Cerebral Palsy within the Bitou Local Municipality. The purpose of this research project is to gain more insight into your experiences in providing community-based rehabilitation in the Bitou Local Municipality. I am interested in learning about the things that you think assisted you in providing community-based rehabilitation – and those things that hindered your practice.

What will I be asked to do if I agree to participate?

You will be asked to participate in a 45 – 60 minute interview that can either be conducted in person or via the telephone or online. We will conduct this interview at a time and location that is convenient for you. The interview will be composed of a set of questions that will focus on your understanding of the term community-based rehabilitation, the physical setting where you have provided community-based rehabilitation services, the factors that you perceive as hinderances or barriers to carrying out community-based rehabilitation as well as the factors that have encouraged and enabled community-based rehabilitation to be implemented.

Would my participation in this study be kept confidential?

As the researcher I undertake to protect your identity contributions towards the study. To ensure your anonymity the following will be undertaken:

- your name will not be included on the interview transcript and other collected data but rather an alias or invented name or a code will be used;
- a code will be placed on the interview transcript and other collected data that will allow the researcher to link the interview to your identity through the use of an identification key
- only the researcher will have access to the identification key.

Safeguarding of all data collected throughout the study will also be ensured and implemented through electronic information and transcripts being kept on the researchers own biometric access-controlled computer and that any hard copies of transcripts and notes taken during the interviews, kept in a locked cabinet that would only be accessed by the researcher. This will be done in order to ensure further confidentiality.

In an event where child abuse, neglect or potential harm to you or others is concerned, the study participants will be informed that confidentiality will need to be broken and relevant information disclosed to appropriate authorities' or individuals in accordance to professional standards and legal requirements.

What are the risks of this research?

The researcher's intent is to minimise risk as far as possible, but due to the human nature of this study, there may be some risk involved in participating. During the course of the discussion, if any participant feels uncomfortable, psychological or otherwise, or has broached topics that are of a distressing nature, the interview will immediately be halted and with the participants consent, where necessary, appropriate referral to a registered counsellor will be made.

What are the benefits of this research?

There is no direct benefit for participating in the study. However, being allowed the opportunity to discuss and reflect on your experience of performing community-based rehabilitation could prove beneficial in a personal capacity. The findings of the study will assist in identifying challenges in implementing community-based rehabilitation, which can then be addressed within the region and potentially assist in developing more effective and efficient service delivery methods.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take participate at all. If you decide to participate in this research, you may stop participating at any time. You may also choose to not answer any questions that you would rather not participate in. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by ***Leslie Labuschagne as part of the School of Public Health*** at the University of the Western Cape. If you have any questions about the research study itself, please contact me at:

Tel: 083 391 1695 or via email: leslie.labuschagne@gmail.com

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Uta Lehmann
Head of Department: School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
ulehmann@uwc.ac.za

Prof Anthea Rhoda
Dean: Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

Reference Number:
(BM21/10/4)

Appendix C: Afrikaans participant information sheet

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

DEELNEMERINLIGTINGSBLAD

Navorsingsprojek Titel: ‘n Verkenning van NRO diensverskaffers se waargeneemde hindernisse en instaatstellers in die besorging van gemeenskap gebaseerde rehabilitasie dienste aan kinders met Serebrale Gestremdheid in the Bitou Plaaaslike Munisipaliteit, Suid-Afrika.

Wat behels hierdie navorsingsprojek?

Die navorsingsprojek word uitgevoer deur Leslie Labuschagne, ‘n Meesters in Publieke Gesondheid student by die Universiteit van die Weskaap. U word uitgenooi om deel te neem in die navorsingsprojek as ‘n terapeut of terapie assistent wat gemeenskap gebaseerde rehabilitasie aan kinders met Serebrale Gestremdheid in the Bitou Plaaslike Munisipaliteit aangebied het. Die doel van die navorsingsprojek is om verkenning te maak van U ervaring wat U beleef het tydens diens-verskaffing in die besorging van gemeenskap gebaseerde rehabilitasie dienste aan kinders met Serebrale Gestremdheid. Ek stel belang om verkenning te maak van faktore wat U waargeneem het as instaatstellers in die besorging van gemeenskap gebaseerde rehabilitasie dienste asook faktore wat U dienste belemmer het.

Wat sal u verantwoordelikhede wees?

U sal genader word om deel van ‘n 45 – 60 minute lank onderhoud te wees wat of in persoon of telefonies of aanlyn uitgevoer sal word. Die onderhoud sal uitgevoer word op ʼn tyd en plek wat gerieflik vir U is. Die onderhoud sal uit vrae bestaan wat fokus op wat U verstaan van die term gemeenskap gebaseerde rehabilitasie, die omgewing waar gemeenskap gebaseerde rehabilitasie dienste uitgevoer was en faktore wat U as hindernisse en instaatstellers in die besorging van gemeenskap gebaseerde rehabilitasie dienste waargeneem het.

Sal my deelname in die navorsingsprojek vertroulik en beskermd gehou word?

Ek, die navorser, onderneem om U identiteit deelname te beskerm en vertroulikheid te verseker. U anonimiteit sal deur die volgende stappe verseker word:

- U naam sal nie in die onderhoud transkripsies ingesluit word of op enige ander versamelde data verskyn nie. ʼn Aangenome naam sal gebruik word.
- ‘n Kode sal op die onderhoud transkripsies en ander versamelde data geplaas word. Die kode sal navorsers toelaat om U identiteit aan die onderhoud deur ‘n identifikasie sleutel te koppel.
- Slegs die navorser sal toegang aan die identifikasie sleutel hê.

Om U inligting verder te beskerm, sal die digitale transkripsies op die navorser se biometries-toegangsbeheerde rekenaar gehou word en enige afskrifte sal in ‘n laai waarin net die navorser toegang het toegesluit word.

In ooreenstemming met wetlike vereistes en/of professionele standaarde, sal enige inligting van kindermishandeling, verwaarlosing of potensiele benadeling aan U of ander, sal dit bekend gemaak word aan die toepaslike owerhede of individue oorhandig word. Indien dit gebeur, sal ons U in kennis stel dat ons vertroulikheid moet breek om ons wetlike vereistes by te staan.

Is daar enige risiko’s verbonde aan u deelname aan hierdie navorsingprojek?

Dit is die navorser se bedoeling om risiko so vêr as moontlike te verminder, maar weens die menslike natuur van die navorsingsprojek mag daar risiko verbonde wees aan U navorsingsprojek se deelname. Geduurend die uitvoering van die navorsingsprojek, as enige deelnemer ongemaklik voel, beide sielkundig of andersins, sal die onderhoud onmiddellik gestop word en toepaslike verwysing na ‘n geregistreerde berader gemaak word.

Is daar voordele van deelname in die navorsingsprojek?

Daar is geen persoonlike voordele in deelname in die navorsingsprojek nie. Die geleentheid vir deelnemers om oor hulle waarnemings te praat kan alhoewel persoonlik voordelig wees. Die bevindings van die navorsingsprojek sal help om hindernisse te identifiseer van diensverskaffers in die besorging van gemeenskap gebaseerde rehabilitasie, wat potensieel meer effektiewe diensverskaffing in die streek kan beinvloed.

Moet ek deel neem in die navorsingsprojek en staan ek vry om op enige oomblik deelname te weier?

U deelname in die navorsingsprojek is volkome vrywillig en dit staan u vry om deelname te weier. As U besluit om deel te neem in die navorsingsprojek, mag U besluit om enige oomblik deelname te weier. Indien U wou, mag U ook op enige oomblik besluit om nie ‘n vraag te beantwoord nie. As U weier om deel te neem in die navorsingsprojek of op enige oomblik besluit om nie meer deel te neem nie, sal U op geen wyse hoegenaamd negatief beïnvloed word of enige voordele verloor nie.

Is daar enigiets anders wat ek moet weet of doen?

Hierdie navorsingsprojek word deur ***Leslie Labuschagne as deel van die Skool van Publieke Gesondheid*** by die Universiteit van die Weskaap uitgevoer. As U enige navrae het oor die navorsingsprojek self, kontak vir my asseblief direk by:

Tel: 083 391 1695 of via e-pos: leslie.labuschagne@gmail.com

As U enige navrae het oor die navorsingsprojek, U regte as ‘n deelnemer, of as U aanmeld wil maak in verband met U deelname in die navorsingsprojek, kontak asseblief vir:

Prof Uta Lehmann
Hoof van Departement: Skool van Publieke Gesondheid
Universiteit van die Weskaap
Private Sak X17
Bellville 7535
ulehmann@uwc.ac.za

Prof Anthea Rhoda
Dekaan: Fakulteit van Gemeenskaps- en Gesondheidswetenskappe
Universiteit van die Weskaap
Private Sak X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Hierdie navorsingsprojek is deur die Universiteit van die Weskaap se Biomediese Navorsings Etieks Komitee goedgekeur:

Biomediese Navorsings Etieks Komitee
Universiteit van die Weskaap
Private Bag X17, Bellville
7535
Tel: 021 959 4111
e-pos: research-ethics@uwc.ac.za

Verwysings nommer:
(BM21/10/4)

Appendix D: English Consent Form

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

CONSENT FORM

Title of Research Project: An exploration of the barriers and enablers that NGO service providers experienced in delivering community-based rehabilitation services to children with Cerebral Palsy in the Bitou Local Municipality, South Africa.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

I agree ☐ / do not agree ☐ to be [audiotaped/video recorded] during my participation in this study.

Participant's name____ Date
.

Participant's signature___________________________________.

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee:

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17, Bellville

7535

Tel: 021 959 4111

e-mail: research-ethics@uwc.ac.za

Appendix E :Afrikaans Consent form

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

TOESTEMMINGS FORM

Titel van Navorsingsprojek: **'n Verkenning van die waargeneemde hindernisse en instaatstellers van NRO diensverskaffers in die besorging van gemeenskap gebaseerde rehabilitasie dienste aan kinders met Serebrale Gestremdheid in the Bitou Plaaaslik Munisipaliteit, Suid Afrika.**

Die studie is in die taal wat ek verstaan verduidelik. Vrae waaroor ek die navorsingprojek gehad het is beantwoord. Ek verstaan wat my deelname behels en ek gee volkome vrywillig toestemming om in die navorsingsprojek deel te neem. Ek verstaan dat my identiteit anoneim sal bly. Ek verstaan dat ek op enige oomblik my deelname kan ontrek sonder rede en sonder enige negatiewe nagevolge.

Ek gee toestemming ☐ k gee nie toestemming nie om g☐rend die onderhoud opgeneem [oudio of video] te word tydens my deelname in die navorsinsprojek.

Naam van deelnemer____Datum_____________________.

Handtekening van deelnemer____.

Hierdie navorsingsprojek is deur die Universiteit van die Weskaap se Biomediese Navorsings Etieks Komitee goedgekeur:
Biomediese Navorsings Etieks Komitee

Universiteit van die Weskaap

Private Sak X17, Bellville

7535

Tel: 021 959 4111 e-pos: research-ethics@uwc.ac.za

Appendix F: Proposed participant interview guide

a) **Good day. My name is Leslie and I am going to be conducting the interview.**
    I. **What language are you most comfortable in for conduction of the study?**
   Provide contextual information about the study.

b) **I will be asking you the following questions just to obtain information for data capturing purposes and creating a coding system**
   a. **How old are you?**
   b. **What is your 'home' language?**
   c. **When did you start working at the NGO?**
   Note: Ascertain the gender and race of participant in a sensitive manner

c) **Please tell me a little about the geographical context where you conducted community-based rehabilitation**
   Probes:
   - *How would you describe the area that you performed CBR?*
   - *What are the premises like?*
   - *What was your patient population like – socioeconomic, insight, caregivers?*
   - *How do you feel about the physical context that you performed CBR?*

d) **Could you tell me a little about what you understand the term community-based rehabilitation means:**
   Probes:
   - *What does community-based rehab mean to you ?*
   - *Which stakeholders would you say are involved?*
   - What are your perceptions of it as a service delivery method?

e) **I would like to find out about what your experiences were of providing CBR?**
   Probes:
   - *Was it enjoyable or unenjoyable for you?*
   - *Did you experience any challenges in providing the service?*
   - *Did you feel you were able to provide services of a similar standard as in comparison to IB? and if not why?*
   - *What were limiting factors for you in your experience?*

f) **I would like to find out more in-depth about your perceived barriers to carrying out CBR**

Probes:

- *where there any resource challenges? And If so what?*
- *Where there any physical and contextual challenges, and if so what?*
- *Where there financial constraints experienced, and if so why would you say so?*
- *Where there any perceived barriers from the community or child receiving therapy?*
- *Did you experience limitations in carrying out interventions?*

g) **I would like to find out more about factors that you would say would enable CBR to be continued to be utilised and potentially benefit other areas.**

Probes:

- *What were the perceived benefits of CBR?*
- *What would you say assisted you in carrying out CBR?*
- *What factors could you note that would encourage or positively influence further utilisations of CBR?*

h) **Why, in your opinion, do you think that the foundation moved away from utilising CBR strategies to predominantly IB strategies?**

Probes:

- *What were the negative/positive aspects of CBR*
- *What were the negative/positive aspects of IB in your opinion?*
- *Why do you think IB was utilised again?*

i) **In your opinion, would you recommend CBR strategies for similar settings?**

Probes:

- *What would you say would assist CBR implementation in other settings?*
- *What would you feel like your setting or institution required to make CBR more successful and sustainable?*
- *What would you say enabled CBR to be successful in your setting or institution?*
- *What would you say was a barrier for CBR to be successful in your setting or institution?*

j) **Do you have any further aspects you would like to add/discuss?**

k) Thank the participants for the valuable information and time.

Appendix G: Ethics Approval Letter from the University of the Western Cape

NHREC Registration Number: BMREC-130416-050

29 November 2021

Ms L Labuschagne

School of Public Health

Faculty of Community and Health Sciences

Ethics Reference Number: BM21/10/4

Project Title: An exploration of the barriers and enablers that NGO service providers experienced in delivering community-based rehabilitation services to children with Cerebral Palsy in the Bitou Local Municipality, South Africa.

Approval Period: 19 November 2021 – 19 November 2024

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project and the requested amendment to the project.

Any further amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

For permission to conduct research using student and/or staff data or to distribute research surveys/questionnaires please apply via: https://sites.google.com/uwc.ac.za/permissionresearch/home

The permission letter must then be submitted to BMREC for record keeping purposes.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias

Research Ethics Committee Officer

University of the Western Cape