The experiences of health service providers working with children with physical disabilities and their caregivers in the Eastern Cape

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By

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Abstract

The prevalence of childhood disability in South Africa is significant. In an attempt to meet the constitutional rights of children with disabilities, there are a variety of services available for children with disabilities. These services are aimed at rehabilitating children with disabilities and integrating them in society. Amongst such services are health services. Due to the nature of some childhood disabilities, it is recommended that they should be seen by a multidisciplinary team. While the field of childhood disability has been researched extensively. Limited research has been conducted on the experiences of health service providers working with children with disabilities and their caregivers.

The current study explored the experiences of health service providers working with children with disabilities and their caregivers in the Eastern Cape. To achieve this aim, the study employed Interpretative Phenomenological Analysis (IPA). Five participants were recruited using purposive and snowball sampling methods. Semi-structured interviews were used to allow participants to freely share their experiences of working with children with disabilities and their caregivers. The interviews were audio recorded and transcribed for analysis purpose.

The analysis process generated five master themes namely: Positive experiences of their work; negative experiences of their work; perception of their role as changing over time; managing challenges in their work; and experiences of a service learning programme as complementary to their work. The findings of the study highlighted both the positive experiences and the negative experiences of their work. On the one hand, the participants reported positive affect and that they found their work meaningful. They also reported a sense of feeling supported by fellow colleagues and enjoying their work at the clinics. On the other hand, the participants reported negative affect in relation to their wok difficulties such as feelings of frustration, feelings of being unappreciated by management and finding the work distressing. The participants reported that professional and emotional growth in conjunction with perspective taking contributed to developing better coping mechanisms. A service learning programme offered in the community was experienced as a good contribution to the work done at the clinics and distinguished as addressing the emotional needs of the caregivers which cannot be addressed at the clinics. The findings of the study supports and expands the literature on the experiences of health service providers working with children with disabilities in South Africa.

Plagiarism Declaration

I declare that this thesis titled "The experiences of health service providers working with children with physical disabilities and their caregivers in the Eastern Cape" is my original work and has not been submitted, in whole or in part, in any previous application for a degree at any other university. I have drawn on the ideas and work of other authors, I have acknowledged all the sources used and have cited these in the reference section using the departmental referencing guidelines

Signature: ________________ Date _________________

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Chapter 1: Introduction

1.1. Background and rationale

Childhood disability is a prevalent health issue in South Africa, with 2,1 million children classified as having disabilities. This makes up 11,2 percent of the child population in South Africa as reported by the Department of Social Development (DSD), Department of Women, Children and People with Disabilities (DWCPD) and UNICEF (2012). Amongst the numerous services available to children with disabilities as stipulated in policies put in place to fulfil government's constitutional obligations towards children with disabilities as per the requirements of the Bill of Rights in the South African Constitution are health services (DSD, DWCPD & UNICEF, 2012; DSD, 2009). There has been extensive research done within the area of childhood disability that has had implications for policy and practice by health service providers working with children with physical disabilities and their caregivers (Chappell & Johannsmeier, 2009; DSD, DWCPD & UNICEF, 2012; DSD, 2009; Saloojee, Rosenbaum & Stewart, 2011; Schneider & Saloojee, 2007).

There are various theoretical modalities of disability that has contributed to how disability is understood which in turn impact on policy regarding service delivery for children with disabilities. These theoretical models include the medical model which views disability as an impairment located in the body of the individual with a disability (Harris & Enfield, 2003). Another model is the social model of disability which emphasises that disabled people are excluded from participating in communities due to environmental and attitudinal barriers because of the manner in which society is organised (Chappell & Johannsmeier, 2009). The third model of disability explored in the study is the biopsychosocial model which emphasises viewing people with disabilities on the individual level, as people with rehabilitation needs, and on the social level, as people with needs for inclusion in society (Schneider & Saloojee, 2007). The theoretical models impact on what services are provided for children with disabilities and the manner in which such services are provided. This study aims to explore how health service providers understand disability in relation to these models.

Due to the nature of childhood disability, the literature emphasises that a multidisciplinary team should see a child with a disability (King, Teplicky, King, & Rosenbaum, 2004). There are numerous reported challenges that are faced by health service providers working with children with disabilities in South Africa, with the significant challenge being a lack of personnel as reported by the Department of Social Development (DSD, 2009). Other studies have reported on the difficulties faced by health service providers working in the public sector, particularly in rural areas that usually results in service providers preferring to work in private practice or urban areas (Ashmore, 2013; Jenkins, Gunst, Blitz & Coetzee, 2015; Nemutandani, Maluleke & Rudolph, 2006). Given this background, it becomes important to explore the experiences of health service providers working with children with disabilities. There has been extensive studies reported on the experience of caregivers who attends facilities that offers health services for children with disabilities. This is seen in the works of Dunst and Trivette (2009); Saloojee, Rosenbaum and Stewart (2011) which explores the impact of Family Centred Services (FCS) for children with disabilities, Murphy, Christian, Caplin, and Young, (2007) exploring the health of caregivers for children with disabilities and that of Chappell and Johannsmeier (2009) aimed at evaluating the impact of Community Based Rehabilitation (CBR) programmes. However, not much research has been conducted on the health service providers' experiences. Thus, this study explores the experiences of the health service providers working with children with physical disabilities in a semi-rural and resource limited setting. While the majority of children seen by the health service providers presents with physical disabilities, some have additional psychological impairments such as intellectual disability.

1.2. Contextualising the study

This study is conducted in a semi-rural setting in the Eastern Cape, which offers particular kinds of health services for children with disabilities and their caregivers. Firstly, there are developmental clinics which takes place once a month whereby a group of health service providers from a local NGO and the Department of Health (DOH) assess children's development and make various recommendations to caregivers, as well as referrals to specialists located in bigger centres, if necessary. Given the context of the current study, the term 'caregiver' is used to refer to the adults that take care of children with disabilities which may include parents, siblings, aunts, grandmothers, nannies, and other people that might not necessarily be blood related to the child with a disability. This includes people that may be paid or unpaid to care for the child with a disability. The health service providers include social workers, occupational therapists and physiotherapists, for the purpose of the study, they shall be referred to as health service providers.

Secondly, a service learning programme, Masibambane (working with caregivers and children with physical disabilities), is a home visiting programme running in this area. The Masibambane programme is coordinated jointly by Rhodes University, working collaboratively with the other stakeholders such as the DOH and the NGO, and involves university students doing home visits for children with disabilities to offer support to caregivers and the children (Saville Young, 2016).

The Masibambane programme involves home visits done in collaboration with the work done at the developmental clinics. The home visits are facilitated by Psychology students with the aim to support the caregivers and children with physical disabilities by stimulating the child through appropriate play while encouraging the parent-child interaction and promoting adherence to home programmes. Further aims of Masibambane includes creating awareness of challenges linked to raising a child with a disability, advocating for the rights of children with disabilities, promoting development for the students involved, promoting intersectoral collaboration, and generating research in this area with the aim of improving policy and practice (Saville Young, 2015).

The students who facilitate the home visits sign up for a 10 seminar course that covers various aspects related to childhood disability and mental health, including an introduction to the concept of mentalisation. Mentalisation which is the ability to be attuned to one's own mental state by paying attention to what they feel or think and the mental states of others (Allen, 2006, as cited in Saville Young, 2015; Fonagy, 2018). During home visits, mentalisation is promoted in three ways, firstly by holding the child in mind by being curious about what they are thinking or feeling, thus modelling that they have a mind. Secondly by holding the parents/caregivers in mind, by being curious about what they feel, think and how it is like to raise their child. This helps to regulate their emotional experiences. Lastly by holding the self in mind which allows for the students to reflect on their own thoughts and feelings because understanding their own thoughts and feelings can help with exploring the thoughts and feeling of others as stated by Saville Young (2015). This study explores the health service providers' experiences within this context.

1.3. Aims and objectives

The aim of this study is to explore the experiences of health service providers working with children with physical disabilities and their caregivers. The following study objectives will enable the researcher to meet the aim of the study:

1. Explore the positive and negative experiences of health service providers in relation to working with children with physical disabilities and their caregivers.

2. Explore health service providers' understanding of their roles as health service providers in relation to the various models of disability.

3. Explore their experiences of service provision for children with disabilities in a semi-rural setting in South Africa.

4. Explore their experiences of the service learning programme, Masibambane, in relation to their work.

1.4. The significance of the Study

Given the challenges experienced by health service providers working in the public sector, particularly in rural areas. It becomes important to explore the experiences of the health service providers working with children with physical disabilities and their caregivers to explore the challenges that they have faced (negative experiences) and motivation (positive experiences) for staying in this line of work and in semi-rural areas despite the challenges that they face. The findings of the study will contribute to the literature on health service providers' experiences in working with children with disabilities in South Africa. Moreover, the study could aid in improving working conditions for health service providers, improving service delivery for children with physical disabilities and aid in the development of policy and practice for health service providers working in the public sector in rural areas in South Africa.

1.5. Research questions

The overarching research question for this study is: "What are the experiences of health service providers working with children with physical disabilities and their caregivers in a semi-rural context in the Eastern Cape"?

The sub questions are: What impact does working with children with physical disabilities have on the health service providers?

How do health service providers understand their roles?

What is their perception of the service learning programme in relation to their work?

What are their experiences of service provision for children with physical disabilities in this context?

1.6. Structure of the research project

This thesis consists of six chapters including the current chapter. The subsequent chapter, chapter two, contextualises the study within the available literature on topics related to childhood disability and the experiences of health service providers working with children with physical disabilities and their caregivers. Chapter three provides a description of the research design and methodology used to address the research questions of the study. This chapter describes how participants were selected and recruited, and how data was collected and analysed in line with the chosen methodology. Furthermore, the chapter also provides a discussion on the ethical principles that have been applied and how trustworthiness and credibility of the study has been ensured. Chapter four of the thesis reports the findings of the study produced from the data analysis process in the form of themes together with interview extracts to support the various themes generated from the analysis process. Chapter five of the thesis provides a discussion of the findings and links the findings to the literature reviewed in chapter two. The last chapter, chapter six provides a summary of the study, a discussion of the limitations of the study and recommendation for further research.

Chapter 2: Literature review

2.1. Introduction

This study is interested in investigating the experiences of health service providers working with children with physical disabilities and their caregivers in the Eastern Cape. This chapter aims to contextualise the current study in the available research on childhood disability and the experiences of health service providers working with children with disabilities and their caregivers. The literature review explores a body of research that focuses on the definition of childhood disability and the prevalence of childhood disability in South Africa (in particular Cerebral Palsy), the different theoretical models of disability which aids in understanding disability, the different approaches to service delivery which are influenced by the various models of disability, health services for children with disabilities in South Africa and the nature of the relationship between caregivers and health service providers.

2.2. Defining Childhood Disability

The World Health Organisation (WHO, 2001) defines disability as a broad term that covers various impairments. This includes physical impairments, activity limitations, and participation restrictions. An impairment is defined as a problem in body function or structure; an activity limitation is defined as a difficulty encountered by an individual in executing certain actions; while a participation restriction is defined as a problem experienced by an individual in involvement in life situations.

According to Schneider and Saloojee (2007) disability may involve one or more impairments which may be diagnosable, while at times not easily diagnosable particularly in the case of internalising impairments such autism or intellectual disability. As per the WHO definition, a child with a physical disability is a child with a health condition and related impairments together with activity limitations in one or more domains of functioning. Childhood disability may take any form, from being visible or invisible, consistent or intermittent and stable or progressive. Moreover, while some disabilities may be diagnosed through tests, some may be diagnosed through observations, for example autism and intellectual impairments (Schneider & Saloojee, 2007)

Examples of diagnosable conditions includes epilepsy, brain damage which may lead to impairments including cerebral palsy, intellectual impairments, and more physical abnormalities such as underdeveloped or missing limbs, malformations of various body organs, genetic disorders such as Down syndrome, various condition affecting hearing and vision, chronic illnesses such as diabetes, HIV/AIDS and more (Schneider & Saloojee, 2007).

In their article on monitoring childhood disability in South Africa, Schneider and Saloojee (2007) elaborate more on activity limitations. Activity limitations are the difficulties that a child may experience in executing certain activities in various domains of functioning as a result of their disability. The relevant domains of functioning include learning and applying knowledge, general tasks, communication, mobility, self-care, domestic life, interpersonal interactions, actions required to engage in education and vocational training, and engagement in community, social and civic life. Environmental factors play a big role in the activity limitations of children with disabilities because the physical, social and attitudinal environment can allow or make it difficult for children with disabilities to execute certain tasks (WHO, 2001).

2.3. The prevalence of childhood disability in South Africa

A report compiled by the DSD, DWCPD and UNICEF (2012) indicates that it has always been challenging to accurately report the prevalence of disability in South Africa due to the lack of a measuring tool in line with the International Classification of Functioning Disability and Health (ICF). Furthermore, census and house hold surveys that did not include questions designed to identify children with disabilities; and individual perceptual differences in what qualifies as a disability. Nonetheless, as from 2009 Statistics South Africa made use of the Washington Group (WG) survey questionnaire for household surveys to determine impairments in seven domains of function namely: seeing, hearing, walking, remembering, concentration, self-care, and communication. Therefore, individuals are identified as having impairments should they have difficulties in two or more of the above mentioned domains of functioning (DSD, DWCPD & UNICEF, 2012).

Using the WG surveys has led to 2,1 million children classified as having disabilities in South Africa, making up 11,2 percent of the child population in South Africa. Furthermore, the prevalence of childhood disability appears high for younger children aged between zero and four years and for male children as compared to female children (DSD, DWCPD & UNICEF, 2012). The census report (2011, as cited in DSD, DWCPD & UNICEF, 2012) indicates that 474 000 children are living with severe and multiple impairments related to vision and hearing in South Africa.

A report compiled by DSD (2009) ranks the different kinds of impairments according to their prevalence, visual impairment is ranked as the highest (36%), followed by hearing impairment (22%), followed by physical impairment (16%) and lastly mental and multiple impairments

(5%). It is reported that South Africa has a high prevalence of Cerebral Palsy (CP) estimated at 10 per 1000 children with disabilities. Birth related trauma has been linked to the high prevalence of CP in South Africa (DSD, 2009). The high prevalence of CP in South Africa seems to be in line with reports by Stanley, Blair, and Alberman (2000, as cited in Saloojee, Rosenbaum & Stewart, 2011) that while it appears that there are various childhood disabilities CP is a major cause of childhood disability worldwide. Due to its high prevalence and complex nature, including the fact that the health service providers in this research project interact largely with children with CP, this condition is discussed in more detail below.

2.3.1. Cerebral palsy

CP has been studied for over 100 years. It was originally reported by William Little in 1861. In the 19th century, Sigmund Freud and Sir William Osler made important contributions to understanding the condition (Bax et al., 2005). While CP has been studied for years, according to Bax et al. (2005) it has always been a challenge to define CP as evidenced by the number of attempts over the years.

During an international workshop on the definition and classification of CP which was held in 2004, CP was 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. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception and/or behaviour and/or by a seizure disorder." (Bax et al., 2005, p.572)

According to Bax et al. (2005) for a diagnosis of CP to be made, there must be motor impairment, and this impairment must originate from a malfunction of the brain. Furthermore, the brain malfunction must be non-progressive and it must manifest early in life. Although the motor impairments of a child with CP are evident in the first 18 months of life, other neonatal difficulties such as feeding difficulties may be evident before the motor function impairments become apparent (Bax et al., 2005).

It is reported that there is no direct cause for CP as it is not a single condition and comprises of a group of disorders. Furthermore, the aetiology of CP in Africa differs from that reported in the United States and Europe, with the most reported aetiology in Africa being asphyxia, kernicterus, and neonatal infection, whereas prematurity and low birth weight have been reported as risk factors in the United States and Europe (Donald, Samia, Kakooza-Mwesige, &

Bearden, 2014). According to Rosenbaum (2014) it was initially believed that CP was caused by difficulties during child birth and a new-born's poor adaptation to postnatal life, this resulted in health service providers being blamed for the poor outcomes. However, technological advancements such as prenatal imaging aided in the growing understanding of CP, resulting in the realisation that problems in brain development, structure and function often causes perinatal and postnatal difficulties.

The manifestation of CP differs from one child to another, while on the one hand some children may be impaired due to CP, on the other hand some children may be mildly affected showing no obvious signs of disability. As a result, CP is often a difficult condition for parents to understand. Thus, it is for this reason that services should be appropriate for the individual child and their family. Furthermore, since children with CP often receive interventions early in life which may impact on their later development, it is important for health service providers to take into account the child's present condition at a given time when recommending interventions, because the child's development may change over time (Braga & da Paz, 2006).

As a result of a mild manifestation of CP, some children with CP may be placed in mainstream schools. While they may function as expected compared to their peers, they often present with learning problems and problems with social interactions. This may be because damage to the area of the brain causing CP often impacts on other brain structures responsible for other functions as stated by Bøttcher (2011).

Since CP is caused by permanent but non-progressive damage to the brain, this means that the condition cannot be cured and has lifelong effects for the child. Moreover, since various aspects of functioning are affected, the management of CP requires a multidisciplinary team (King et al., 2004). According to King et al. (2004), children with cerebral palsy often have complex long-term needs requiring long term interventions. Therefore, due to the complex and long-term needs of children with cerebral palsy and other neurodevelopmental disorders, a family centred service model of service delivery is better suited to address such needs, in order to empower parents to take an active role in the care of the children with disabilities (Dempsey & Keen, 2008).

It is crucial for interventions to view the development of the child as a whole and intervention outcomes should include, but not be limited to, those of the child's physical, emotional, social, and cognitive functioning. Moreover, engagement in meaningful activities and community participation of the child are also considered primary goals of paediatric rehabilitation (King et al., 2004). Furthermore, the way in which professionals support children with disabilities and their families has the potential to enhance or to impede child and family outcomes (Dempsey & Keen, 2008). This shall be discussed in detail later in the paper.

2.4. The different theoretical models of disability

There are various approaches to disability. These approaches are the framework to understanding disability and thus impact on the kind of services that disabled children receive. The significant approaches that have contributed to understanding disability are the medical, social and biopsychosocial models of disability (Harris & Enfield, 2003; Schneider & Saloojee, 2007; Watermeyer, Swartz, Lorenzo, Schneider & Priestley, 2006). These theoretical models provide a foundation for not only understanding disability, but for understanding how service providers might understand their roles in relation to their work based on their frame of reference regarding how they perceive disability. These models and their implication for service delivery are discussed below.

2.4.1. The medical model of disability

The medical model is considered a traditional approach to disability in which health service providers use their expert knowledge to render the required services. According to Schneider and Saloojee (2007):

> “Traditionally disability has been conceptualised as a problem of the individual and needing interventions focused on the individual. Experts (mostly medical) took it upon themselves to provide what they thought to be the best interventions for the disabled person. This became known as the individual model which is also referred to as the medical model” (p.192).

The medical model views disability as being located in the person with the disability and therefore the focus is on working with this individual to solve the problem (Swartz & Watermeyer, 2006). This, in turn, results in the person being defined solely in terms of the disability, as a patient with medical needs, rather than as a whole person with a range of needs (Harris & Enfield, 2003). Therefore, a critique of this approach is that the medical model focuses on the individual with a disability and fails to view the person with a disability in context as stated by Swartz and Watermeyer (2006). In viewing CP from the medical model of disability, a child with CP may be viewed as having a brain lesion leading to impairment, failing to take into consideration that a child with CP has to engage in social situations with other children without any disabilities and has got other needs in addition to their needs for physical rehabilitation (Bøttcher, 2011).

According to Harris and Enfield (2003), the medical model views people with disabilities as having physical problems that need to be cured. Therefore, the medical model involves various rehabilitation programmes for various impairments aimed at typically problematising the child with a disability (McKenzie & Muller, 2006). From a critical perspective, this disempowers the child with a disability as they adopt the passive role of a patient, with medical professionals making all the decisions about their lives even beyond the impairment to issues related to how they should dress and what they should eat. With its individualistic approach, the medical model fails to meet the social needs of children with disabilities (Barnes, 2009). Furthermore, with its focus on the individual with a disability, the medical model fails to acknowledge issues of discrimination for children with disabilities and their families (Watermeyer, 2012).

2.4.2. The social model of disability

Due to the limitations of the medical model to address certain social needs of people with disabilities, the social model emerged. In the early 1980s, disability activists developed the social model which places disability within a broader social context allowing the child with a disability to be viewed in context, as their contexts determine how they experience their disability (Oliver, 1990, cited in Scheider & Saloojee, 2007). Advocates of the social model reject the medical model (Shakespeare, 2006).

The social model emerged as a response to various economic and social deprivations encountered by disabled people (Barnes, 2009). The social model indicates three barriers encountered by disabled people which are: physical or environmental (inaccessibility in the environment), institutional (exclusion from legal, educational, vocational, religious and political institutions) and attitudinal (negative perceptions of disabled people by able bodied people) as indicated by Harris and Enfield (2003). Thus the social model emphasises lifting societal, economic and environmental barriers for disabled people to participate in society. The social model has resulted in organisations for people with disabilities, by people with disabilities (Barnes, 2009).

From a social model perspective, even the terminology of disability in itself matters. According to Harris and Enfield (2007) the term disability is preferred over the term impairment. The former emphasises the limitations of opportunities for people with disabilities to take part in the life of the community on an equal level with others and is commonly used by disabled people's organisations, whereas the latter is described by Goodley (2001) as a condition in the body or mind as a result of lacking all or part of a limb; having a defective limb, organ or mechanism of the body. Shakespeare (2006) also argues for using the term 'disabled people' which emphasises issues related to social oppression over the term people with disabilities which emphasises medical related issues.

The social model emphasises that the environment plays a big role in how disability is experienced, as it can often be inaccessible leading to disadvantages for a disabled child. The environment is not only limited to the physical environment but goes beyond that to include social and attitudinal barriers which may lead to the exclusion of a disabled child in society (Harris & Enfield, 2003; Schneider & Saloojee, 2007).

The social model views the exclusion of disabled people from participating in communities due to environmental and attitudinal barriers as disabling and caused by the way in which society is organised, which in turn, makes disabled people vulnerable to oppression and poverty (Chappell & Johannsmeier, 2009). This model indicates that disability is a human rights concern, as disabled people often do not get to experience the pleasure of employment, leisure and education that able bodied people get to experience. Gathiram (2008) argues that disabled people in South Africa compete for limited resources with able bodied people and the challenge is attempting to achieve equality in an unequal society. Therefore change should take place within families, communities, and societies in which disabled children live. Changing negative community attitudes is an important component of the social model (Harris & Enfield, 2003).

Particularly in the case of children, there are certain environmental factors which need consideration as they can contribute to creating barriers to learning and development in general. These factors includes access to early diagnostic and intervention services; support services for family and school; social security to ensure adequate access to basic requirements; adequate transport; an accessible physical environment; adequate access to health, education, and recreational services to ensure that they develop and maintain a sense of wellbeing; and positive inclusive attitudes of families, health and educational professionals, and society as a whole towards disability (Schneider & Saloojee, 2007).

One of the critiques of the social model of disability is its outright rejection of medical intervention. Schneider and Saloojee (2007) argue that adopting a social model of disability should not mean rejecting any form of medical rehabilitation, rather it requires changing the way in which services and assistance should be given, emphasising placing them in the wider context of disabled people's lives. Moreover, rehabilitation devices can make a difference to the quality of life and independence of disabled people; while this is not enough it is nevertheless a first step towards empowering people with disabilities to gain access to all other services (Harris &

Enfield, 2003). Critics of the social model argue that integrating medical interventions into a wider framework of social change should be the goal (Harris & Enfield, 2003).

2.4.3. The biopsychosocial model of disability

Schneider and Saloojee (2007) argue that both the medial and social model have limitations when used in exclusion of the other. While on the one hand the medical model may misrepresent the experience of an individual with a disability, on the other hand the social model can fail to take into account the presence of impairments and other personal factors. This criticism is echoed by Shakespeare (2006) who argues that the social model of disability implies that impairment is not important whereas for people with degenerative disorders, discomfort or pain, impairment can be just as important as their social needs. In criticising the social model, Watermeyer (2012) argues that the social model is more focused on the material barriers to inclusion without acknowledging the unique individual struggles of disabled people, particularly people from ethnic and sexual minority groups. Thus, the combination of the two calls for a biopsychosocial model.

Shakespeare (2006) argues for a more sophisticated approach to disability beyond the social model, one which will be more in line with the ICF initiated by the WHO. As already discussed in this section, the WHO considers disability to be multifaceted to include impairment, activity limitation and participation restriction (WHO, 2001). Therefore, there is a need for an approach that can integrate the different facets of disability.

The biopsychosocial model of disability seems particularly suitable for addressing the multifaceted nature of childhood disability. It emphasises viewing a person with disability on the individual level, as well as on the social level. In viewing disability from this dual approach, children with disabilities are viewed as having rights to survival, protection, development, and participation in society similarly to any other child. However, to be able to realise such rights they may require additional support, services and technical assistance to enhance their ability to take up opportunities and be included in society (Schneider & Saloojee, 2007).

This model ensures that the rights of children with disabilities are upheld. This requires ensuring that children with disabilities have the necessary technological, attitudinal, personal and policy or legislative support to manage their disability in a way that allows them to participate in various aspects of life (Schneider & Saloojee, 2007).

The above discussion highlights how the different theoretical models provides a foundation for understanding disability. This foundation also determines the terminology to use when referring to people with dsabilities, for instance whether it is disabled children, children with disabilities or children with impairments. For the purpose of this study, the term ‘children with disabilities’ is used to emphasise on the multifaceted nature of disability as determined by the ICF requirements.

2.5. Health services for children with disabilities in South Africa

As stated earlier in this section, the theoretical models of disabilities discussed above provides a framework for understanding childhood disabilities which also impacts on what kind of services are provided for children with disabilities and how they are provided. This section explores the approaches used to deliver health services for children with disabilities in South Africa.

According to Braga and da Paz (2006) due to CP rehabilitation services requiring a large number of health service providers from multiple disciplines, it may be difficult for professionals to maintain a good relationship with the family of the child with CP. It can be effective to have a case manager from any of the disciplines, who will foresee, organise, and integrate the team, family and the rehabilitation process. While there may be various approaches to health service delivery for children with disabilities, various studies emphasise community-based rehabilitation and family centred services. These approaches are discussed below.

2.5.1. Community-based rehabilitation (CBR)

Community-based rehabilitation (CBR) emerged in South Africa in the 1980s, as a result of traditional rehabilitation services failing to meet the needs of many disabled people in South Africa in terms of availability and appropriateness, as a result of the traditional services being based on the medical model of disability (Chappell & Johannsmeier, 2009; Rule, Lorenzo & Wolmarans, 2006;). According to Werner (1993, cited in Rule et al., 2006) traditional rehabilitation attempts to change what is perceived as being abnormal in people with disability so that they can fit into society instead of changing society so that it can have the ability to accommodate a variety of human differences without discriminating between able bodied and disabled people. CBR appears to be more in line with the social model of disability.

CBR is defined by WHO, UNESCO and ILO (1994, as cited in Rule et al., 2006, p.274) as follows:

> “A strategy within community development for the rehabilitation, equalisation, of opportunities and social integration of people with disabilities. CBR is achieved through the combined efforts of people with disabilities, their families, the communities, and the appropriate health, vocational, educational, and social services”.

According to Hartley (2009) people with disabilities and the organisations for people with disabilities contributed to the development of CBR through voicing out their concerns. These concerns have contributed importantly to the evolution of CBR and resulted in increased recognition of discrimination and exclusion, and the need to address social and political aspects of disability.

CBR aims to empower disabled people to take control of their lives and be more involved in services for themselves. Children with disabilities and their families should also be empowered to be more involved in services meant for them and participate in decision making about such services. This can be achieved through research investigating their needs which will allow for them to articulate their needs in terms of their age and disability (DSD, 2009). Furthermore, CBR should take place as part of the process of developing a community as opposed to taking place as a separate process, and decision making should be based on a bottom-up approach, whereby decisions are made by people with disabilities and their caregivers (Rule et al., 2006).

CBR is particularly pertinent to any community where environmental barriers, economic restrictions, resource and service limitations restrict opportunities for the participation of people with disabilities in rehabilitation, community activities, education, employment and other areas of life, which is usually the case with most low income and under resourced communities (Madden et al., 2014).

According to Chappell and Johannsmeier (2009) CBR programmes mostly use mid-level rehabilitation workers known as community rehabilitation facilitators (CRFs) who have received training in CBR for a duration of two years. Mid-level workers are used to facilitate CBR programmes due to difficulties in getting more qualified professionals to work in communities. It is reported that in 2009 there were 200 CRFs working in more than 100 disadvantaged communities in South Africa in six of the nine provinces namely, Mpumalanga, Gauteng, Kwazulu Natal, Free State, North West, and Limpopo (Chappell & Johannsmeier, 2009).

Similarly, to other services for children with disability, for CBR programmes to be successful, they need to be connected to the Departments of Education, Health, Labour, Social Services and Housing, thus, this calls for intersectoral collaboration. However, it is reported that there has been a history of poor collaboration between departments and poor coordination of projects in South Africa (DSD, DWCPD & UNICEF, 2012).

In relation to childhood disability, CBR envisaged a shift in caring for children with physical disabilities, from care for the disability to care for the child, the family and the community, this was a result of a growing understanding that care was best delivered through a comprehensive, coordinated, multidisciplinary, and multiagency approach centered on the child, family, and community (Mcpherson et al., 2004).

While CBR seems like an effective strategy to meet the various needs of people with disabilities in theory, Chappell and Johannsmeier (2009) indicate that in South Africa there is little empirical evidence of the effectiveness and efficacy of CBR programmes. It is reported that in some cases, the ideas of professionals still outweigh the ideas of people with disabilities and in some cases so called CBR projects are managed without the input of the community members and people with disabilities (Disabled People International, 1994, cited in Rule et al., 2006; Lang, 1990). This challenge of whose ideas matters more raises the question of the dynamics between health service providers, the children with disabilities, their families and the community at large in the current study.

Another criticism of CBR is that it focuses on rehabilitation to the exclusion of aspects of social inclusion and equalisation of opportunities for people with disabilities (Chappell & Johannsmeier, 2009). Furthermore, in failing to take into account the principles of CBR such as social inclusion and equalisation of opportunities, CBR can become just another cost effective and easily accessible mechanism delivering the same old traditional rehabilitation services in communities instead of institutions (Harris & Enfield, 2003).

Regardless of the shortcomings of CBR, it seems to have made a significant impact in the lives of people with disabilities. This is seen in a research study conducted by Chappell and Johannsmeier (2009) to evaluate the impact of CBR projects in South Africa. On the individual level, people with disabilities reported positive outcomes as a result of practical interventions such as exercises and assistive devices which improved their self-awareness and self-esteem. On the family level, CBR helped family members gain more confidence in caring for their disabled family member, particularly parents caring for their children. This, in turn, improved family relationships and acceptance of the disability. On the community level, people with disabilities reported a change in community attitude towards people with disabilities and increased physical access as a result of the disability awareness campaigns carried out in the community. A systematic review of CP in Africa conducted by Donald, Samia, Kakooza-Mwesige, and Bearden (2014) indicates that caregivers reported that CBR programmes were effective in increasing access education and assistive devices.

2.5.2. Family-centred service (FCS)

The family centred service (FCS) approach to service delivery involves services directed at the level of the family. According to Mackean, Thurston, and Scott (2005) family centred care emerged as a result of the advocacy of persons with disabilities and parents of children with special health care needs in particular. King et al. (2004) regards FCS as both a philosophy and an approach to service delivery that is considered to be the best practice in early intervention and paediatric rehabilitation.

King et al. (2004) define FCS as follow:

> "Family-centered service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centered service recognizes that each family is unique; that the family is constant in the child's life; and that they are the experts on the child's abilities and needs. The family works together with service providers to make informed decisions about the services and supports the child and family receive. In family-centered service, the strengths and needs of all family members are considered" (p.79).

The notion of family-centered practice derived from Carl Rogers' work in the 1940s with families of "problem" children. This resulted in the growing need to promote a more holistic approach to care for children in hospitals. The approach led to a growing understanding of the role of the family in the child's life and the importance of the insights of parents into their child's abilities and needs. This approach to service delivery for children with disabilities is based on the family systems theory which emphasise the importance of the family's well-being to the child's well-being. Therefore, the aim of working with a family who has a child with a disability, according to the FCS approach, is to improve the quality of life for not only the child but for all family members (King et al., 2004).

Involving the family in the child's treatment raises the question of how involved the index client is in their treatment? Does it become a collaboration between caregivers and health service providers to the exclusion of the child? In answering these questions, Franck and Callery (2006) argue that the child must become involved in their own treatment, particularly to enhance their ability to monitor their own symptoms so that they are able to spend time away from the caregivers.

FCS is perceived as the gold standard in service provision for children with cerebral palsy as it leads to better health outcomes as reported by Rosenbaum, King, King and Evans (1998, cited in Novak & Cusick, 2006). It is increasingly utilised to care for children with disabilities by various health service providers with the aim of enhancing health care services for children. Furthermore, FCS is currently practiced in various countries including South Africa (Dunst & Trivette, 2009). FCS focuses on the strengths and resources of the child and family, within an ecological context. The FCS framework is strengths-based and enablement-oriented (King et al., 2004). Therefore FCS focuses on improving the caregiver's well-being which in turn has an impact on the child's wellbeing as stated by Ballweg (2001, cited in Dunst & Trivette, 2009).

Dempsey and Keen (2008) identified four underlying assumptions of FCS; firstly, the family and not the professional is constant in the child's life; secondly, the family is knowledgeable about the needs and well-being of the child; thirdly, the child is best helped by also helping the family and sometimes the family's community too; lastly, the family makes decisions about the provision of services while the professionals works collaboratively with the families and treats them with respect.

FCS requires treating families with dignity and respect; sharing information with families about their child's condition so that they are well informed and knowledgeable about their child's condition and care; and involving families in decision making and care of their children. Moreover, FCS places an emphasis on establishing a working alliance between health care professional and caregivers (Dunst & Trivette, 2009).

For the successful implementation of FCS, according to Law, Hurley, and Rosenbaum (2003): the following family-centred behaviours should be carried out: (1) formally adopting a family-centred approach to service delivery; (2) having a specific person lead the development of FCS; (3) providing information about FCS to families starting with the initial visit; (4) training staff in FCS delivery; (5) employing more family centred procedures and (6) providing a friendly environment.

Based on the above literature about FCS, it appears suitable to cater for the complex needs of children with disabilities and their families. However, in practice, it seems that FCS is not as easy as it sounds to implement, as the literature on FCS indicates a number of challenges. This is seen in a research study conducted by Mackean et al. (2005) on parents of children with disabilities in Canada which indicates that more emphasis is placed on training caregivers of children with disabilities to take a more active role in their child's care, care management, and advocacy, while less emphasis is placed on the other principles of FCS such as acknowledging the uniqueness of each child or family, development of a collaborative relationship between health service providers and care givers and facilitating family support and networking, despite these principles being just as important as empowering caregivers. In relation to the concerns around the principles of FCS, Franck and Callery (2004) indicate that the FCS principles can be interpreted differently by health service providers and caregivers, therefore, it is of importance to clarify the implications of FCS for all those involved in treatment of a child and evaluating the efficacy and effectiveness of FCS. Another challenge about FCS raised by Mackean et al. (2005) is that it may be misused to save money in the health care system by shifting care responsibilities onto the families, leaving the family, particularly women, with the responsibility of caring for their child with a physical disability.

King et al. (2004) conducted a review of the existing literature on FCS which indicates that FCS is held in high esteem by both health service providers and caregivers. This review further indicates that FCS leads to positive outcomes for the child and the caregiver, although there is little evidence for the family unit as a whole. Moreover, the review indicates that while the principles of FCS are evaluated, the 'accepting diversity' principle has received little attention. Similar to this study, a meta-analysis conducted by Dunst and Trivette (2009) indicates that FCS has a positive influence on caregivers' self-efficacy beliefs and wellbeing.

In evaluating the impact of FCS in South Africa, Saloojee, Rosenbaum, Westaway, and Stewart (2009) conducted a research study using 263 caregivers who regularly attended cerebral palsy clinics in public hospitals in Gauteng and Limpopo provinces. The results of the study indicates that caregivers were mostly satisfied with the services received and reported gaining something from the services. The study further indicates that caregivers appreciate being treated with respect, the caring attitude of health service providers, and being informed about the rehabilitation process or decision making processes. However, caregivers reported frustrations around logistics and administration difficulties such as long waiting list for appointments and lack of assistive devices.

According to Novak and Cusick (2006), FCS makes use of home programmes. Furthermore "not only does FCS support and frame the use of home programmes but in a practical way occupational therapy home programmes are integral to achieving FCS" (Novak & Cusick, 2006, p. 252). Hinojosa and Anderson (1991, cited in Novak & Cusick, 2006) argue that home programmes are used as a strategy aimed at improving the child's functioning performance and ability to interact with his/her physical environment.

Novak and Cusick (2006, p. 251) define home programmes as

> "Therapeutic activities that the child performs with parental assistance in the home environment with the goal of achieving desired health outcomes".

Taylor, Dodd, Mcburney, and Graham (2004) states that research evidence indicates that home programmes can be beneficial for people with cerebral palsy if there is adherence to the programmes. Home programmes are considered crucial in helping families achieve health outcomes for their children with physical disabilities, particularly for children with cerebral palsy (Novak & Cusick, 2006).

It appears that the rationale for home programmes is to make up for resource constraints, long waiting lists and limited access to therapy services; thus home programmes have become an alternative to one on one service provision (Novak & Cusick, 2006). This is supported by a systematic study conducted by Donald et al. (2014) on CP in Africa which indicates that home programmes are more convenient in resource limited settings (most countries in Africa) due to their minimum requirement for resources. Furthermore, home programmes have proven to strengthen the bond between caregivers and children with disabilities (Donald et al., 2014).

Since home programmes are framed within FCS, the FCS principles need to be practiced. This transformation recognises that families are better positioned than health professionals to direct, plan and prioritise their child's health care (Winton & Bailey, cited in Novak & Cusick, 2006). Donald et al. (2014) argue that there is lack of evidence of the efficacy of home programmes in Africa, instead research on the efficacy of home programmes has been conducted in high income countries.

The focus of home programmes is on enhancing the caregiver's competency so that the development of the child with cerebral palsy (for example) is effectively managed, within the context of the family's daily life and family goals. Home programmes requires different therapy roles from those traditionally taken in the rehabilitation of children with disabilities. These roles reflect shifts in parent–therapist relationships, with therapists taking on the role of expert partners liaising with parents to support their child's development and health by enhancing caregiving competency. This may be challenging for most therapists, as they may be used to an individualistic approach (medical model) (Novak & Cusick, 2006).

Within the FCS framework, home programmes are directed and evaluated by families who have developed the necessary competencies through interacting with health service providers. It seems that much emphasis is placed on enhancing caregiver's competencies in rendering home programmes. What does enhancing caregiver's competency entail? Novak and Cusick (2006) state that this involves enabling families to make informed decisions regarding the health and the development of the child by having knowledge, skills, and resources to support their choices and actions. Therefore, this requires supplying families with knowledge, skills, and resources to enable them to identify problems in their daily routines that arise from CP and be equipped to address such problems and get specialist support where necessary. This process empowers families to be able to determine if progress is being made and to be able to set goals in line with family priorities and goals.

Based on the literature on home programmes, it seems that home programmes entail health service providers spending a significant amount of time with caregivers. As discussed above, while research shows that home programmes do play a role in the rehabilitation of children with disability, it does not indicate how home programmes are experienced by health service providers (Donald et al., 2014). Furthermore, the effectiveness of home programmes depends on adherence, it appears that among other factors such as the process of coming to terms with a child's disability, the relationship between caregivers and health service providers play a role in the adherence or non-adherence to home programmes. The relationship between the two parties is discussed later in this section.

2.5.3. The experiences of health service providers working in the public sector in South Africa

Although not much research has been conducted on the experiences of health service providers working with children with disabilities in SA, there has been a lot of research conducted with the interest of understanding the experiences of health service providers more broadly working in the public sector, particularly in rural areas in South Africa. A number of studies conducted on the experiences of health service providers working in the public sector in South Africa indicates that there are a number of challenges faced by these health service providers which makes them prone to burnout and likely to migrate to private practice or urban areas (Ashmore, 2013; Jenkins, Gunst, Blitz & Coetzee, 2015; Nemutandani, Maluleke & Rudolph, 2006).

The vulnerability to burnout is reported in a study conducted by Van der Colff and Rothman (2009) investigating the relationship between occupational stress, a sense of coherence, coping, burnout, and work engagement of registered nurses in South Africa working in both private and public practice. Their findings indicate that the nurses experience a variety of stressors due to a lack of organisational support resulting in insufficient personnel and poorly motivated colleagues. Another significant stressor reported in the study that caused distress for the participants is observing patients as they suffer with their physical conditions. This study suggest that the lack of organisational support combined with the demands of the nursing job resulted in emotional exhaustion and depersonalisation for the participants.

The findings of the study conducted by Van der Colff and Rothman (2009) also highlights coping mechanisms that can possibly prevent emotional exhaustion in light of the challenges faced by health service providers. The findings of the study suggest that a sense of coherence results in better coping mechanisms in relation to the work stressors. A sense of coherence is defined by Antonovsky (1987, as cited in Van der Colff & Rothman, 2009) as an extent to which one feels confident that one's environment is predictable and that things will work out as well as can reasonably be expected. A sense of coherence contains three components which are: Comprehensibility which is the extent to which events are perceived as making logical sense; Manageability which is the extent to which a person feels they can cope; and Meaningfulness which is how much one feels that life makes sense. It is reported that health service providers with a sense of coherence perceived the difficulties experienced as manageable and had more active coping mechanisms as compared to their co-workers with a weak sense of coherence who very often employed passive coping mechanisms such as avoidance and venting of emotions, which in turn made them vulnerable to emotional exhaustion.

The problem of shortage of personnel appears to be a challenge in health service delivery for children with disability in SA. Census indicates that there is a shortage of staff from both governmental departments and non-profit organisations (NPOs) to render health services in rural areas because the country has few trained professionals and the majority of these professionals are working in urban areas (DSD, DWCPD & UNICEF, 2012). In addition to the shortage of staff, other challenges reported in the provision of services for children with disabilities in South Africa includes poor collaboration between governmental departments and NPOs, and poor coordination of services. Given the shortage of personnel in rural areas, national policies developed strategic plans to attract and retain health service providers in rural areas. The strategies includes a rural allowance received by heath service providers working within the public sector in rural areas; compulsory community service for health service providers whereby they are obligated to work for one year in a public health facility; and recruiting health service providers from other countries (Mburu & George, 2017).

In investigating the shortage of health service providers in rural areas, Nemutandani, Maluleke, and Rudolph (2006) conducted a cross sectional descriptive study on community service doctors working in the Limpopo province in South Africa. The study indicates that the shortage of health service providers in rural areas is due to a dissatisfaction with the working conditions, and inadequate support and supervision from senior doctors which in turn negatively impacts on health service providers' ability to cope with the demands of their work and their sense of competence. As a result of these difficulties doctors prefer to work in big cities and medical schools with better working conditions (Nemutandani et al., 2006).

Investigating the reasons for health service providers to remain working in rural district hospitals in South Africa, Jenkins, Gunst, Blitz, and Coetzee (2015) conducted a workshop using a group nominal technique. Their findings indicate that a deep sense of purpose and meaning in relation to making a difference in the lives of others and the community was reported as a major reason for staying in rural areas. Other reported reasons include a sense of being part of a team that allows for sharing difficulties, celebrating successes and supporting one another. This sense of feeling supported involves receiving positive feedback from management, colleagues and patients which is regarded as highly valued by the participants in the study. Another significant reason reported is that the environment should provide room for professional development. Moreover, the environment should allow for balancing work life with personal or family life. These factors are regarded as crucial for developing resilience (Jenkins et al., 2015). Another reported incentive for working in the public sector, in rural areas is a rural allowance received by health service providers working in rural areas. This is seen in a study conducted by Mburu and George (2017) focusing on the challenges faced by health personnel against strategies aimed at attracting and retaining health personnel in underserved areas. While there were reported positive experiences in relation to receiving this allowance. The study also highlighted the challenges experienced in relation to the rural allowance which seems to stem from the classification criteria for rural and non-rural areas and difficulties around professional rankings determining who receives the rural allowance and how much they receive (Mburu & George, 2017)

Expanding on the above research findings, a study conducted by Ashmore (2013) highlights both the positive and negative experience of working in the public sector as compared to working in the private sector in South Africa. The study highlights that while health service providers in the public sector experience difficulties with the lack of resources, distrust of the DOH, and a lack of personnel, there are also positive experiences. The reported positive experiences reported in the study include a sense of feeling needed and relevant, exposure to more academic opportunities and a sense of being part of the team. This study, similar to the findings reported above, also emphasises the importance of having support from management and receiving recognition for good performance which is appreciated and viewed as a motivation to remain within the public sector. A difficulty faced by health service providers working in public hospitals is non-compliance from patients which leads to feelings of frustration (Ashmore, 2013).

An additional difficulty for health service providers working in rural areas is reported in a study conducted by Mburu and George (2017) on health service providers in Kwazulu Natal in South Africa which is a difficulty in referring patients to higher level medical facilities for further treatment and management.

2.5.4. The relationship between health service providers and caregivers

It seems that a partnership between caregivers and health service providers is of importance when working with children with disabilities, as indicated in the different approaches to service delivery which have been discussed in this chapter. A collaborative relationship between health service providers and caregivers is emphasised particularly for the implementation of home programmes (Novak & Cusick, 2006).

In their research aimed at challenging the conceptualisation of family-centred care, Mackean et al. (2005) state that while their research supports the importance of developing a collaborative relationship between caregivers and health service providers, it highlights that the collaborative relationship is often conceptualised in a manner that leads to devolution of responsibility to parents. Moreover, the determination of what role each of these parties will play and the resulting outcomes of the partnership are not jointly determined as they are often determined by the health service providers. This indicates that while FCS emphasises treating families as equals to health service providers, there is evidence of superior and inferior positions in decision-making.

Mackean et al. (2005) raise concerns regarding the relationship between caregivers and health service providers pointing out that FCS is defined by experts and then carried out with families. Furthermore, even though caregivers are involved and have a role to play, this role is defined and driven by the health service providers as stated by Leiter (2004, cited in Mackean et al., 2005). In relation to the role of caregivers Leiter (2004, cited in Mackean et al., 2005, p. 81) raised the following question: “Does family centred care mean that the mothers take on therapy work (providing therapy for their children at home), or does it mean that the services that the program provides should be sensitive to individual family’s needs”? She found that the majority of health-care providers working with families operationalized family-centred care as the former.

With the above discussion in mind, it is important to note that things do not always go smoothly between caregivers and health service providers. In questioning the concept of partnerships between these two parties in South Africa, McKenzie and Muller (2006) explored the difficulties within this relationship. They argued that there are power dynamics that structure the relationship between health service providers and caregivers which undermine the caregiver’s ability to care for their child and to know what is in the best interest of their child. For McKenzie and Muller (2006), due to these difficulties, the relationship between health service providers and caregivers can be regarded as a collaboration rather than a partnership, where the former refers to working together towards a shared goal, while the latter requires shared control and decision making.

Paterson, Piggot, and Hocking (2002) emphasise that caregivers' participation in therapy programmes positively impact on the relationship between caregivers and health service providers. However, McKenzie and Muller (2006) argue that raising a child with a disability is a dynamic process with different responses based on how the child is managing. Therefore the health service providers need to be more understanding and sensitive towards this process.

It appears that communication plays an important role in the development of a positive relationship between health service providers and caregivers of children with disabilities. This is indicated in a discourse analysis on caregiver-practitioners talk conducted by Hodge and Runswick-Cole (2018) on health service providers and caregiver of children with disabilities in the UK. Hodge and Runswick-Cole (2018) argue that miscommunication between these two parties, where the caregivers hears a message in a different manner than what was intended, prevents the development of a positive relationship. Therefore, to make up for such communication difficulties, it may be necessary for health service providers to imaginatively engage with the point of view of the caregivers (Mackenzie & Scully, 2007). It is interesting to consider how these communication difficulties might apply to the South African context given the issues around language barriers.

According to Mackenzie and Scully (2007) imaginatively engaging with the view of another person might lead to understanding their minds. This is very similar to the concept of mentalisation which entails being attuned to one's mental state and that of others as discussed in chapter 1 of this report (Fonagy, 2018). According to Mackenzie and Scully (2007) there are three different modes of imaginatively engaging with the perspective of others. Firstly, there is imagining the self in a different situation and explore how they would act in such a situation. Secondly, the in-the-other's-shoes imagining involves imagining the self from the inside as the other person and this depends on the person's experiences allowing them to engage with the perspective of the other. Lastly, the empathic imagining involves completely leaving one's perspective behind to imagine the inside of another. According to Mackenzie and Scully (2007) in the process of imaginatively engaging with the perspective of others, people are actually very likely to project their own perspectives onto the other. Thus, people are more likely to make use of the imagining the self in a different situation and the in-the-other's-shoes imagining rather than the empathic imagining approach.

Lipsky (1971, as cited in Hodge & Runswick-Cole, 2018) argues that the difficulties within the relationship between health service providers and caregivers is the result of the emotional distress that comes with working directly with caregivers through a system that does not adequately accommodate the needs of those who use the services due to a lack of resources. Thus, due to these difficulties health service providers develop defence reactions such as ‘simplification’ whereby caregivers are viewed as difficult for challenging their advice while those who accept their advice are considered as good. However, these difficulties should be reflected upon so that health service providers can realise that they also play a role in the communication breakdown because of how they engage with caregivers (Lipsky, 1971, as cited in Hodge & Runswick-Cole, 2018). It is worth exploring whether health service providers in South Africa have similar experiences to those described by Hodge and Runswick-Cole (2018) considering the under resourced health system used to render services.

While the literature consulted provides information on the relationship between health service providers and caregivers, this information is mostly based on the experiences of caregivers and the experiences of the health service providers is inadequately reported in these resources. While the study conducted by Paterson, Piggot, and Hocking (2002) in New Zealand focused on the experiences of both caregivers and health service providers, the results are more focused on the experiences of caregivers and there is little report on the health service providers’ experiences. This literature on the relationship between health service providers poses the question of how the participants of the current study experience the relationship with caregivers, whether it is more in line with a collaborative relationship or a partnership?

The partnership between caregivers and health service providers should be based on teamwork, cooperation, shared decision-making, equality, and empowerment as stated by Novak and Cusick (2006). In working collaboratively caregivers and health service providers work together towards a common goal concerning the child’s health. This requires effective communication between the parties involved, as effective and open communication is valued by both caregivers and health service providers (Novak & Cusick, 2006).

Furthermore, there are certain characteristics of the health service providers valued by caregivers, these include being respectful, non-judgemental, enthusiastic, flexible, treating families with dignity, honesty, trustworthy and sensitivity as stated by Novak and Cusick (2006). It is crucial for health service providers to view caregivers as equal partners. In this partnership, the caregiver should be empowered to take the lead, while the health service providers encourages them (Novak & Cusick, 2006). Although this goes back to the issue of power dynamics between the two parties since empowering caregivers implies that they are disempowered and need to be empowered by health service providers.

According to Lipsky (1971, as cited in Hodge & Runswick-Cole, 2018) caregivers are more likely to have positive relationships with health service providers that they can relate to, who seems to understand and appreciate their experiences rather than more qualified or experienced health service providers. This indicates that what matter most is the manner in which health service providers engage with caregivers. The current study explores how health service providers experience the relationship with caregivers in order to contribute to this literature.

2.6. Conclusion

The purpose of this literature review was to explore the available literature on the experiences of health service providers working with children with disabilities. This chapter explored childhood disability, its prevalence in South Africa and the various theoretical models of disability and how these influence how disability is understood and how service delivery is approached. This chapter also acknowledges that there is limited literature on the experiences of health service providers working with children with disabilities due to a lack of research on the experiences of health service providers, particularly for the South African context. Nonetheless the literature review has aided in understanding key aspects of disability that may influence the experiences of the health service providers, furthermore the literature highlighted the challenges faced by heath service providers working within the public sector in South Africa. Given the gaps in the literature on the experiences of health service providers and the reported challenges experienced in the public sector, it becomes of importance to explore the experiences of health service providers working with children with physical disabilities in a resource limited area like Grahamstown.

Chapter 3: Research design and methodology

3.1. Introduction

The current study aims to explore the experiences of health service providers working with children with physical disabilities and their caregivers. For this qualitative study, an Interpretative Phenomenological Analysis (IPA) was employed as the research methodology. Wagner, Kawulich, and Garner (2012) describe qualitative research as an approach that aims to gather an understanding of human behaviour and the reasons behind such behaviours. Qualitative research is concerned with the words and stories of the participants and mostly requires the researcher to spend time with the participants by talking with them and/or by observing them in their natural settings and ask them questions that will lead to an understanding of why they do what they are doing. Thus qualitative research is called naturalistic research. IPA is a relatively recent approach to qualitative research which is rapidly growing and has been used by other human, social, and health sciences disciplines other than psychology (Smith, Flowers, & Larkin, 2009).

A qualitative stance, taking on an IPA approach, was useful for the purpose of the current study as it contributed to an understanding of the experiences of health service providers, specifically how they understand their experiences. IPA will be discussed in detail in the below section, including the theoretical underpinnings of this method that determined how the experiences of the health service providers was explored, recruitment and sampling procedures, data collection, data analysis, trustworthiness of the data and ethical considerations.

3.2. Interpretative Phenomenological Analysis (IPA)

Smith et al. (2009) describe IPA as an approach to qualitative, experiential and psychological research with a particularly psychological interest in how people make sense of their experience. Larkin and Thompson (2012) argue that IPA is concerned with meaning and processes, rather than with events and their causes. This method therefore is interested in exploring the experiences of the health service providers as they perceives them. Thus, since it is important from a phenomenological point of view to understand an experience from the perspective of the individual with the specific experience, the current study focused on the experiences of the health services providers, how they made sense of their experiences, what meaning they attached to these experiences paying attention to how they spoke about their experiences.

IPA originated in the 1990s; its origins can be traced to a paper written by Smith (1996, as cited in Shinebourne, 2011) in which he argued for an approach to psychological research that captures the qualitative and experiential dimensions, yet still dialogues with mainstream psychology. Smith argued that psychology could and should be both experimental and experiential. Smith drew on theoretical ideas from phenomenology and hermeneutics, and on an engagement with subjective experience and personal accounts (Shinebourne, 2011; Smith et al., 2009).

IPA is informed by concepts and debates from three key areas of philosophy of knowledge. These areas are phenomenology, hermeneutics and idiography (Smith et al., 2009). These theoretical underpinnings shall be discussed in more detail below.

3.2.1. Phenomenology

Phenomenology is a philosophical approach to the study of experience. It is a careful examination of human experience. Phenomenology is concerned with what the experience of a human is like and how they constitute their lived world (Smith et al., 2009). The phenomenological philosophy initiated by Edmund Husserl presents IPA with guidelines of how to examine and comprehend lived experiences (Shinebourne, 2011). A principle argued for by Husserl is that experience should be investigated in the way that it occurs on its own terms (Smith et al., 2009). Since it is important from a phenomenological point of view to understand an experience from the perspective of the individual with the specific experience, the current study focused on the experiences of the health services providers, how they made sense of the experiences, and what such experiences meant to them.

For Husserl, phenomenology involved stepping outside of everyday experience, which he referred to as our natural attitude, and moving towards adopting a phenomenological attitude that requires looking away from objects in our world and looking inwards into our perceptions of such objects (Smith et al., 2009). Larkin and Thompson (2012) argue that this requires "identifying and suspending our assumptions in order to get at the universal essence of a given phenomenon, as it presents itself to consciousness" (p.102).

Thus Husserl's work made a significant contribution towards how to examine and comprehend lived experiences and particularly to the IPA researcher's focus on the process of reflection and taking up bracketing which involves shutting out one's preconceptions to allow for phenomena to show itself as itself (Larkin, Watts, & Clifton, 2008; Pietkiewicz & Smith, 2012; Shinebourne, 2011). According to Larkin, Watts, and Clifton (2008) bracketing is a difficult process as IPA researchers are people in context and cannot fully shut out their preconceptions. Nonetheless this does not mean that one should not try. Thus, it is important to shut out such preconceptions while still examining them.

3.2.2. Hermeneutics

The second theoretical underpinning of IPA is Hermeneutics. For Heidegger, Merleau-ponty and Sartre (as cited in Shinebourne, 2011; Smith et al., 2009), a person is viewed as embedded in a world; in a historical, cultural and social context in which they get caught up in activities and relationships through which the world appears to them and is made meaningful. According to Shinebourne (2011) from Heidegger's views, IPA considers phenomenological inquiry as an interpretative process. Thus the meaning of a phenomenological description lies in the interpretation of the phenomenology. Therefore, hermeneutics becomes a prerequisite for phenomenology.

There is a great emphasis in hermeneutics on making what is latent, manifest. According to Shinebourne (2011) this process of making what may not be visible become visible requires interpretation. However, it appears that one cannot interpret a phenomenon without influencing what is interpreted. In acknowledging the role of the researcher in making sense of the experience of participants, Smith (2004, cited in Shinebourne, 2011) refers to the double hermeneutic. The double hermeneutic or dual interpretation process means that on one level participants are trying to make sense of the experiences, while on another level the researcher is trying to make sense of the participants making sense of their experiences (Smith & Osborn, 2008 as cited in Pietkiewicz & Smith, 2012). Double hermeneutics involves the researcher utilising their own 'fore conception' as a way into the participant's experience. Therefore the researcher's prior understanding has an influence on the research. Thus, this requires critical and reflective evaluation of how this prior understanding influences the research as stated in the previous section (Shinebourne, 2011). Reflexivity was used for this study, which allowed for a continuous reflection on the role that my own preconceptions might have played in the study.

3.2.3. Idiography

The third theoretical underpinning of IPA is idiography. Idiography is described as the in depth analysis of single cases and examining individual perspectives of study participants in their unique contexts (Pietkiewicz & Smith, 2012). This requires focusing on the particular rather than the general or universal (Larkin & Thompson, 2012; Pietkiewicz & Smith, 2012; Smith et al., 2009) . According to Smith et al. (2009) focusing on the particular involves thorough analysis of each case and a thorough examination of similarities and differences across all cases involved. This aids in understanding how a particular phenomenon has been understood by particular people and what makes the specific experience unique from other experiences (Pietkiewicz & Smith, 2012).

According to Larkin and Thompson (2012) “the outcome of a successful IPA study is likely to include an element of ‘giving voice’ (capturing and reflecting upon the principal claims and concerns of the research participants) and making sense (offering an interpretation of this material which is grounded in the accounts, but may use psychological concepts to extend beyond them)” (p.8). The analysis process of the current study involved a thorough line by line analysis of each transcription to produce patterns of meaning and reflections that assisted with the understanding of particularity in the experiences of the health service providers.

3.3. Sampling and recruitment

Since IPA is an idiographic approach that involves the understanding of a particular phenomenon in a particular context, sampling in IPA is purposeful instead of random (Smith et al., 2009). Creswell (2007) describes purposeful sampling as a method of sampling that involves purposefully selecting individuals for a study that can contribute to understanding the research problem, whereas random sampling requires that each individual from a broader population has an equal chance of being included in the sample (Wagner, Kawulich, & Garner, 2012).The participants for the study were selected on the basis that they can grant access to a particular perspective on the phenomena under study. For the current study, the phenomena under study is the experiences of health service providers working with children with physical disabilities and their caregivers. Therefore, the participants have to represent a perspective rather than a population, which means that a homogenous sample was used, for whom the research questions were meaningful as stated by Smith et al. (2009). A homogenous sample is described by Smith et al. (2009) as one that is similar in certain important variables, in this study, the participants are all working as health service providers with children with physical disabilities and their caregivers at the developmental clinics in a semi-rural context in the Eastern Cape. Therefore, they were able to give access to a particular perspective of the phenomena under study (the experience of working with these children and their caregivers) and thus, addressing the research questions of the current study.

For the above stated reason, the participants of the study were sampled using a purposive sampling method. Permission to recruit participants from the local NGO was sought from the chairperson of the organisation. A letter was written for this purpose (see appendix B) and I was granted permission to recruit participants. Thereafter, once permission was granted I went to the offices of the local NGO where I was able to introduce myself to the health service providers and find out which of them were providing services at the developmental clinics. The potential participants were given the information sheet with further information about the study and were given the opportunity to ask me questions (see appendix D).

Visiting the recruitment site in person and introducing myself and the research study allowed for establishing rapport with the participants. According to Pietkiewicz and Smith (2012) an IPA researcher should have the ability to establish rapport with the participants and gain their trust. This can be achieved through a warm up discussion prior to the interview taking place to ease the participant’s tension so that they may be in a position to discuss sensitive and personal information.

The study also made use of the snowball sampling technique. The snowball sampling technique involves finding participants that meet the inclusion criteria and asking them to introduce the researcher to other prospective participant with similar characteristics (Wagner, Kawulich, & Garner, 2012). The DOH is a big organisation with a large number of health service providers, it was going to be difficult to determine which allied health service providers from DOH were involved in the developmental clinics at the research site. Therefore, I asked the participants from the NGO to introduce me to the allied health service providers from DOH who they work with at the developmental clinics. The participants from the NGO informed the service providers from the DOH about the study and those who were interested in participating were sent an email containing the information sheet. The purposive and snowball sampling procedures made it possible to recruit participants that were suitable for the purpose of the study. The participants from DOH were only recruited after permission was granted by the Department of health and by the CEO of one of the local hospital in the Eastern Cape (See permission letter in appendix C and approval letter in appendix H).

Eight participants, four from the NGO and another four from DOH were contacted regarding participating in the study. However, only five participants from this group indicated their interest in participating in the study. As a result, five participants who are/were providing allied health services to children with physical disabilities from a local NGO and DOH in the semi-rural town made up the sample. The sample included Occupational therapists, Physiotherapists and social workers. Larkin and Thompson (2012) emphasise that it is the quality and not the quantity of the data that matters in IPA and it is for this reason that IPA studies uses relatively small samples to allow for a thorough analysis of each case.

3.4. Participants

As discussed in the above section, while a number of potential participants were targeted for the study, only five participants consented to taking part in the study. The participants differed in occupation and experience in terms of the duration of working with children with physical disabilities. The study was conducted in a small town whereby participants could easily be identifiable. Therefore, pseudonyms have been used to protect the identity of participants, their professions and demographic backgrounds have been disguised for this purpose. The participants are referred to as health service providers. Furthermore, given the small number of participants and the small pool of health service providers from which the participants were recruited, the location of the participants (NGO or DOH) is not divulged in order to protect anonymity. While it is recognised that working at an NGO or government sector setting is likely to be experienced differently by the participants, both settings involve engaging with clients from low resource settings. Furthermore, at the research site, health service providers from the NGO and DOH work together at the local clinic. The characteristics of the participants have been summarised below:

- Gugu is working as a health service provider. She has been working with children with physical disabilities for six years. She got involved with working with children with physical disabilities as part of the responsibilities of the post that she applied for.
- Rose is working as a health service provider. Rose started working with children with physical disabilities in 1993 before the developmental clinics started running, she worked for 15 years, and then she took a break for two years after experiencing burn out and later returned to working with children with physical disabilities on a part time basis.
- Angel used to work for public services but currently works in private practice. She worked with children with physical disabilities at the developmental clinics from 2006 until she left recently.
- Lindy has been working as a health service provider for children with physical disabilities since 1976, due to stipulations from her bursary that she had to work with people with disabilities which she was not aware of until she qualified as a health service provider.
- Candy is working as a service provider. She has been working with children with disabilities for less than a year.

3.5. Data collection

As already stated in the previous sections, IPA is mainly concerned with exploring rich, detailed, and first-person accounts of experiences and phenomena under investigation. This requires in-depth one on one interviews to achieve the IPA goals as stated by Pietkiewicz and Smith (2012). For this study, semi-structured interviews were used to explore the experiences of the health service providers involved at the Developmental Clinics, with a focus on what is has been like for them to work with children with physical disabilities, how they have experienced their roles, and their experiences of broader health service provision for children with physical disabilities in the semi-rural town where they are based Semi-structured interviews allowed for participants to freely tell their stories regarding their experiences in relation to their work. Furthermore, a semi-structured interview approach allowed for a dialogue to take place in real time, while providing the flexibility for unexpected issues to arise, which were then investigated further by probing for more information through further questions.

Smith et al. (2009) argues that the interviews with participants should address the research question, however, the research question is usually abstract and requires a series of questions that will contribute to answering the research question. An interview schedule was prepared to help guide the discussions (see appendix A) for the current study, the research questions were informed by the broader research question with guidance from the literature review regarding areas to explore in relation to the research question. How participants responded to the questions determined how the interview unfolded, through probing for more details where necessary. The interviews were audio recorded and transcribed for analysis purposes by the researcher. Each interview took between 45 to 60 minutes. Participants gave written consent for interviews to be audio recorded for analysis purposes (see appendix B).

Pietkiewicz and Smith (2012) indicate that it is not only what is said which is of importance, it is also how it is said, this emphasises not only focusing on the verbal communication but also on the non-verbal cues that may be indicative of sensitive subjects for the participants. Thus, during the interview the participant's non-verbal communication was monitored. Paying attention to the nonverbal cues allowed for focusing not only on what was said during the interviews but also how it was said. To capture how participants expressed themselves the Gail Jefferson system of transcription notation (see appendix C) was used as adapted by Atkinson and Heritage (1984). Transcription took place within the same week of the interview in order to record the non-verbal aspects of the interview that were still fresh in the researcher's mind. This allowed for familiarity with the data and contributed to the emergence of exploratory comments that contributed to the analysis process.

3.6. Data analysis

Interview transcripts were analysed using the IPA guidelines of analysis. The analysis method allowed for examination of patterns within the data that assisted with interpreting the experiences of the health service providers and the meaning they attach to these experiences.

The data was analysed using the IPA method through a series of steps as stated by Smith et al. (2009) which are as follows:

Step 1: Reading and re-reading

This phase involves transcribing data, reading and re-reading the transcripts. This stage requires immersing oneself in the data in a way that results in the participant being the focus of the analysis. For the current research study, the transcription process aided this phase, as it required repeatedly listening to audio recordings and re-reading the transcripts to ensure that participants' experiences were accurately captured as reported by the participants.

Step 2: Initial noting

Step 2 involves coding the important aspects of the data in a systematic fashion across the entire transcript and making notes. This promotes familiarity with the data and can aid in identifying ways in which a participant talks about, understands and thinks about an issue. A line by line coding system was used for the study, while writing notes or comments alongside the text with the aim of summarising and interpreting the data gathered from the participants.

Stage 3: Developing emergent themes

This step involved shifting from working with transcripts to working with the initial notes taken, and generating significant emergent themes. Themes were expressed as phrases that reflect the researcher's interpretations.

Stage 4: Searching for connections across emergent themes

The emergent themes were clustered together according to their similarities for general or specific (sub-ordinate) themes with a new name for the cluster. This was achieved by exploring their connection between the different themes. This is called abstraction and requires linking similar ideas across themes (Pietkiewicz & Smith, 2012).

Stage 5: Moving to the next case

This stage involved moving to the next transcript and repeating stage 1 to 4 (Pietkiewicz & Smith, 2012). Smith et al. (2009) cautions against allowing the analysis of the first transcript to influence the analysis of the second transcripts and emphasises following the outlined steps for each and every transcripts to avoid this. Therefore, the outlined steps were systematically repeated for each and every transcript.

Stage 6: Looking for patterns across cases

This step involves seeking for connections across cases. The numerous subordinate themes generated from the different transcripts were examined for connections and generated master themes. In addressing the research questions of the study, the subordinate themes were clustered into five master themes. A table of the master themes and the related subordinate themes is provided below.

Table 1: Themes

Master themes	Subordinate themes
Positive experiences of their work	• Positive emotional reactions in relation to their work • Positive interactions with caregivers • Positive interactions with colleagues
Negative experiences of their work	• Negative emotional reactions in relation to their work • Experiencing challenges in their work • Negative interactions with caregivers • Negative interactions with colleagues
Perception of role as changing over time	• A view of their professional role as changing in relation to their experiences • Advocating for children with disabilities
Managing challenges in their work	• Perspective taking in relation to their work • Experiencing gradual growth in relation to their work
Service learning programme experienced as complementary to their work	• Service learning programme experienced as filling the gabs in service provision for children with disabilities • Service learning experienced as addressing the emotional needs of caregivers

Stage 7: Writing the analysis report

The final step involves reporting findings on the analysis process. A detailed discussion of the findings of the study is provided in the upcoming chapter.

3.7. Trustworthiness and credibility of the data

According to Stiles (1993) research should be believable and useful to parties beyond those who participated in the study. Reliability refers to the trustworthiness or dependability of the data, where dependability refers to the degree to which a reader may be convinced that the findings did actually happen as stated in the research report. While validity refers to the trustworthiness of the interpretations or conclusion as stated by Silverman (2013). Therefore, a distinction can be made between procedural and interpretative trustworthiness.

For the current study the guidelines outlined by Yardley (2000) have been employed to ensure the trustworthiness of the procedures employed and the interpretations of the data, thus ensuring the quality of this qualitative study. These guidelines were used in integration with the works of Saville Young (2016) and Silverman (2013). The guidelines outlined by Yardley (2000) for ensuring the trustworthiness of the data are sensitivity to context, commitment and rigour, transparency and coherence and lastly impact and importance. These guidelines are discussed below.

- **Sensitivity to context:** This principle requires different levels of sensitivity: sensitivity to the context of theory as indicated by an understanding of previous enquiry of similar topics; sensitivity to the sociocultural setting of the study; and sensitivity to the differing perspectives of those involved. As is evident from Chapter two, I conducted an extensive review of the literature in topics relevant for exploring the experiences of health service providers working with children with disabilities in South Africa and internationally, while evaluating the relevance of international studies for the South African context. Furthermore, I was sensitive towards the participants by ensuring that interviews were scheduled according to their preferences and did not in any way conflict with their work or personal schedules. Moreover, each participant was provided with the space to freely express their unique experiences.
- **Commitment and rigour:** Commitment involves a thorough engagement with the topic at hand and gaining mastery in the methods used (Yardley, 2000). Throughout the process of completing the current study, I have thoroughly engaged with literature about IPA and studies that have used IPA in order to become competent in using IPA methods. I have also immersed myself in the data collected by transcribing it and thoroughly

reviewing it. I have furthermore used conversations with my supervisor about the research to refine my skills. On the other hand rigour refers to the comprehensiveness of the data collection, data analysis and interpretations processes which depends on the ability of the sample to provide information that addresses the topic at hand (Yardley, 2000). My description of these processes above attest to their comprehensiveness.

- **Transparency and coherence:** For Yardley (2000), this principle involve detailing every aspect of conducting the study and rules used to code data. For Silverman (2013) transparency requires methodologically awareness which is described as the commitment to show as much as possible regarding the procedures used and evidence that resulted in certain conclusions. Transparency about the procedures satisfy the coherence principles which is concerned with the suitability of the methodology to address the research questions (Saville Young, 2016; Yardley, 2000). Transparency requires disclosing all the relevant aspects of the research together with a disclosure of how the researcher's assumptions and intentions may have influenced the research product because the subjectivity of the researcher plays a role in how a phenomena is understood (Saville Young, 2016). This process is referred to as reflexivity (Saville Young, 2016; Yardley, 2000). According to Saville Young (2016) reflexivity should go beyond simply stating personal affiliations. It should contain a reflection on the meaning behind such affiliations in relation to the research project at hand. All the relevant aspects relating to conducting this research study have been discussed under the relevant sections and extracts from the data collected to substantiate themes. Moreover, a reflexivity section has been included towards the end of this chapter that discusses the role that my own assumptions, beliefs and intentions played in this study.
- **Impact and importance:** This principle is concerned with the significance and relevance of the study. According to Yardley (2000) the impact and importance of the study concerns both the theoretical and practical impact of the study. The significance and importance of the current study has already been discussed in the introductory section. The study expands on the literature related to understanding the experiences of health service providers working with children with physical disabilities in South Africa (theoretical). Moreover, the results of the study can be used to improve practice or even policy for health service providers (practical).

3.8. Ethical considerations

Ethics are rules that guide how a research study should be conducted to protect the welfare of the research participants. The study was granted ethical approval by the Department of Psychology's Research Project and Ethical Review Committee (RPERC) of Rhodes University (see appendix D). The current study adhered to the ethical standards of the RPERC which are in line with the ethical principles discussed later in this section.

Prior to contacting participants, permission was requested from the DOH Eastern Cape and the chair of the NGO to recruit participants. Two permission letters were written for this purpose, one letter was emailed to the NGO chairperson (see appendix E). Permission from the DOH was requested through filling out an on online application, in which the proposal of the study was submitted on the National Health Research Database website (http://nhrd.hst.org.za/).

Permission was granted by the NGO chairperson after 4 weeks of submitting the request to recruit participants and it took roughly the same duration to receive approval from the DOH and an approval letter was received from the Eastern Cape DOH (see appendix F). The approval letter received from DOH together with the permission letter to recruit participants from DOH (see appendix G) were emailed to the District Manager and after following up on the request, I learnt that the District Manager that the letter was addressed to had recently resigned from her post. After numerous attempts to follow up on the matter, my request was forwarded to the CEO of the local hospital. There was no response from the CEO and numerous attempts to do a follow up on the matter were unsuccessful. Nonetheless, permission was eventually received from the CEO to recruit participants from the hospital.

According to Blanche, Durrheim, and Painter (2006) the purpose of ethics in research is to protect the welfare of participants. This means that the researcher has a moral obligation to protect the research participants from harm, unnecessary invasion of their privacy and the promotion of their well-being. Blanche et al. (2006) argues that there are a number of aspects that needs to be considered when doing research in order to ensure that the research study is ethical. There are four widely accepted principles that are applied in various ways to determine whether a research study is ethical or not. These principles are as follows:

- **Autonomy and respect for dignity of persons**

A study respects participants and their autonomy if anonymity is guaranteed and if the participants are allowed to partake in the study on a voluntary basis, and are allowed to withdraw at any stage without negative consequences. For this purpose, it was crucial to get informed consent from the individuals that took part in the study. Informed Consent involves the procedure by which an individual may choose whether or not to participate in a study, as participation in the study was voluntary, based on full information provided to them. I took the responsibility of ensuring that the participants had an understanding of the purpose and methods to be used in the study, and the demands placed upon them as a participant. I also ensured that the participants understood that they had the right to withdraw from the study at any time during the data collection phase without any repercussions.

For the current study, all the participants were provided with an information sheet containing the aims of the study and what would be required from them (see appendix H). The option to ask questions was provided and they were given the opportunity to decline to participate in the study. Participation on the study was voluntary. To ensure anonymity, pseudonyms are used and any identifying information (profession) was withheld, only the researcher has access to the unedited data. The name of the NGO and the actual research site are also withheld. Participants were requested to provide written consent for participating in the study, for interviews to be recorded and for the data to be stored for a period of 5 years in which it could be used for publication purposes (see appendix I).

- **Non maleficence**

The researcher is obligated to protect the research participants from harm. In the context of research ethics, harm is broad, as it goes beyond extreme physical pain, but also involves such factors as psychological stress, personal embarrassment or humiliation, or other influences that may adversely affect the participants in a significant way. For the current study, participants were informed that should they get distressed as a result of the interview, a referral would be made to relevant counselling services. Furthermore, care was taken to protect participants from harm by adhering to the ethical principles of consent, privacy and not deceiving the participants.

- **Beneficence**

This philosophical principle obliges the researcher to attempt to maximise the benefits that the research will afford to the participants in the research study as stated by Blanche et al. (2006). Research should be beneficial to individuals, groups and humanity in general. Even though not everyone may benefit from the research, care should be taken that while some may benefit, no one should be harmed in the process (Blanche et al., 2006). The outcomes of the study will contribute to an understanding of the experiences, both positive and negative of heath service providers working with children with physical disabilities and their caregivers. The results of the study will be made available to the organisations providing health services at the developmental clinics in report format and might help improve working conditions for the health service providers and improving service delivery for children with disabilities.

- **Justice**

This principle requires that the researcher treats all the participants with fairness and equity. Therefore research is considered just to all involved if everybody is treated equitably. In this research study all the participants were treated equally and none were given special preference over others. Therefore this study was just to all involved.

3.9. Reflexivity

As already established in this paper, it is challenging to always bracket out our assumptions because researchers are people in context. Furthermore, the researcher’s assumptions may play a role in their understanding of the phenomena. Saville Young (2006) suggests a number of reflexive methods including keeping a reflective journal which details how interpretations were made and recording observations during data collection with details of relevant personal responses. Using a Reflexive journal allowed for recording how my assumptions, beliefs, intentions, or actions may have influenced the research.

I am a 26 years old, Black, Siswati speaking female. I have a 9 years old daughter. I was born at Driekoppies, a semi-rural place located in Nelspruit, Mpumalanga and closer to the Swaziland border. The population mostly comprises of families with a low socioeconomic status and most have to utilise public services. Due to these demands, it is possible that health service providers from such public facilities might be overwhelmed because the service is of poor quality. Thus, I have always held negative perceptions about public health service providers because of my prior experience. I have always perceived them as being disrespectful, insensitive and impatient and I have always had little faith in the services rendered.

When I started working on the current study, I was aware of my preconceptions and tried to ask questions in an exploratory and open manner. The interview schedule helped me in ensuring that I stuck to the relevant questions and refrained from satisfying my own curiosity. After interviewing the first participant for the current study, I was sensitised into how overwhelmed health service providers are and how they have to deal with difficulties around lack of resources.

At some point I started empathising with them, particularly as I am also in a profession that involves working therapeutically with children and I am a mother. Their experiences reminded me of my own frustrations of working with children and feeling frustrated by parents I perceived as contributing to the difficulties that children are experiencing. It also reminded me of my need to be protective of children as I often relate to children as a mother. Perhaps it is possible that this sense of relating to their experience might have led to more exploration of certain experiences over others. Nonetheless, I was aware of such feelings and reflected more on them particularly when analysing the transcripts. I had to evaluate the evidence for the themes generated to ensure that they captured the participants' experiences.

My educational background played a big role in gaining access to the participants. I could see the reaction I would receive after sharing that the study is conducted as part of my Master's Degree in Clinical Psychology. It is possible that my educational background allowed for me to access information that I would not have otherwise been able to access without it. It is also possible that it might have been a barrier to accessing certain information due to concerns around being judged from the participants' part. I picked up on how the participants started to relate to me as more of a colleague and would comment on how they hope the information provided will be useful in completing my Degree and some would even ask I would be able to make sense of it when transcribing or analysing the data.

Throughout the different phases of conducting this research study, I have been aware of my own frustrations about public health service delivery, the feelings of empathy and relating to the participant's experiences. While bracketing these feeling completely out might have been impossible, I have attempted to do so and using the interview schedule has helped to ensure that I asked exploratory questions that addressed the research questions of the study.

3.10. Conclusion

An IPA approach was used for this study. This chapter has outlined the theoretical foundations of IPA, and how IPA has governed decisions made regarding the sampling procedures, data collection and data analysis for the current study. The chapter also provided discussions around ethical considerations, the issues of credibility and trustworthiness in qualitative research and reflections of how my preconceptions may have impacted on the study.

Chapter 4: Findings

4.1. Introduction

This chapter describes the findings of the study generated from the data analysis process of the interview transcripts which were analysed using the IPA guidelines for data analysis as stipulated in the previous chapter. The analysis process produced five master themes (see table 1 for the list of themes) which addresses the research question of the study: What are the experiences of health service providers working with children with physical disabilities and their caregivers in a semi-rural town in the Eastern Cape? And the sub questions: What impact does working with children with disabilities have on the health service providers? How do health service providers understand their role? What is their perception of the service learning programme in relation to their work? What is their perception of service provision for children with physical disabilities? A description and interpretation of the themes is provided below together with verbatim extracts from the transcripts to substantiate the findings.

4.2. The master and subordinate themes generated by the interpretative phenomenological analysis of the data

4.2.1. Positive experiences of their work

This master theme captures the positive experiences reported by participants in relation to their work. The participants reported a number of positive experiences in relation to their work and described how these impacted on them. Mostly the positive experiences are portrayed in the form of the meaningfulness of the work done with children with disabilities and the meaningfulness of interactions in this kind of work context. This theme contains three subordinate themes namely: positive emotional reactions in relation to their work, positive interactions with caregivers and positive interactions with colleagues.

4.2.1.1. Positive emotional reactions in relation to their work

A common experience shared by the participants is that of enjoying or loving their work despite challenges faced. In the extract below, Rose describes experiencing the developmental clinics as one of the highlights of her work, she describes loving the interactions at the developmental clinics. For Rose, even though the experiences at the developmental clinics can be overwhelming, she describes how when she looks beyond such difficulties she actually loves the work particularly when the caregivers are invested in the process.

Extract 1: Rose "*The development Clinic has always been one of the highlights of my work. I love the interaction. I love to see how the children did progress when the caregiver were willing to do the exercises and understood what the purpose of doing those exercises were for the child and the benefits to the child.*"

In the extract below, Candy describes experiencing the work she does at the clinic as fulfilling for her. She seems to perceive her contribution as meaningful in the sense that it improves the quality of life for these children and their caregiver. She described the contribution she is making to improve the quality of life for these children as good enough reason for her to continue doing this kind of work despite challenges faced in working in a resource limited setting.

Extract 2: Candy *"So I do find it to be rewarding in a sense that we get to help and enable these children to perform better and to improve quality of life. I think is very important for lots of them coming out to the clinic"*.

In extract 3 below, Angel shares how she loves the work done at the developmental clinics which for her differs from traditional occupational therapy done outside of the developmental clinics. She describes a sense of experiencing the work at the developmental clinics as meaningful and unpredictable unlike the 'first world problems' she faces in private practice. She talks about how doing this work led to her developing passion for working with children with disabilities and it is actually one of the things she misses. It seems that while she experiences a sense of relief from not working at the clinics anymore, Angel also misses working there.

Extract 3: Angel "*I loved it, you know the traditional views of therapy is that your child comes if they've got a learning disability or a handwriting problem and I consider those first world problems whereas the children that we see at the developmental clinics are very much third world problems in that you've got to think about things in a different way. It's not your traditional Therapy you've got to think outside of the box to try and assist the children and assist these families and I absolutely loved it when you can see the progress that the children made. I really felt quite passionate about that and I miss it, it is definitely one of the things that I miss about working, about not working at the hospital"*.

4.2.1.2. Positive interactions with caregivers

This subordinate theme focuses on the health service providers' positive experiences of their relationship with caregivers. For most of the participants, the interaction with caregivers was experienced as positive. Amongst these participants is Gugu who reported in the extract below that she has always had a good relationship with caregivers. She believes that her good personality also contributes to her good relationship with caregivers and that they feel comfortable around her to ask her to help out with various aspects related to their children and families. Gugu shares a sense that the kind of person she is, a warmth towards caregivers actually helps maintain a good relationship with caregivers and it conveys that she is approachable to caregivers.

Extract 4: Gugu "*Good, maybe it's also my personality I'm very good yeah, so they love me. To be honest they are very good with me, they always call me when they come here and I'm not here and they take my phone number and then they will call me "Gugu I need this, Gugu I need that". So yeah the relationship with my caregivers it's really good."*

In extract 5 below, Angel shares how she still randomly meets some of the caregivers that she used to work with. She describes sharing a bond with caregivers so strong that it is sustained over time. Meeting caregivers, being recognised by them and their warmth towards her seems to be experienced as an acknowledgement of her contribution towards these families and their children. She perceives this as an indication that her contribution might have had a good-enough impact for the caregivers to show her affection whenever they see her.

Extract 5: Angel: "*I still bump into some of our moms on the streets or I'll see someone and we'll come running on the street towards each other so that we can greet each other."*

Similar to the extract above, For Rose, also describes forming a bond so strong with the children she worked with that they are able to recognise her later in life when they are all grown up. She describes viewing herself as part of their lives and it seems that being recognised by them emphasises her contribution to their lives and is experienced as rewarding.

Extract 6: Rose "*So that was lovely, you know that families and even the client's those who were small when I met them and now they are adults and they still see me you know it's nice to be part of their lives and you build up a special bond and you know."*

4.2.1.3. Positive interactions with colleagues

This subordinate theme captures the participants' positive and enjoyable experiences of the interactions with fellow colleagues and a sense of receiving support from colleagues. In extract 7 below, Rose describes finding it helpful for a multidisciplinary team to work together to see children with disabilities with each contributing something different to the team. She describes that having a team working together has helped the multidisciplinary team to learn that all the professions are equally important. She describes a sense of some professions perceived as being more important than others. She describes positive affect in relation to her profession being viewed as an integral part of the work done at the developmental clinics.

Extract 7: Rose *"it's wonderful I really enjoy working with a team of different health service providers with each having something to contribute and yeah I think it's helped, it has helped the other health service providers to see that my profession has an important place and it needs to be part of a team and not to just send a family to see a health service provider separately from what they do maybe in a ward round. All the different health service providers should also be there. I think we've helped to change attitudes they have about my profession being viewed in isolation."*

In the extract below, Lindy describes how she initially experienced her work with children with disabilities as terrifying as a result of uncertainty around working with children with disabilities However, with the help and support of colleagues she gain insight regarding working with children with disabilities which led to perceiving children with disabilities more positively. There is a sense that the support from colleagues allowed for Lindy to gain Mastery over her work and she describes a great desire to pass over her wisdom to new health service providers who are in the same position she found herself in when she started working with children with disabilities. It seems that Lindy is concerned that without this kind of support, beginner health service providers might feel overwhelmed and give up on this kind of work without reaching the point of experiencing positive experiences. Lindy describes a deep long lasting emotion connection with the children she works with by perceiving them as staying in her heart forever

Extract 8: Lindy "*I was terrified but from the first day my whole attitude changed it was the biggest discovery I think of my life. I had people to support me, you know colleagues and I discovered that these children were just amazing. You know they were fantastic and I never looked back and that was in 1976. I always tell the young health service providers my story and how I got into what I do so I always say to them be careful, you never know you might think that you don't like this area, give it a chance don't decide before you've even worked with these children because they might just Creep into your heart and stay there forever."*

Below, Candy describes a sense of being thrown into the deep end of the ocean when she started working with children with disabilities. She feels that her training could not have prepared her for what she was about to experience at the developmental clinics. However, she experienced the support from more experienced colleagues as more of a life line which helped her to cope and achieve a sense competence in her work.

Extract 9: Candy "*I think to be honest, the university didn't prepare me for what was to come this year because I'd feel like I do not have sufficient knowledge and, but actually became comfortable quite quickly because the other health service providers were quite supportive, helpful and encouraged me and taught me a little bit about disability pretty much for the first time".*

This master theme captured the participants' positive experiences in relation to their work which is dominantly conveyed in the form of emotional connections with others; experiencing the work as meaningfulness and a passion for the work as evidenced by the desire to help children and their families. Other aspects reported to have contributed to the positive experiences of their work has been enjoyable interactions with caregivers and with fellow colleagues. The interactions with colleagues has been perceived by most as supportive and encouraging.

4.2.2. Negative experiences of their work

This master theme captures the negative experiences reported by the participants in relation to their work. The participants reported struggling to cope with the difficulties of their work resulting in the experience of negative affect. The negative affect seems to arise from difficulties of the work, as well as from difficulties experienced in work relationships with others. This theme contains four subordinate themes namely: negative emotional reactions; experiencing challenges in their work; negative interactions with caregivers; and negative interactions with colleagues.

4.2.2.1. Negative emotional reactions

This subordinate theme captures the experience of negative affect in relation to various aspects of the participants' work. This theme captures a sense of feeling overwhelmed, frustrated and unappreciated for the effort and trouble of rendering services at the clinics. In the extract below, Rose describes how her compassion for the children and their families led to her getting emotionally involved to an extent of doing more than what was expected of her which left her feeling resentful for not empowering the caregivers. Rose states that this experience contributed to her experiencing burnout.

Extract 10: Rose "*Some children we were sending to special schools in neighbouring cities where they come home every 2 weeks. I would always be the one on Friday fetching the child from the bus taking her home and the family didn't have to do anything. Sunday night I would come and fetch their child and take them to the bus, to take them back but that was also not good for me and it burnt me out and I started to feel resentful that I had not empowered the parents."*

For Gugu, the work done at the developmental clinics impacts on her on an emotional and psychological level because she puts herself in the shoes of the child to imagine what life must be like for the child with a disability and finds it difficult to see children struggling. Gugu describes being emotionally involved as inevitable when working with children with disabilities. It seems that for Gugu, observing children with disabilities suffering is experienced as being difficult to an extent that she felt the need to assume a false self, by avoiding being her true self which is someone who is emotional, she felt a great need to be strong in order to cope.

Extract 11: *Gugu "Emotionally and psychologically, yes because I am putting myself into that child's shoes and see that this child can't do anything and this child can't move by himself or herself and need someone to move and to turn him one side and another side. When you see a child playing, it makes you happy but when you see a child who can't walk, does not talk, doesn't.. Yeah as a human being, it is affecting me. At the beginning I was not myself but yeah with time I am getting used to"*

In extract 12 below, Gugu continues to share that their work with children with disabilities is overwhelming and it affects health service providers emotionally and psychologically. This for her, calls for a platform to discuss the emotional and psychological impact of the work which is currently not available. It seems that having a platform to discuss these difficulties for Gugu, would normalise the difficulties she is experiencing and give her a sense that she is not alone, and that other health service providers experiences similar difficulties.

Extract 12: *Gugu "Maybe some recommendation of what as profession do we need in terms of overcoming our emotions. We are affected maybe a briefing session as health service providers. It would be good for us, if we sit and share challenges and experiences of working with caregivers and their children. We never had that platform of sharing about our experiences. We just meet at the clinic and then after that we just discuss our cases but as heath service providers we never have the platform to sit and talk about ourselves and our emotions we never had the platform. If there would be such a platform where everyone could sit and discuss how the clinics are affecting them. If we had some time for ourselves that would be really good".*

Among the participants, there was a shared feelings of frustrations over a sense of feeling unappreciated mostly by authorities and a sense that authorities do not understand what it takes to render services at the developmental clinics. Below, Angel shares how much preparation went into preparing for the developmental clinics and how she felt like there was no appreciation of the efforts they put into it, she repeats that 'management' did not seem to care so as to emphasise it. Angel seems frustrated by the lack of appreciation for services rendered, particularly given the difficulties faced in rendering these services.

Extract 13: Angel "*Sometimes there wasn't transport for the health service providers to go to the clinic and you know that you've made a commitment to be there because you only go once a month. Then you would then have to use your own transport so that you wouldn't miss the appointment because your client starts viewing you as undependable, particularly when they go through so much effort to get there themselves. I don't think anyone appreciated that also from a management level there wasn't really I don't want to say thank you that's not the right word but there wasn't ever appreciation for the service that was being rendered. I don't think there was any appreciation from that side of things and no one ever attempted to come to the developmental clinic they never once asked if they could attend to see the service that we were rendering on behalf of the organisation. No one from the management side really seem to care although it looked good on the stats that we were doing Outreach I don't think anybody really cared enough to come and see exactly what we were doing (..).*"

In the extract below, Gugu is of the opinion that bad treatment from management, the organisation being disorganised has been problematic and resulted in some health service providers leaving the organisation which has caused more problems for those left behind due to an increased workload as a result of lack of sufficient personnel. Gugu describes a sense of being frustrated and helpless because she has a great desire to help the children she works with and their caregivers but not always being able to because of the lack of particular health service providers or resources and very often they have to send some children back home without being seen because the relevant health service provider they need to consult with no longer works there.

Extract 14: Gugu "*Now there is a shortage of staff at the clinics, recently we lost four professionals, they left because of the treatment from the organisation being disorganised. Management doesn't hire people, they don't provide the necessary resources and that's why they are leaving yeah so the shortage of staff*"

In relation to the above extracts, Lindy also describes her frustrations over management emphasising on seeing more clients in a very short period of time which she experiences as very difficult due to her desire to treat these children more humanely and her need to do more to provide the best service she can possibly provide. Lindy paints a picture of management failing to be sensitive to the individual nature of each child's disability and that the time spent on each child differs based on their presenting difficulties.

Extract 15: Lindy "*When you are working with human beings and when you are dealing with children and with children with disabilities you cannot apply time principles in the same way because they are human beings and this is something that the authorities forget, when you working on a computer or imagine you can get the computer to work faster.*"

4.2.2.3. Experiencing challenges in their work

This subordinate theme captures the experience of challenges in relation to the health service providers' work. Challenges arising due to differing demographic backgrounds between health service providers and caregivers were reported by most of the participants. Amongst the demographic factors reported by participants which has led to difficulties is language. Most of the participants cannot communicate in IsiXhosa which is the dominant language used by caregivers and their children. Race was also reported as a difficulty as some participants reported feeling that caregivers were not able to challenge them because they were white while most of the caregivers were black. Educational background was also another factor reported to have brought about difficulties as most of the caregivers are usually not educated or have a lower level of education as compared to the health service providers. These demographic differences are experienced as barriers to building partnerships with caregivers because they place the health service providers in a position of power. This is viewed as placing caregivers in a passive position of accepting whatever is said by health service providers despite not being on the same page as the health service providers. This is indicated in extract 16, 17 and 18 below from the interviews with Angel, Rose and Lindy.

Extract 16: Angel "*Oh sorry another challenge language barrier. I'm not IsiXhosa speaking and most of the clients were Xhosa. I can mostly speak Afrikaans and English. Cultural there is quite a big difference between being sort of a white middle-class health service provider who is educated and automatically you're almost placed in a position of power. I think if one could speak Xhosa the barriers would also have been broken down and I think in South Africa we've also got a long way to come. I don't know if the mothers would have necessarily challenged me being in this position of power. If I said to them stand on your head three times a day and your child will be fine because I'm a white girl with a degree they didn't feel that they were able to challenge me on those sort of things and even possibly ask questions.*"

Extract 17: Rose "*Yes. Sometimes they say what they think you want to hear and it is not the truth so that is a challenge because they want to please they want to say what you want to hear and because of the situation in our country where a white person needs to be obeyed it's not a (..)it doesn't help much.*"

Extract 18: Lindy “*When someone doesn't understand English I can't do anything to help them holistically.”*

Another significant challenge experienced by all the participants as a great source of distress which leads to a sense of feeling helpless and frustrated is limited resources. This is perceived as making it challenging to render their services due to the desire to do more for the children they work with, yet being unable to do so due to the limited resources. The awareness of resources that could help make life easier for the children with disabilities and the inaccessibility to such resources conveys a sense of disappointment on the heath service system failing to meet the needs of these children. Given the limited resources in this semi-rural context, very often children are referred to neighbouring cities to seek further treatment or other mobility devices. Referring caregivers and their children to neighbouring cities has been experienced by some health service providers as very distressing. The health service providers reported disappointment over the inaccessibility of health services and the ineffective referral systems. In extract 21 below, Angel reports a sense of being helpless as she watches caregivers as they try to access services that she perceives as inaccessible. For her, the inefficient system makes it understandable or perhaps acceptable for caregivers to give up on seeking further treatment. These difficulties are indicated in extract 19, 20 and 21 from the interviews with Rose, Lindy and Angel.

Extract 19: Rose “*it's frustrating since we don't always have a quiet space, we are in a clinic set up where we taking somebody's office often or else we'll work in the waiting area which is noisy where we have people walking around there's no privacy and noisy.”*

Extract 20: Lindy “*I think in our situation here too the resources that we have available are so few compared to what is out there, you know that's a negative because you know of things that could help them more but you don't have access to them.*

Extract 21: Angel *“I'm not saying the healthcare that they receive is not of a quality but they don't have access to timeous appointments. You get an appointment for 6 months or for 12 months and very often you can't just pick up the phone, call another hospital and say I've got a client that has to see a health service provider, can I set up an appointment for them. The parent actually has got to go to the other hospital to make an appointment with the health service provider and then come back all the way back. That's a whole day that they just used to make an appointment and I just think it's totally inefficient and exhausting and I can just see why the mothers give up on further treatment because it's physically daunting to actually get there*

4.2.2.4. Negative interactions with caregivers

This subordinate theme captures the negative experiences of the participants' relationship with the caregivers they work with. The interaction with caregivers has been described as being challenging at times. For the most part this stems from health service providers' perception of the child not being well taken care of at home; caregivers not coming for clinic appointments; caregivers not doing activities that they have been instructed to do at home with the children and caregivers and health service providers not seeing eye to eye on certain matters concerning the child.

In the extract below, Gugu responds to a question about challenges experienced within the relationship with caregivers. She emphasise on the importance of taking a step back when challenges arise and viewing such challenges in the context in which they occur. For her, viewing challenges in this manner makes her understand that caregivers are going through unique individual difficulties in relation to their child's disability and other family or personal difficulties. She also describes that some caregivers come to the clinic with hopes of their child's condition improving and when this does not happen, the health service providers are then faced with caregivers' emotions related to coming into terms with this realisation.

<u>Extract 22:</u> Gugu "*Sometimes the relationship becomes sour it is always because of frustration and out of desperation. As a professional I always understand, I say this mother reacted like this because of frustration yeah so bad yeah, yeah.*"

In the extract below, Lindy shares her difficulties concerning caregivers who do not engage with the treatment process for their children. It seems that she questions whether such children are worthy of her time because her efforts are not reciprocated if the caregiver is not invested in the process. This gives a sense of the importance of caregivers and health service providers meeting each other half way and working together towards helping the child with a disability. Lindy questioning whether it is worth it to continue seeing a child while their caregiver is not invested in the process communicates the disappointment of investing in a relationship and not getting any rewards out of it. Thus, leaving her questioning whether it is worth sustaining this relationship. Lindy also describes engaging in a process of trying to make sense of the caregiver's behaviour due to being uncertain of the motivation behind the caregiver's behaviour. She seems frustrated by the responsibility placed on her while the caregivers take on a passive role.

<u>Extract 23:</u> Lindy "*I don't really know I think in some cases where there isn't a lot of support for that child and you can see that nobody is actually willing or able or believe that it is worth*

doing anything for that child and that the experts must do it all so they'll keep on bringing the child to the clinic but they won't actually be doing anything at home that's the negative because it's almost not worth them bringing them at the clinic".

In extract 24 below, Rose shares her frustrations around caregivers not being honest. She seems to perceive this as caregivers thinking that they cannot disagree with the health service providers or renegotiate appointment dates with them, so they would rather be dishonest with the health service providers.

Extract 24: Rose "*It gets frustrating when people are not being honest. Don't bother to say that you are going to be here or that you going to do this task if you really not going to have time or you gonna have something else on. Yeah, that's when it's frustrating when people say something when they know they kinda have something that would have come up."*

4.2.2.5. Negative interactions with colleagues

This subordinate theme captures the negative experience in the relationship with fellow colleagues. The participants reported that very often the interactions among colleagues are not always positive and sometimes there is conflict among the health service providers due to differing opinions in the process of supporting one another and the children with disabilities and their caregivers.

Below, Rose describes how her compassion for the caregiver, her understanding that they have a lot happening in their lives in addition to their child with a disability was perceived by a fellow colleague as disempowering the caregiver and dissolving them off responsibility towards their child leading to the caregiver not taking proper care of their child as they should. This differing opinions led to experiencing conflict within the relationship with colleagues for Rose.

Extract 25: Rose "*I have often had clashes with one of the professionals who said I got too involved with a family and I allowed the family to not take the kind of care that they would perhaps would but I was saying that this mother is under stress. Therefore, you have to understand that she's not going to be able to take the child to school every single day because she also has other responsibilities, of course the child needs to go to school perhaps more than an abled bodied child and I got in a bit of trouble.* "

Extract 26 and 27 below describes difficulties with fellow colleagues who would very often give their own opinions concerning what to do or not to do with clients to colleagues which is viewed as confusing for the caregivers. Angel and Candy seems unhappy with having people telling them what to do and not to do. There also seems to be concerns about how caregivers might make sense of having the treating health service provider being told what to do and what not to do by other health service providers. This also highlights concerns around one's competencies as a health service provider being questioned.

Extract 26: Angel *"One of the challenges was limited space at the clinics so there was very limited privacy sometimes when you were seeing some of the clients it was not great. There were so many health service provider and we had only one room to treat in very often you would treat a child while other health service provider would chip, not chip but would make a comment and it becomes very challenging when you are the treating therapist with three or four people standing around you with everyone giving you an opinion of what you should do or shouldn't do"*

Extract 27: Candy *"I think the trouble comes in for me when people don't stick within their scope of practice. So it does bother me sometimes when other health professional wants to kind of overstep. I also think often we give out personal opinions to patients which are not always the most meaningful because we come from such different backgrounds as well. So I do find it conflicting when different health professionals give their personal opinion without understanding the person's cultural background or understanding the full context of the person".*

For Lindy, determining how to effectively use time at the clinics is understood and interpreted differently depending on work experience and academic training. She feels that her extensive experience in working with children with CP affords her the ability to appreciate having more time to spend with each child. Whereas she is of the opinion that beginner health service providers with minimal experience lacks this appreciation.

Extract 28: Lindy "*If we go to a clinic and 3 children arrive I'm quite happy. I won't regard it as a waste of time whereas I know there are other health service providers who regards that as a waste of time and in a way I understand that because for the most part they are young, inexperienced health service providers who haven't had a lot of experience with children with cerebral palsy"*

This theme captures the negative experiences reported by the health service providers in relation to their work. The reported negative experiences results in the experience of negative affect for the caregivers. The work done at the developmental clinic is described by some participants as emotionally challenging. In addition to the emotional difficulties faced by health service providers as a result of working with children with disabilities, with some children perceived as suffering more than others, there were numerous challenges reported by the participants which contributes to the experience of negative affect. These includes demographic background differences, limited resources, negative interactions with caregivers and negative interactions with colleagues.

4.2.3. Perception of role as changing over time

This Master theme captures the participants' perception of their roles. There is a shared sense among the participants that their roles change over time as they acquire more knowledge and become more experienced in working with children with disabilities. This theme has two subordinate themes namely, a view of their professional role as changing in relation to their experiences and advocating for children with disabilities.

4.2.3.1. A view of their professional role as changing in relation to their experiences

This subordinate theme captures the participants' perception of their professional roles as continuously changing. The participants experienced their roles as not static but as continuously developing with the growing understanding of how to work with children with disabilities and their caregivers.

In extract 29 below Angel shares how her perception of her role has changed over the years from focusing on the child with a disability to focusing on how to support the family to care for their child with a disability. She feels that becoming a mother herself impacted on her work and the manner in which she views her role. She describes that becoming a mother contributed to her becoming more compassionate of the difficulties faced by caregivers of children with disabilities because it opened her eyes to the difficulties of parenting an abled bodied child. This is turn allowed for her to imagine what life could be like for her if she were to parent a child with a disability. This then allowed for her to be more emphatic to the caregivers she works with and motivated her to train further to determine ways of supporting the families to support their children.

<u>Extract 29:</u> Angel "*Again, I think over the years my role, my perception of my role has changed. When I did further academic training it became abundantly clear to me that my role is not to work with the child, my role is to work more with the parent or the caregiver and to look at empowering the caregiver to.. do what's best for the child. I think my role has definitely changed to one more of looking at how we can support the family to look after their child with a disability".*

Below, Lindy states that although her role concerns the physical rehabilitation aspects of the child's disability, she has learned that she cannot do that in isolation from other aspects of the children's daily living. Lindy gives an impression that she gained this understanding gradually over the years through working with children with disabilities and gaining insight over their disability being more than a physical disability. She learned to view them in context.

Extract 30: Lindy "*So that's the one thing and the other thing is because my skill is in my profession that is assessing and facilitating that child to gain skills and abilities in the area of movement mainly as far as they possibly can go so I again it's helping them reach their physical potential but over the years too I have learnt you can't do that you can't isolate it and just worry about their movement.*"

4.2.3.2. Advocating for children with disabilities

This theme captures the experience of extending the professional role to that of an advocate for children with disabilities with the aim of doing what is perceived as best for the child. The participants reported a need to do what is best for the child and mirror how caregivers should engage with their children so that caregivers can learn to treat their children with disabilities more humanely. This theme captures a sense of health service providers being protective of the children that they work with because they perceive children with disabilities as being vulnerable to neglect and abuse.

For Rose, this involves emphasising the importance of school for children with disabilities and treating the child more humanely, as someone with a mind. Rose is of the opinion that people forget that a child with a disability is still a human being with a mind. Therefore to emphasise that they too, have a mind, she models appropriate ways of interacting with the child by being curious about what they are thinking, feeling or their preferences on certain aspects by talking to them instead of talking over them as if they are not in the room. This is indicated in extract 31 below.

Extract 31: Rose "*Just to reinforce that schooling is important, helping the child become independent, not doing too much for their child but also not neglecting their needs. Perhaps be a mirror for the parents in the way that you talk to the child rather than talking to the parent, if the child can speak, rather than talking to the parents and remember that by talking to the child we are reminding them that he has a mind.*"

In the extract below, Angel shares that her dissatisfaction with the medical model and her personal experiences of motherhood motivated her to find alternative ways of practising that would be relevant for children with disabilities and their caregivers within the South African context with the aim of integrating interventions into family routines. For her, this helps her with integrating the child with a disability into family routines. Thus, allowing family members to realise that the child with a disability can still participate in family routines. She hopes that this will integrate them into their communities instead of being kept at home, indoors.

Extract 32: Angel "*Yes, and I think that it also changed, you know we trained very much in the medical model. You tell the mother that just do the range of movements, exercise every day, they come back a month later, haven't been doing the exercises and obviously you kind of get exasperated. When you become a parent, you suddenly realise that the most important thing is not necessarily the therapist telling you what to do with your child. You're actually worried about putting food on the table, you're worried about your other children, or there's just a lot that might be going on in someone's mind than just a child with a disability. Then when I sort of had this moment of realisation, I did further training to try and find alternative ways of practicing so that it is more appropriate to the South African environment to try and looking at the child as part of the family and rather enhancing those routines that they have at home rather than trying to burden the parent or the family with the additional responsibility of exercises.*"

In the extract below, Lindy emphasised that children with disabilities are not sick and prefers to see them in non-medical facilities in order to destigmatise disability from being viewed as an illness in society. This seems important to Lindy so much that she even highlighted that she still prefers community halls even though they are in a disappointing and dissatisfying state.

Extract 33: Lindy "*You see children with physical disabilities are not sick so I don't even actually like having these clinics at the clinics that's why I like going to the halls in their shocking conditions I prefer that the children not come to a medical facility because they are not sick but when the caregivers bring them to a clinic the connotation is that they are sick."*

This master theme captured how the participants perceives their roles. This theme highlights that the manner in which health service providers perceives their role in not fixed. It is rather changing in conjunction with numerous aspect such as professional growth and personal events. For instance some participants found their experiences of parenting their own children as influencing the manner in which they do their work. Part of their perception of their role, most of the participants reported a great desire to advocate for the rights of children with disabilities which seems to stem from a great desire to protect these children from harm.

4.2.4. Managing challenges in their work

This master theme captures participants' experiences of managing the challenges experienced in relation to their work. This theme contains two subordinate themes which are perspective taking in relation to their work and gradual growth in themselves in relation to their work. These two subordinate themes capture how participants have manage to handle the difficulties experienced in their work by employing perspective taking and gradually growing.

4.2.4.1. Perspective taking in relation to their work

This subordinate theme focuses on a shared sense of using perspective taking which involves imagining the difficulties experienced by children and their caregivers to understand the difficulties they face. In the extract below, Angel shares how being a parent herself has afforded her the ability to imagine how difficult it must be to parent a child with a disability which enables her to be more understanding of the difficulties faced by caregivers of children with disability. Angel gives a sense that being in a similar situation, becoming a parent in her case, contributed to the ability to put herself in the shoes of the caregivers and imagine what life is like for the caregivers.

Extract 34: Angel "*Yes, I think also becoming a parent myself changed my perceptions of these mothers, instead of being angry with them for not bringing them to the developmental clinic or not taking them to their specialist appointment. I had a better understanding of the challenges they faced as parents and the additional, I don't want to say burden, of having a child with a disability. I am not saying that the mothers consider their child a burden but there are considerable responsibilities that comes with having a child and a lot of them are exhausting and draining because they do need extra care and attention and that can be quite exhausting.*

In extract 35 below, Gugu shares that she has had put herself in the shoes of the caregivers to understand that sometimes caregivers become rude or uncooperative as a result of their difficulties concerning their child's disability and that she has learned not to hold their behaviour against them and be more understanding that it comes from a place of great distress from the caregiver's side.

Extract 35: Gugu "I *don't blame them I just try to understand that when sometimes they become rude or frustrated there's something that made them become like this because sometimes they would do that and then apologize if you see that someone is showing remorse it means that there was something which cause that behaviour. It is a challenge because people are desperate, people who are expecting change, but there's no change, change won't happen. When there's no improvement the mother becomes frustrated, withdrawn, rude and uncooperative."*

4.2.4.2. Experiencing gradual growth in relation to their work

This subordinate theme focuses on a shared sense that the longer they do this kind of work, there was a sense of growing within their work and a change in how to work with children and caregivers differently. This sense of growing is perceived as leading to better coping skills in light of the difficulties experienced at work. In the extract below, Lindy described how she used to find it “nice” to be needed by caregivers and has learned that she needs to help them help themselves through empowerment so that they can function independently.

Extract 36: Lindy “*I don't want people to be dependent on me that's scary but I had to learn that too because at one stage it was quite nice, it felt like you had to be there or otherwise no one would help but I've learnt over the years that it is not realistic, not practical and it is actually not right”*

For Candy, this sense of growth occurred on both the professional and individual level. Professionally as she gained mastery of her work, she felt more confident and felt that she was giving sound advice to caregivers. She describes how the experience with children with disabilities also contributed to her learning more about herself and her ability to cope in difficult situations.

Extract 37: Candy “*I think if anything, I think my confidence has increased working with these children because I feel like right now I'm doing a lot more, I’m able to give sound advice to parents and has also made me a little more introspective and more aware of, of some of the determinants of mental health that I hadn't really considered much before.”*

This theme highlighted the methods that the health service providers employ to manage the challenges they face in relation to their work given the numerous challenges they face which have been highlighted in the previous section. Some of the participant reported that putting themselves in the shoes of the caregivers allowed for them to be more understanding and compassionate to caregivers. However, they also highlighted that the ability to engage to engage with the other’s perspective developed gradually over time as they gained more experience in the field. The subtheme capturing the sense of gradual growth shows that both professional and person growth which occurs gradually over time has allowed health service providers to feel better equipped to cope with the demands of their work and allows for perspective taking to take place.

4.2.5. Masibambane experienced as complementary to their work

This master theme captures the participants’ experiences of the Service learning programme (Masibambane) in relation to their work. They reported viewing Masibambane as a good addition to their work, as addressing the gaps in service delivery for children with disabilities (subordinate theme 1) and addressing the emotional needs of caregivers (subordinate theme 2).

4.2.5.1. The service learning programme (Masibambane) experienced as filling the gabs in service provision for children with disabilities

This subordinate theme captures the sense that the service learning programme fills in the gaps in service delivery for children with disabilities. Below, Angel discusses how she feels that the service learning programme provides a unique service and she doubts anyone else could be able to offer support to the caregivers in the manner in which the service learning programme does. She is of the opinion that the service learning programme allows room for caregivers to share their experiences and difficulties in a non-judgemental space and addresses some of the caregivers' needs that might not be met at the developmental clinics.

Extract 38: Angel "*I firmly believe that Masibambane has got a very important role to play at the developmental clinics. I don't see anyone else providing the families with that kind of support for children with disabilities. I feel that very often these families are Islands floating around trying to access different services and has got no idea of where to go. Masibambane gives them a bit of an anchor to be able to just breathe, have an opportunity to speak to someone and not be judged for anything that they say or anything that they might feel. I think it's very often the first opportunity that families get to be able to speak to someone in a non-judgmental way.*"

Candy shares in the extract below that the service learning programme promotes the work that is done at the developmental clinic. She described how the students encourage and remind caregivers about clinic appointment. She describes a sense that the service learning programme helps caregivers to adhere to treatment interventions, thus making it easy for her to do her work.

Extract 39: Candy *"I think that the students make a positive impact on the families. I also think that that the support the families receive from the students is very useful. It directly affects me as well because the students usually encourage the parents to bring their children to the clinic."*

4.2.5.2. Masibambane experienced as addressing the emotional needs of caregivers

This subordinate theme captures the participants' perception of Masibambane as addressing the emotional needs of the caregivers which are usually not addressed in the developmental clinics due to time constraints and confidentiality difficulties given the physical layout of the venues. In the extract below, Lindy shares that she has been amazed about how the students from the Masibambane programme are able to build trusting relationships that allows caregivers to share details that they would not share with health service providers.

Extract 40: Lindy "*yeah the one thing that has been very interesting and I haven't been here since it started is the way that the students have been able to build a relationship with the parent to the extent that they would share things with them that they wouldn't share with us.*"

Rose's experience of Masibambane is that it gives caregivers the experience of having someone showing care and interest in them and acknowledging what the caregivers is doing for the child. She believes that this validates caregiver's experiences.

Extract 41: Rose *"it makes a difference for the child and the family to have someone that really cares that shows interest it just makes them see things differently and actually acknowledges what the caregiver is doing for the child and what the caregiver is facing".*

The extracts above capturing the experience of the service learning programme positively. The findings of the study indicates that the health service providers have experienced the service learning programme as a valuable contribution to the work that they do at the developmental clinics. Most of the participants described as addressing the emotional needs of the caregivers and offering a greatly needed support for caregivers and their children with disabilities.

4.3. Conclusion

This chapter has reported the findings of the study with the aim of addressing the research question of the study which aims to explore the experiences of health service providers working with children with physical disabilities and their caregivers. The results of the study produced five master themes namely: positive experiences of their work; negative experiences of their work; role perception as changing over time; managing challenges in their work; and experiencing the service learning programme as complimentary to their work. The findings indicate that the health service providers working with children with physical disabilities and their caregivers have positive experiences and negative experiences in relation to their work. Furthermore, their understanding of their roles is constantly changing and developing with the growing understanding of how to work with children with disabilities and their caregivers. The findings shed some light into the challenges experienced by the health service providers and how they have managed these. Moreover, the findings indicate that the Masibambane service learning programme has been experienced as a good addition to the work done by the health service providers. In this section, quotes have been extracted from the interviews with the participants to support the findings.

Chapter 5: Discussion

5.1. Introduction

This chapter provides a discussion of the findings of the study which were reported in the preceding chapter. Based on the master themes generated from the data analysis process, the findings of the study indicate that the participants have had positive experiences in relation to their work. They have also had negative experiences in relation to their work which for the most part stems from challenges experienced in their work with children with disabilities and their caregivers at the developmental clinics. The results of the study also indicate how growth and perspective taking allows the participants to manage the challenges that they face in relation to their work. The study also highlights how they perceive their roles as continuously developing in relation to personal and professional growth and how they have experienced Masibambane, the service learning programme, as a good contribution to their work. The findings of the study shall be discussed below in integration with the literature reviewed in chapter two of this paper.

5.2. Discussion of the main findings of the study.

5.2.1. Positive experiences of their work

The participants in the current study have reported positive experiences in relation to their work. It is seen in the study that such positive experiences have been linked to continuing with working with children with disabilities at the developmental clinics in Grahamstown despite the challenges.

5.2.1.1. Positive emotional reactions in relation to their work

The participants perceived their work at the developmental clinic as meaningful in comparison to work done in other contexts that they are involved in. For some, the work was perceived as a highlight of their work; the interactions were viewed as enjoyable particularly observing children develop further and obtain certain skills. There is a shared sense that the work done at the clinic is fulfilling.

The experience of finding the work done at the developmental clinic as meaningful supports the research findings reported by Jenkins et al. (2015) which highlights that a sense of feeling like one is contributing to the lives of others or the community at large, and a perception that the work done is meaningful has proven to be a major motivating factor for remaining in public hospitals which are located in rural areas despite other challenges that might be faced.

5.2.1.2. Positive interactions with caregivers

Positive interactions with caregivers of children with disabilities was experienced positively by the health service providers. The participants reported that their relationship with caregivers is usually of good quality, they reported developing emotional connections with caregivers which is long lasting. The warmth from the caregivers, their recognition of the health service providers even after longer periods of not working together seem to be experienced by the health service providers as acknowledgement of their contribution towards the lives of the children they work with and their caregivers. These findings slightly support the importance of making a difference in the lives of others as reported by Jenkins et al. (2015).

5.2.1.3. Positive interactions with colleagues

Another great source of positive experiences observed from the study is the positive interactions amongst health service providers. There is a shared sense of feeling supported by fellow co-workers. For most of the participants in the study, working with children with physical disabilities proved to be difficult at first and they struggled with observing children suffer and also struggled to determine how they should work with such children. There is a shared sense that having colleagues around to offer support helped them with their own individual difficulties. There is a sense of being thrown into the deep end and having colleagues as a life line was appreciated by most of the participants. This is in line with the studies conducted on the experiences of health service providers working in the public sector in South Africa which indicates that a sense of being part of a team that provides support as well as positive feedback is highly valued by health service providers (Ashmore, 2013; Jenkins et al., 2015)

5.2.2. Negative experiences of their work

Alongside positive experiences this study found that, for these particular health service providers, working with children with physical disabilities can be overwhelming and can lead to negative experiences in the work place. The participants reported numerous negative experiences in relation to their work. These negative experiences have been linked to working in difficult working condition and a sense of not being appreciated for the services rendered. Other contributing factors includes differing demographic backgrounds (race, language or educational background), limited resources, negative interactions with caregivers and negative interactions with colleagues.

It has been described by most participants that it is only humane to be emotionally involved in the work as it differs in the sense that it involves working with children who are powerless and vulnerable to neglect and abuse. This for most of the participants has led to feelings of hopelessness and sometimes frustrations. Furthermore, there seems to be a sense that there are no support structures in place that help health service providers deal with the negative emotional impact of their work.

5.2.2.1. Negative emotional reactions

There is a shared sense that health service providers are expected to go into community work with children with disabilities and their caregivers, leave and get back to their lives. However, the current study highlights that the work done at the clinics is difficult and that it evokes feelings of distress for the health service providers. However, due to time constraints the context of the developmental clinics does not allow room to address and contain such emotions. This has required employing various coping mechanisms to protect the self from such feelings. One participant reported not being her true self at the clinics as it required toughening up in order to cope. The discussion on coping mechanism will be returned to later in this chapter. These difficulties support the findings of the study conducted by Van der Colff and Rothman (2009) who argue that observing patients' suffering was observed to be a significant stressor leading to emotional exhaustion and a sense of depersonalisation for the participants who took part in their study.

Another reported emotional difficulty was the experience of feeling unappreciated by authorities or management in their organisations. The participants in the study discussed in detail the efforts that goes into rendering services at the developmental clinics. However, there is a shared sense that there has not been communication or actions of appreciation from management in their organizations. The importance of receiving positive feedback or recognition for good performance from colleagues, clients or management is regarded as important and very often appreciated by health service providers. The study by Jenkins et al. (2015) regarded receiving positive feedback as necessary for developing resilience while Ashmore (2013) regarded such positive feedback as an important incentive for health service providers to remain in rural areas. The participants of the current study reported a lack of such feedback and thus, this was linked to the experience of feeling unappreciated. Furthermore, the study highlights that this appreciation or positive feedback is sought mostly from management because the participants seem to have an understanding that caregivers might not always be able to be appreciative due to having their own personal difficulties that they have to battle with.

5.2.2.3. Experiencing challenges in their work

The participants in the study reported that different demographic backgrounds led to challenges in their work with children and their caregivers at the developmental clinics. Language was perceived as significant challenge because very often it was experienced as a barrier in engaging with caregivers and their children. Some of the participants reported feeling like these differences, particularly race acted as a barrier to building partnerships because they felt that caregivers were not able to challenge them on certain aspects of their children's treatment.

MacKean et al. (2005) reports that in their research there is indication of superior and inferior positions in the relationship between caregivers and health service providers. The current study supports and expands on this view: There seems to be a sense of health service providers being perceived to be in a superior position while caregivers take on an inferior position. The study indicates that this is not solely based on the professional role and the power that this role carries. The study highlights other factors that create this sense of inequality. These factors include race, language, socioeconomic status and educational background of the health service providers. The caregivers and children attending the developmental clinics are mostly black, illiterate, coming from poor socioeconomic conditions and can mostly communicate in IsiXhosa, whereas the health service providers are predominantly white, educated, English or Afrikaans speaking and mostly comes from a middle class socioeconomic background.

A significant experience which has been reported as a challenge is the eagerness to do more for the children but being unable to do so due to the limited resources at the developmental clinics. The town in which the research was located has limited resources particularly health service resources for children with disabilities. Due to the lack of resources and personnel in the town most of the children have to be referred to neighbouring cities for specialised services which are not provided. This has been experienced by most of the participants as very difficult as they are unable to secure appointments on behalf of their clients. They reported that caregivers have to go to another town and spend the whole day there just to obtain an appointment date which they do not always manage to secure at first attempt before they can go for the actual consultations. The participants reported that this was difficult for them to observe and it is perceived by most of the participants as unmanageable as it is beyond their control and they have no power over the situation. While the lack of resources is of particular difficulty, the lack of personnel seems to be experience as a great challenge.

The reported difficulties experienced as a result of limited resources is in line with the report compiled by DSD, DWCPD and UNICEF (2012) which reported that there is a shortage of trained professionals rendering health services in rural areas as most trained professionals prefer to work in urban areas. In addressing the reasons behind this preference for urban areas, Nemutandani et al. (2006) argues that dissatisfaction with the working conditions in rural areas results in health service providers preferring to work in big cities with better services and infrastructure.

Another study supported by the current study is that of Mburu and George (2017) which also describes the difficulties experienced in referring patients to higher level medical facilities. The study highlights the difficulties involved in referring clients due to a lack of proper referral systems in place for patients who require specialised services from higher level medical facilities (Mburu & George, 2007).

5.2.2.4. Negative interactions with caregivers

The relationship between caregivers and health service providers seems to be a challenge and a source of distress for the participants. The reasons provided for this were caregivers missing appointments or not following up on suggested interventions, caregivers not being honest to the participants and for the most part it is due to the participants' concerns regarding the child's wellbeing in the care of the caregiver. The relationship with caregivers whom are perceived by the participants as not invested in the treatment process for their children as evidenced by the above mentioned reasons, has been experienced negatively by the participants. These findings are in line with the emphasis made by Paterson et al. (2002) that caregiver's participation in therapy programmes contributes positively to the relationship between caregivers and health service providers.

Contrary to the study conducted by MacKean et al. (2005) questioning whether the collaborative relationship between caregivers and health service providers leads to a devolution of responsibility to the caregivers. The findings of the current study indicate that the participants often battled with maintaining a balance between getting too involved with families and empowering the caregivers. The study further indicates that this balance is achieved gradually over time and with more experience in working with children with disabilities and their caregivers. Moreover, it is seen in the study that this process is unique for each health service provider.

5.2.2.5. Negative interactions with colleagues

The literature on relationship difficulties indicates difficulties in the collaboration between NPOs and governmental departments as reported by DSD, DWCPD and UNICEF (2012). While the current study did not report significant collaboration challenges between different departments, it did highlight challenges within the relationships among the health service providers. Most of the participants reported negative interactions with fellow colleagues alongside positive interactions. The difficulties seem to stem from disagreements regarding treatment options and there seems to be a sense that health service providers who have been working with children with physical disabilities for longer regard themselves as more experience in the field and in an attempt to support, they give advice which is sometimes not required or welcomed by the health service providers regarded as inexperienced. This suggests that while the sense of being part of a team can be experienced as enjoyable and form part of a support system for most health service providers, it is not without challenges.

The study shows that a significant relationship which has been experienced negatively is that between health service providers and management. The relationship with management has been experienced by most of the health service providers as unsupportive and uncaring for the wellbeing of the health service providers. Most of the participants reported that management personnel showed no interests in the services they are providing at the developmental clinics and they only focused on the statistics which indicated that such services were being provided to the community. Some participants linked this sense of being unappreciated to the increased number of health service providers who had left work in the public sector for work in the private sector.

5.2.3. Role perception as changing over time

Depending on their professions, some of the participants reported they trained within a medical model of disability, particularly those who are involved in the physical rehabilitation of children with disabilities. They reported that during the course of doing their work and in gaining more knowledge and experience in working with children with physical disabilities, they came to a realisation that the medical model is not suited for the South African context and they cannot isolate interventions from the child’s daily living conditions.

5.2.3.1. A view of professional role as changing in relation to their experiences

A great realisation reported by the participant was that caregivers had other responsibilities in addition to parenting a child with disabilities. Therefore, it is perceived by most participants as insensitive to give them additional therapy activities to do at home while they already have other family responsibilities and difficulties to worry about. This resulted in an attempt to integrate therapy into the family routine so that it does not feel like an additional responsibility, while also doing some rehabilitation related activities during clinic visits. This seems to be more in line with the biopsychosocial model of disability which emphasises taking into consideration the individual rehabilitation needs of a person with a disability while also paying attention to their need for inclusion in society and social needs as stated by Schneider and Saloojee (2007). It was also evident in the study that this insight into perceiving the child as someone with other needs in addition to their needs for rehabilitation took place over a period of time.

The study highlights that it is not only training and personal experience but also personal events that impact on the understanding and perception of one’s professional role for the participants. For some, starting their own families and becoming parents led to a change in the manner in which they understand their roles as there was a reported sudden insight over the difficulties of parenting and a growing understanding of the difficulties faced by caregivers of children with disabilities.

5.2.3.2. Advocating for children with disabilities

It seems apparent from the findings of the study that the participants’ perception of their role is not fixed, it is however, constantly changing as a result of getting more experience and knowledge in the field. For most of the participants, their roles have expanded to include advocating for the rights of children with disabilities. Advocating for the children with disabilities seems to stem from feelings of compassion for the child. Advocating for these children for the participants has involved emphasising that they are not sick so as to destigmatise disability from being viewed as an illness. Working in community halls instead of medical facilities is perceived by the participants as a way of destigmatising disability from being viewed as an illness. It also involves emphasising to caregivers that children with disabilities needs to be in school just like able bodied children. Moreover, it also involves emphasising treating such children humanely by modelling such behaviour during clinic appointments such as talking to them instead of talking over them.

This desire to advocate for children with disabilities, ensuring that they are integrated in their families and the community at large, ensuring that they go to school and most importantly, that they are viewed as children in a particular context, and not as children with disabilities is more in line with the social model of disability.

5.2.4. Managing challenges in their work

The study highlights the challenges faced by health service providers working in a semi-rural area with limited resources. The participants reported experiencing a variety of challenges, some are perceived as manageable while some are perceived as beyond their control and unmanageable. The experience of challenges in relation to their work has required finding ways to cope with such challenges. Perspective taking and a sense of growing allowed for coping with the challenges experienced by the health service providers.

5.2.4.1. Perspective taking in relation to their work

In light of the challenges experienced by health service providers in their work with children with physical disabilities, most of them have reported using perspective taking to help them understand what it must be like for caregivers with a child with a disability and what it must be like for the child. Most of the participant described experiencing a shift from being frustrated and often angry at caregivers for missing clinic appointment or not doing tasks that they were supposed to do with the child at home, to becoming more understanding. This shift comes about as a result of imagining what it is like for the caregiver who has to take care of a child with a disability, have to worry about other family issues while e struggling financially. The participants in the study reported that trying to put themselves in the shoes of the caregivers has helped them to realise just how difficult it is to be a caregiver of a child with a disability and this has helped them to become more understanding of caregivers missing appointments and of caregivers appearing as disrespectful at times. Such behaviour has been perceived as reactions by caregivers due to going through a lot as they come to terms with their child's condition while faced with other difficulties.

It became evident in the current study that the manner in which perspective taking took place, differed from one health service provider to another. It appears that health service providers' personal experiences allowed them to imagine what it is like to be the caregivers they work with. This was more evident with health service providers who are also parents. They reported that their own difficulties of parenting in a supportive family system with adequate resources, allowed them to put themselves in the shoes of the caregivers and imagine what it was like to be a parent with additional responsibilities that comes with parenting a child with a disability. This seems to be more in line with the in-the-other's-shoes-imagining reported by Mackenzie and Scully (2007).

Some of the health service providers experienced caregivers' disengaged behaviour as a sign that they do not care about their children. This supports the argument raised by Mackenzie and Scully (2007) that people are more likely to project their own desires and feelings onto the other in the process of imagining what it is like for the other person to be in the situation that they are in. The findings of the study suggest that it is indeed implausible to imagine being another person as required by empathic imagining. Therefore, it seems more plausible to imagine being in a different situation or to imagine oneself in the shoes of another as argued by Mackenzie and Scully (2007).

5.2.4.2. Experiencing gradual growth in relation to their work

Another method of coping reported by the participant in the study was that of gradually growing within their work which allowed for room to be more understanding of not only the caregivers' and children's difficulties but to also grow within their work and understand the work better. The participants reported a sense of growing both emotionally and psychologically and a sense of feeling increasingly equipped to handle the challenges of their work. This growth has been reported by most of the participants as allowing for them to cope better with the demands of their work at the developmental clinics.

This sense of growing allowed for viewing problems in the context in which they occur and a sense of viewing problems in a non-catastrophic manner and sense of being able to manage such problems. This links with the study conducted by Van der Colff and Rothman (2009) which indicates that a sense of coherence leads to better coping mechanisms for health service providers and those lacking a sense of coherence employ passive coping mechanisms such as avoidance and venting of emotions. As discussed in chapter two of this paper, a sense of coherence contains a manageability principle, which is a person's perception that they can cope with certain difficulties.

5.2.5. Masibambane experienced as complementary to their work

As reported in the first chapter of this report, part of the study, was to explore how the service learning programme, Masibambane has been experienced by the health service providers in relation to their work at the developmental clinics. The findings of the study suggest that the service learning programme has been experienced positively by the participants in the study. They have experienced the programme as a valuable contribution to their work that fills the gaps in services for children with disabilities and also addresses the emotional needs of the caregivers. As already reported in this chapter, time constraints at the developmental clinics is perceived as preventing addressing the caregiver's emotional difficulties thus health service providers valued Masibambane as addressing this gap.

5.2.5.1. Masibambane experienced as filling the gaps in service provision for children with disabilities

Masibambane has been experienced by the participants in the study as complimentary to their work. Some of the participants described the Masibambane programme as providing a unique and much needed service that no one is offering to the families of children with disabilities. Furthermore, there was a shared sense among the participants that the students who visits these children and their families are able to link them to other required services and thus filling in the gaps in service provision for these children and their families. Furthermore, there was a sense reported by some of the participants that the service learning programme supports the work that do at the clinics and the students encourage caregivers to go to the clinics for their appointment. Thus, promoting adherence to treatment interventions.

These findings about the service learning programme links to the study conducted by Donald et al. (2014). It emphasises that home programmes are more convenient in resource limited settings like the semi-rural context in which the study was conducted due to their minimum requirement for resources.

5.2.5.2. Masibambane experienced as addressing the emotional needs of caregivers

A significant contribution of Masibambane that was reported by the participants in the study, was its ability to address the emotional needs of the caregivers. The participants perceived the caregivers and families of children with disabilities as isolated without much support. Furthermore they are of the opinion that the physical setting of the developmental clinic and time constraints makes it impossible to attend to the emotional needs of the caregivers. However, the students involved in the service learning programme are able to do this which offers some much needed emotional support for the caregivers and families of children with disabilities.

The participants in the study reported a sense of being amazed by the student’s ability to create a safe space that allowed the caregivers to feel free to a point of sharing difficulties that they are not able to share with health service providers at the developmental clinic. This was linked to the students’ ability to create a non-judgemental space in which caregivers could share their experiences and difficulties without feeling judged for their feelings. For one participant, she felt that caregivers often require some kind of assurance for all that they do for their children with disabilities and she is of the opinion that Masibambane does give such an assurance which is regulating for the caregivers. Moreover, she felt that while the developmental clinics is solely focused on the child, Masibambane also focuses on the caregivers, with students showing an interests in the caregiver’s feelings. This is in line with the use of mentalisation for the masibambane programme, with the aim of not only keeping the child in mind but to also keep the caregivers in mind as reported by Saville Young (2015).

5.3. Conclusion

This chapter has highlighted the experiences of the health service providers working with children with physical disabilities at the developmental clinics running in a semi-rural town in the Eastern Cape. The current study has highlighted that the health service providers who participated in the study reported positive and negative experiences in relation to their work. The reported positive experiences were finding the work done at the developmental clinics meaningful leading to the experience of positive affect such as a sense of enjoyment. The participants also experienced interactions with caregiver positively, they reported feeling like they have made emotional connections with the caregivers which were long lasting. Moreover, they reported feeling supported by fellow colleagues and enjoyed feeling like part of a team. These positive experienced seems to be perceived as incentives to continue working in this semi-rural area. However, despite the positive experiences, the participants also reported negative experiences. The negative experiences were linked to challenges experienced in relation to their work. These included demographic background difference difficulties; limited resources; feeling unappreciated by management for the work rendered on behalf of their organisation; negative interactions with colleagues; and negative interactions with fellow colleagues.

The chapter has also explored how the participants cope with the challenges that they face in relation to their work and their experience. The findings indicated that perspective taking and gradual growth has enabled to heath service providers to cope better with the challenges the face in relation to their work. It is evident in the study that personal experiences also aided in coping with challenges and the manner in which the participants perceive their roles. The findings of the study also highlighted that the participants have experienced the service learning programme positively. They have experienced as complimentary to their work and as addressing the emotional needs of the caregivers. The discussion of the main findings of the study has been discussed in conjunction with the literature reviewed for the current study. For the most part the findings of the study have supported the literature and expanded it in some areas. The limitations and recommendations of the study are addressed in the subsequent concluding chapter.

Chapter 6: Conclusion

6.1. Introduction

This study has explored the experiences of health service providers working with children with physical disabilities in the developmental clinics running in a semi-rural town in the Eastern Cape. This concluding chapter provides a summary of the current study. The chapter further highlights the importance of the findings of the study, limitations of the study and recommendations for further research.

6.2. Summary of the study

In exploring the lived experiences of health service providers working with children with disabilities in South Africa, a review of the literature indicated that there has not been a lot of research done to understand the experiences of health service providers working with children with physical disabilities and their caregivers. Whereas the experiences of caregivers of children with disabilities has been studied extensively (Chappell & Johannsmeier, 2009; Dunst & Trivette, 2009; Murphy et al., 2007; Saloojee et al., 2011).

The literature reviewed on the experiences of health service providers working in the public sector, particularly in rural areas with limited resources indicated that there are various challenges involved in working in rural areas. These challenges include unsatisfactory working conditions that involves limited resources, lack of adequate personnel to handle the demands of the work, lack of proper referral systems and the emotional distress of observing people's suffering (Ashmore, 2013; Nemutandani, Maluleke & Rudolph, 2006).

The literature also highlighted that despite the challenges involved in working in the public sector, particularly in rural areas, there are certain reasons for health service providers remaining in such contexts and which prevent them from moving to urban areas with better infrastructure and better working conditions. There reasons that were reported to be incentives for health service providers to remain in rural areas includes a sense of feeling like they are making a meaningful contribution to the lives of others and the community at large, a sense of feeling like they are part of a team, receiving positive feedback for their performance and a sense that there are opportunities to grow professionally (Ashmore, 2013; Jenkins et al., 2015).

For the current study, the experiences of the health service providers were explored by allowing them to share their experiences of working at the developmental clinics with children with physical disabilities and their caregivers. Therefore, the study focused on the meaning that the participants had attached to their experiences. Semi structured interviews allowed for achieving this goal.

The participants in the study reported positive experiences in relation to their work at the developmental clinics in the Eastern Cape. They described the work done at the clinics as meaningful and making a change in the lives of the children with disabilities and their families. They have experienced interactions with caregivers as enjoyable and believe that they have established long lasting emotional connections with the children and caregivers they work with. The health service providers also reported positive experiences in relation to their interaction with fellow colleagues. There was a shared sense of feeling like part of a team and feeling supported by fellow colleagues. These positive experiences were perceived as good enough motivation to continue working in this semi-rural and resource limited context. These findings supports the previous studies that highlighted that finding the work meaningful and feeling like part of team was linked to health professionals remaining within the public sector or rural areas (Ashmore, 2013; Jenkins et al., 2015).

The participants reported some negative experiences in relation to their work with children with physical disabilities and their caregivers as a result of challenges they experience in their work. There was a shared sense that the different demographical background between caregivers and health service providers resulted in challenges in rendering their services. Language difficulties were experienced as a barrier to rendering services. Race was also experienced as a challenge, there was a sense that white health service provider were perceived to be superior by black caregivers resulting in caregivers taking on a passive role in their interactions with the health service providers. This was experienced negatively by the health service providers and led to experiencing negative affect such as feelings of frustrations. The findings on the difficulties experienced in relation to demographic background differences expanded on Mackean et al. (2008) which argued that there are superior and inferior positions in the relationship between caregivers and health service providers. The current study highlighted that different demographic background plays a role in the issue of superior and inferior positions.

Most of the participants shared the distressing nature of their work, for most of them they experienced the work as distressing because it involved children and it was distressing for them to see children suffering as a result of their disabilities. Another significant concern reported by some of the participants which led to feelings of frustration, was a sense of feeling like they are not appreciated for the work they do at the developmental clinics by authority figures or management. Another concern reported was a lack of organisational support and this together with positive feedback has been regarded as highly valued by health service providers in numerous studies that explored the motivational factors behind health service providers who remain in rural areas despite the challenges experienced (Ashmore, 2013; Jenkins et al., 2015; Nemutandani et al., 2006; Van der Colff & Rothman, 2009). The lack of resources has also been experienced negatively by the participants in the study. The lack of resources also contributed to feelings of frustration and a sense of helplessness because it made it difficult for them to render their services despite the great desire to help the children that they work with and their caregivers. The lack of resources requires referring clients to neighbouring cities for further treatment and management. The findings of the study as highlighted the difficulties involved in referring clients to other facilities in other cities.

The participants reported challenges within relationships with others. It was evident from the study that there are challenges experienced in the relationship with caregivers and in relationships with other fellow health service providers. The challenges within the relationship with caregivers seems to stem from the health service provider's concern's regarding the child's wellbeing in the care of the caregiver, caregivers missing clinic appointments and caregivers not being compliant with suggested interventions. The challenges within the relationship with fellow colleagues seems to stem from disagreements regarding treatment options for children. In relation to the difficulties with colleagues, the participants reported challenges within the relationship with management in their organisations. These findings expanded on the report by DSD, DWCPD and UNICEF (2012) which highlighted collaboration difficulties between NGOs and governmental departments, by highlighting the relationship difficulties within organisations, between colleagues and between employees and management.

The findings of the study also highlighted that personal experiences play a role in how health service providers perceive their professional role. Furthermore, this perception of their role changes over time as a result of personal events and growth within their work. Moreover, the participants reported that perspective taking has enabled them to be more understanding of the difficulties faced by caregivers and children with disabilities. The understanding of such difficulties was reported to have taken place gradually over time and it was evident that personal events such as becoming parents themselves contributed to this growing understanding.

6.3. Implications of the findings

The findings of the current study have highlighted implications for practice and policy for health service providers working with children with disabilities. Firstly, the current study highlighted that financial rewards were not regarded as an incentive to stay in rural areas or reasons to move to private practice or urban areas. However, non-material benefits such as positive feedback from management acknowledging the services rendered on behalf of the organisation or the lack thereof in the case of the participants who took part in the study was implicated as the major reason for leaving work in public service in a semi-rural area for work in urban areas or private practice. The policy on public hospitals in rural areas emphasise a rural allowance which might be perceived as an incentive to remain in rural areas (Mburu & George, 2017). Research shows that despite this rural allowance, health service providers prefers to work in urban areas with better resources (Ashmore, 2013; Mburu & George (2017). This makes it pressing for management to create an environment that will allow for heath service providers to feel appreciated. This sense of appreciation is not dependent on material benefits and has been linked with resilience and a sense of coherence in relation to employees' work as seen in the research studies conducted by Van der Colff and Rothman (2009) and that conducted by Jenkins et al. (2015). This emphasises the importance of non-material reinforcement for the service rendered by health service providers.

Secondly, based on the findings of the study, there is a great need for management in the public sector to be more attuned to the emotional needs of the health service providers because the work that they do is perceived as emotionally exhausting and as unappreciated. This calls for support structures that would allow for health service providers to address such emotions in a safe space and feel emotionally supported. Even though most of the participants reported receiving supervision, they perceived it as insufficient for addressing their emotional distress and only allowed for discussing work related matters. Perhaps support groups, counselling or other forms of emotional support structures might allow for addressing the emotional difficulties.

Lastly, other valued factors that played a role in motivating health service providers to remain in rural areas despite challenges, was a sense of being part of a team that is supportive and allows for celebrating successes. Therefore, this emphasises the importance of creating a context that allows for health service providers to interact and have a sense of being part of a team. This could also enhance relationships among health service providers and between management and health service providers.

6.4. Limitations of the current study

There was a lack of prior research studies on the topic of health service providers working with children with disabilities in South Africa to help lay a foundation for understanding the experiences of this target group. Therefore, it is possible that there might be certain areas of the health service providers that were not accessed due to the lack of this foundation of prior knowledge and thus, limiting the findings of the study.

IPA was used to explore the experiences of the health service providers. As discussed in chapter 3 of this report, IPA emphasises that the researcher cannot interpret a phenomenon without influencing the phenomenon under interpretation. This might have had an impact on the reported themes and the manner in which they were interpreted. Particularly because I am a novice researcher and this required reading extensively on studies conducted using IPA to gain familiarity with this approach. Nonetheless, this was kept in mind and chapter 3 of study contains a reflexivity sections that allowed for reflecting on how my own prior knowledge might have played a role.

It is important to take into account the context in which the study was conducted. The results of this study may not be generalised to other health service providers who might not experience similar challenges to those experienced in this semi-rural area.

6.4. Recommendations for further research

The limited research in the area of health service providers working with children with physical disabilities despite the extensive research studies exploring the caregiver's experiences serves as grounds for conducting further research in this area.

Furthermore, none of the participants that took part in the study consciously made a decision to work with children with physical disabilities at the developmental clinics and most of them reported feeling underprepared for the emotional difficulties they experienced. It would be of interest to do further research targeting health service providers who chose to work with children with disabilities to determine how their experience may differ from those of the participants who took part in the study and if this helped them to cope better with the demands of their work.

6.5. Conclusion

This report presents a study of the experiences of health service providers working with children with physical disabilities and their caregivers in a semi-rural town in the Eastern Cape. An IPA approach was used to explore the experiences of the health service providers. The findings of the study highlighted both the positive experiences and the negative experiences of their work. On the positive aspect of things, the participants reported a sense of enjoying their work and finding it meaningful. They also reported enjoying receiving support from fellow colleagues and enjoying the interactions with caregivers and children at the clinics. On the negative experiences, the participants reported emotional difficulties in relation to their work and expressed a sense of feeling unappreciated by management. The participants reported how they have used perspective taking to cope with the difficulties experienced at work and how their growth in this line of work has also contributed to better coping mechanisms. Moreover, the participants experienced the Masibambane service learning programme as a good contribution to their work. The concluding chapter has highlighted the limitations and recommendations of the study.

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Appendix A: Interview schedule

Broadly working with children and caregivers

1) How did you get involved in working with children with physical disabilities at the Developmental Clinics?
2) Can you tell me more about your experiences of working with children with disabilities and their caregivers?
3) What is your understanding of your role in working with children with physical disabilities and their caregivers?
4) What does working with children with disabilities and their caregivers mean to you and what do you get out of this experience, what are the rewards?

Developmental clinics VS office/ hospital

1) What has it been like working at the Developmental Clinics?
2) How do you experience working at the Developmental Clinics as compared to working at the hospital (office for APD)?
3) How does working at the Developmental Clinics impact on you?
4) What is your experience on broader health services provision for children with physical disabilities at the Developmental Clinics?

Relationship with caregivers

1) How do you experience the relationship with caregivers?
2) How has working with children with disabilities and their caregivers changed the way you think or feel about yourself, if it all?
3) What does it mean to you, for the caregiver to be on the same page as you are about intervention programmes?
4) Could you tell me more about the challenges you have experienced in working with caregivers and how do you overcome these challenges

Service learning programme

1) What is your experience of Masibambane in relation to your work?

Appendix B: Consent form

Consent to Participate in Research (Health service providers)

The purpose of this form is to provide you with information that may affect your decision as to whether or not to participate in this research study. The person performing the research will describe the study to you and answer all your questions.

I, ____ (name) agree to participate in the research project of ____________________(researcher's name) on my experiences of 1) working with children with disabilities and their caregivers; 2) my role as a health service provider; and 3) service provision for children with disabilities and 4)the service learning programme, Masibambane

I understand and agree on the following:

1. The researcher is a Rhodes University student who is conducting the research as part of the requirements for a Master's Degree in Clinical Psychology.

2. The researcher may be contacted on 0769829323 (cell phone) or yollandah77@gmail.com (email). The research project is being supervised by Lisa Saville Young, an associate professor in the Psychology Department at Rhodes University. Lisa Saville Young may be contacted on 046 603 8047 (office) or at l.young@ru.ac.za (email).

3. The researcher will audio record and transcribe the interview.

4. I am free to withdraw from the study at any time during the data collection phase of the study.

5. I am invited to voice to the researcher any concerns I have about my participation in the study.

6. The report on the project may contain information about me, but the report will be designed in such a way that it will not be possible to identify me. Findings of the report will be made public.

7. Feedback will be provided to me based on the research. This feedback will be provided by the researcher. If I feel I need additional support due to the effects of the research, the researcher will refer me to the appropriate psychological support.

Signed on (Date): ____

Participant: ____

Researcher: ____

Appendix C: Transcription notation

1. General transcription notation (adapted from that developed by Gail Jefferson in Atikson &Heritage, 1984)

(.)	Shortest pause
(..)	Longer pause
Cu-	A dash signals a cut-off of the previous word or sound
(Word)	Word in brackets represent a transcriber’s guess at an unclear section of the recording
( )	Unclear speech with no approximation made by the transcriber
?	Arising tone
.	A natural end
,	A comma like pause
[ ]	square bracket denote over lapping talk

Appendix D: RPERC ethical clearance letter

RHODES UNIVERSITY
Where leaders learn

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RESEARCH PROJECTS AND ETHICS REVIEW COMMITTEE

22 June 2017

Yollandah Mathaba
Department of Psychology
RHODES UNIVERSITY
6140

Dear Yollandah,

ETHICAL CLEARANCE OF PROJECT PSY2017/40

This letter confirms your research proposal with tracking number PSY2017/40 and title, *'The experience of health service providers working with children with physical disabilities and their caregivers'*, served at the Research Projects and Ethics Review Committee (RPERC) of the Psychology Department of Rhodes University on 14 June 2017. The RPERC notes that this project is supervised by Prof. Lisa Saville Young. Your project has been given ethics clearance.

Please note that should your project require consent from institutional gatekeepers, the RPERC requires that you submit written confirmation of this consent. Kindly also ensure that the RPERC is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators.

Yours sincerely

Mr. Werner Bohmke
CHAIRPERSON: RPERC

Appendix E: Permission letter (NGO)

Chairperson

10 April 2017

Dear Sir/Madam

RE: Permission to undertake research with health service providers working with children with physical disabilities and their caregivers

I am writing to request your permission to recruit allied health service providers from your organisation as research participants for a research study I will be conducting on the experiences of health service providers working with children with physical disabilities and their caregivers. I will be conducting this study as part of my Master's Degree in Clinical Psychology at Rhodes University, under the supervision of Professor Lisa Saville Young, who can be contacted on 046 603 8047 and via email at l.young@ru.ac.za .

The study will involve interviewing research participants. The interviews will be audio recorded and transcribed. The purpose of this study is to provide a rich description of the health service provider's experiences of 1) working with children with physical disabilities and their caregivers; 2) their roles as a health service providers, and 3) service provision for children with disabilities and 4) the service learning programme, Masibambane.

Ethical approval for this research has been granted by the Department of Psychology, Rhodes University and I attach a copy of this for your information. I also attach the information sheet and the informed consent forms that will be shared with the health service providers.

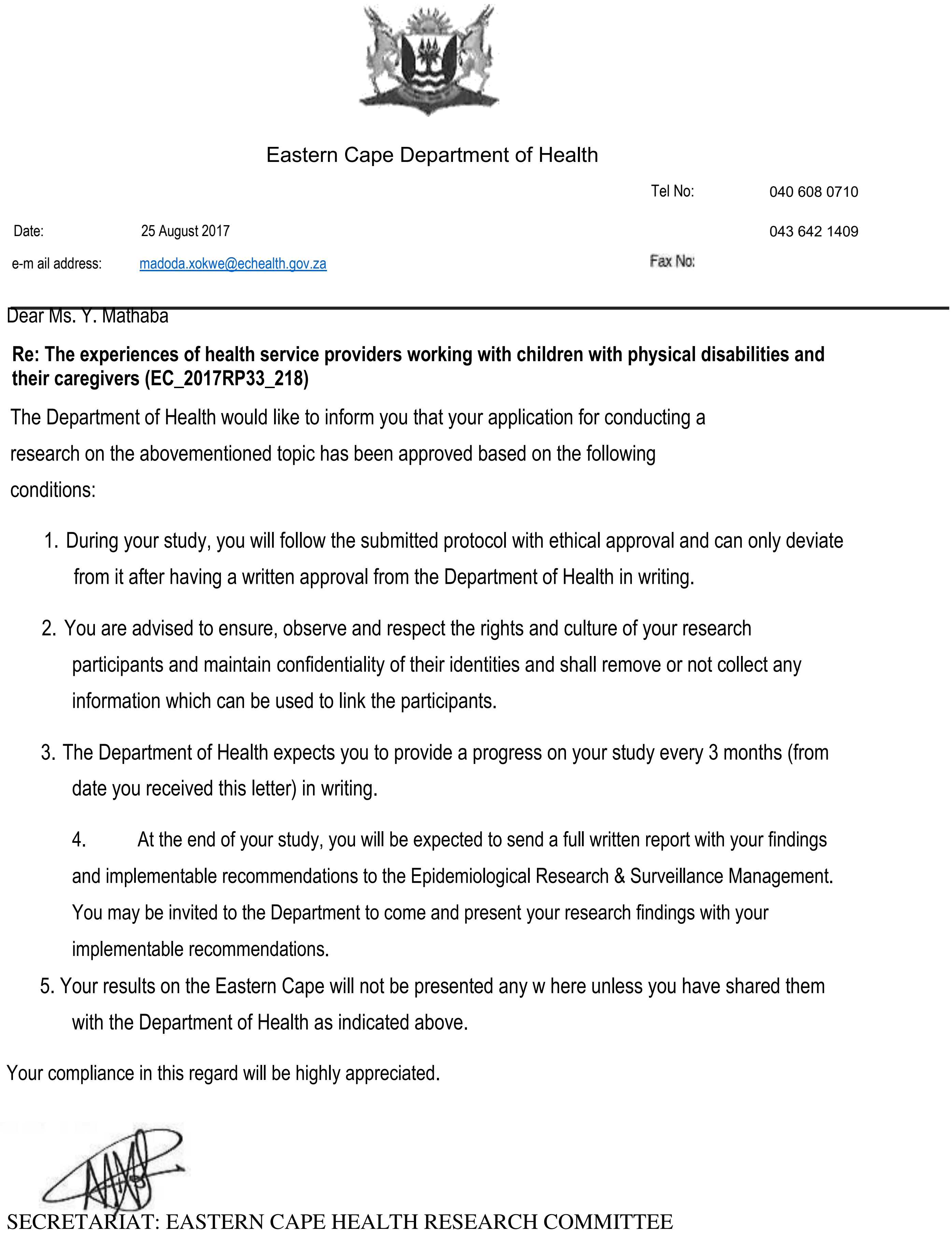
The findings of the research will be used to provide feedback to your organisation and to other health and allied service providers in the Eastern Cape that provide care at the Developmental Clinics. The findings will also be used to improve the service learning programme. Furthermore, the findings of the study will aid in understanding the experiences of health services providers better, both positive and negative experiences.

Please do not hesitate to ask me any questions that you may have about the research. You can contact me on 0769829323 or via email at yollandah77@gmail.com

I look forward to receiving your response.

Yollandah Mathaba (Researcher)	Professor Lisa Saville Young (Supervisor)
______________________________	______________________________

Appendix F: DOH ethical approval letter



Eastern Cape Department of Health

Tel No: 040 608 0710
043 642 1409
Fax No:

Date: 25 August 2017
e-m ail address: madoda.xokwe@echealth.gov.za

Dear Ms. Y. Mathaba

Re: The experiences of health service providers working with children with physical disabilities and their caregivers (EC_2017RP33_218)

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the Department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented any w here unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE

Appendix G: Permission letter (DOH)

District Manager

Department of health

10 April 2017

Dear Sir/Madam

RE: Permission to undertake research with health service providers working with children with physical disabilities and their caregivers

I am writing to request your permission to recruit allied health service providers from your organisation as research participants for a research study I will be conducting on the experiences of health service providers working with children with physical disabilities and their caregivers. I will be conducting this study as part of my Master's Degree in clinical Psychology at Rhodes University, under the supervision of Professor Lisa Saville Young, who can be contacted on 046 603 8047 and via email at l.young@ru.ac.za ..

The study will involve interviewing research participants. The interviews will be audio recorded and transcribed. The purpose of this recording is to provide a rich description of the health service provider's experiences of 1) working with children with disabilities and their caregivers; 2) their roles as a health service providers, and 3) service provision for children with disabilities and 4) the service learning programme, Masibambane.

Ethical approval for this research has been granted by the Department of Psychology, Rhodes University and I attach a copy of this for your information. I also attach the information sheet and the informed consent forms that will be shared with the health service providers.

The findings of the research will be used to provide feedback to your organisation and to other health and allied service providers in the Eastern Cape that provide care at the Developmental Clinics. The findings will also be used to improve the service learning programme. Furthermore, the findings of the study will aid in understanding the experiences of health services providers better, both positive and negative experiences.

Please do not hesitate to ask me any questions that you may have about the research. You can contact me on 0769829323 or via email at yollandah77@gmail.com.

Yollandah Mathaba (Researcher) Professor Lisa Saville Young (Supervisor)

_____________________________ _________________________________

Appendix H: Information to the participants

Dear prospective participant

I would like to invite you to take part in a research study about the experiences of health service providers working with children with physical disabilities and their caregivers. I, Yollandah Mathaba will be conducting this study as part of my Master's Degree in clinical Psychology at Rhodes University. I will be conducting the study under the supervision of Professor Lisa Saville Young, who can be contacted on 046 603 8047 and via email at l.young@ru.ac.za.

The purpose of the study is to explore the experiences of health service providers working with children with physical disabilities and their caregivers. I am interested in how you understand your role, your experiences of service provision for children with disabilities and their caregivers (both positive and negative experiences) and your experience of the service learning programme in relation to your work.

What would be expected of you? Your participation will involve being interviewed. The duration of the interview will be about an hour. The interview will be audio recorded and transcribed. The interview will take place at a time and place convenient to you. You will be required to sign a consent form before participation in the research study. Participation in the study is voluntary and you have the opportunity to withdraw from the study at any point during the data collection phase of the study.

The information gathered in the study will be confidential, no one other than myself will have access to the raw data. To ensure anonymity your name and occupation will be disguised. Therefore the findings of the study will not link directly to you.

The findings of the study will be used to provide feedback to your organisation and to other health and allied service providers in the Eastern Cape that provide care at the Developmental Clinics. The findings will also be used to improve the service learning programme. Furthermore, the findings of the study will aid in understanding the experiences of health services providers better, both positive and negative experiences.

Should you get distressed by discussing your experiences, referral to appropriate counselling services will be arranged.

You are welcome to contact me should you have any questions. You can contact me on 0769829323 or via email at yollandah77@gmail.com.

Thank you for considering to participate.

Yollandah Mathaba (Researcher) Professor Lisa Saville Young (Supervisor)

_____________________________ ___________________________________

Appendix I: Permission release form

Rhodes University — Department of Psychology

USE OF TAPE RECORDINGS FOR RESEARCH PURPOSES PERMISSION AND RELEASE FORM

Name of participant			
Participant's contacts details	Email address: Phone number:		
Name of researcher			
Level of research	Honours	Masters	PhD
Brief title of project			
Name of supervisor			

DECLARATION

(Please initial/tick blocks next to the relevant statements)

1.	The nature of the research and the nature of my participation have been explained to me.	Verbally	
		in writing	
2.	I agree to be interviewed and to allow recordings to be made of the interview.	Audiotape	
		Videotape	
3.	I agree to and to allow recordings to be made.	Audiotape	
		Videotape	
4.	The tape recordings may be transcribed	without conditions	
		only by the researcher	
		by one or more nominated third parties	

5. I have been informed by the researcher that the tape recordings will be erased after a period of 5 years after the study is complete and the report has been written.	
6. I give permission for the tape recordings to be retained after the study and utilised for publication purposes	

Signature of participant: __________________ Date___________________

Witnessed by researcher: _____________ Date ___________________