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**A Case-Series Evaluation of the Impact and Processes of a  
Service-Learning Programme on and for Caregivers and  
their Children with Neurodevelopmental Disabilities.**

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A thesis submitted in the fulfilment of the requirements for the degree of

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### **Abstract**

This thesis presents a series of three case studies from data collected as part of a research project exploring the process and impact of a service-learning programme with caregivers and their children with neurodevelopmental disabilities. Following a descriptive case series design, both quantitative and qualitative data are presented to create a comprehensive and rich understanding of each case. In particular, the data tracks change processes in the subjective well-being of the caregiver, the quality of the caregiver-child relationship and the functional development of the child over a twenty-one-week period of receiving public health services and an eight-week period of adding the service-learning programme. The paper also presents qualitative data on the caregivers' perceptions of and experiences of the public services and the service-learning programme that the caregivers and their children received. The findings provide important insight into the caregivers' perceptions of giving and receiving care, with the caregivers' experiencing significant levels of distress and prominent barriers to accessing healthcare that were seemingly eased with the addition of the service-learning programme. The findings also point to a notable disparity between the quantitative findings and the qualitative interviews with questions being raised about the research being viewed as an intervention in itself.

*Keywords: Childhood Disability, Service-Learning Programme, Case-Series Design, Process, Impact*

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## CHAPTER 1

### Introduction to the Research

This research thesis aims to evaluate the impact and processes of a service-learning programme in the Eastern Cape of South Africa. The service-learning programme at the centre of this research is run as a collaboration between the Department of Health, a local non-profit organisation for persons with physical disabilities, and a local University's Psychology Department. The programme aims to help caregivers and their children with neurodevelopmental disabilities living within a disadvantaged community. This is done by engaging Psychology Honours Students in a service-learning course whereby they utilise what they are learning in class by applying it to community problems. This process involves reflecting on their experiences in order to achieve real objectives for the community, and a deeper understanding and skills for themselves (Eyler & Giles, 1999; as cited in Mouton & Wildschut, 2005). The distinctive element of service-learning is that it aims to empower the community through the support services it provides (Mouton & Wildschut, 2005).

This chapter aims to introduce the reader to disability studies, particularly childhood disability and briefly contextualize it within the South African setting. Thereafter, the conceptualization of the service-learning programme will be charted and the aims of the current service-learning programme will be delineated. Finally, the structure of the thesis will be outlined in detail for readers' convenience.

#### 1.1 Overview of Disability Studies

To some degree, every person will be temporarily or permanently impaired at a point in his or her life (World Health Organisation, 2011). According to Waldschmidt (2017), impairment is a common experience in human life and we are all, to some extent, differently able-bodied. However, it is important to acknowledge that while we may all experience impairments during our lifetime, being disabled is a specific social identity of the minority (Shakespeare, 1994). It is estimated by the World Health Organisation (2011) that 15% of the world population is considered to

have a disability, which equates to over 1 billion people. This number is believed to be growing annually due to global factors such as extended life expectation, and increases in chronic diseases, cardiovascular diseases and mental illness (World Health Organisation, 2011). Disability affects people worldwide; causing poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty (World Health Organisation, 2011).

The field of disability studies is considered to be a relatively young academic discipline, with the first publications stemming from the 1950s and only gaining momentum in the 1970s (Barton & Oliver, 1997; Vergunst, 2016). Despite this relatively short history, disability studies has seen the emergence and transformation of various stances and frameworks on disability from academics, activists, and critics alike.

One of the key conceptual distinctions that transformed disability studies was the conscious movement beyond the psychological and medical discourses of disability to engaging with the emancipatory politics thereof (Barton & Oliver, 1997; Vergunst, 2016). Where the traditional Medical Model of disability claimed disability to be a medical problem located in the individual's body that required medical or rehabilitative attention, the emergence of the Social Model denied that disability was fundamentally an individual impairment but rather a social disadvantage experienced by an individual created entirely by social, cultural, and economic conditions (Bickenbach, Posrac, Cieza, & Kostanjsek, 2015). Goodley (2013) explains that traditional, late-twentieth century disability studies was associated with establishing factors that led to the structural, economic and cultural exclusion of people with disabilities to which the politicization thereof helped focus disability studies on creating nuanced theoretical responses to these factors.

This resulted in the development of various models of disability that represent different theoretical, ideological and scientific positions. However, it is important to note that no single model alone can fully explain disability (Pfieffer, 2016). Rather, there has been a movement to view disability for what it truly is; complex, dynamic, multidimensional and often highly contested due to the different perceptions, models, and classification systems that are multiple, systemic and varying with context (World Health Organisation, 2011).

### **1.1.1 Defining Childhood Disability**

There is no single, universally accepted definition of disability, which is in part due to the wide array of different perceptions, models, classification systems and contexts that influence our understanding of disability (Vergunst, 2016). Due to the complexity of disability, it has not been defined, measured, or analysed in a consistent manner (Vergunst, 2016). Pfeiffer (1999, as cited in Vergunst 2016) states that we tend to view disability as permanent or dichotomous whereas it should be seen as more fluid and continuous to accommodate the complexity and multidimensionality of disability. This point is reiterated by Schneider (2006) who says that disability can no longer be seen as a static feature of an individual, rather, it needs to be seen as a dynamic and changing experience determined by the shifting nature of the environment.

The transition from viewing disability as neither medical nor social has led to an interactional understanding of disability as an evolving concept through its dynamic interaction between the medical and social aspects (Bickenbach et al, 2015; Vergunst, 2016). Disability should be viewed in a balanced approach, acknowledging all of the different aspects of disability (Bickenbach et al., 2015). This research aims to take this point of view by using the bio-psychosocial model, which represents a balance between the medical and social models- understanding functioning and disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental (World Health Organisation, 2011).

Classifying disabilities in children is more difficult than in adults due to adults having relatively stable characteristics while children go through constant developmental changes as they grow (DSD, DWCPD & UNICEF, 2012). These evolving characteristics complicate the task of assessing functioning and distinguishing disabilities from delays in the normal developmental processes (DSD, DWCPD & UNICEF, 2012). Thus, the classification and coding of disability in children requires the careful consideration of an array of items which are encompassed under the bio-psycho-social model, including: significant limitations of body functions, body structures, activities and participation in physical, social and psychological development (DSD, DWCPD & UNICEF, 2012).

**1.1.1.1 Definition of childhood disability.** The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) has become the most widely accepted description of childhood disability in terms of the bio-psychosocial model. The ICF-CY regards disability as a complex phenomenon that reflects the interaction between the features of a person's body and the features of the society in which the person lives (World Health Organisation, 2012; World Health Organisation, 2016). Disability is therefore defined as, "the interaction between health conditions and environmental and personal factors" (World Health Organisation, 2012, p.7).

Through this classification, disability can be seen as an umbrella term that encompasses a wide variety of disabilities occurring at the following three levels; impairments, activity limitations, and participation restrictions (World Health Organisation, 2011). Impairments are seen as a problem in the body's functioning or structure, through damage, loss or weakening. An activity limitation is a limitation in activity, whereby the functioning is restricted to certain limitations (World Health Organisation, 2011). Lastly, a participation restriction is when a child may be excluded or denied access, such as from school (World Health Organisation, 2011)

**1.1.1.2 Definition of childhood disability in South Africa.** Although the ICF-CY's definition of childhood disability is the most widely accepted definition at this present time, it is important to note that South Africa does not utilise a standard definition or measuring tool in line with the ICF for the collection of data on childhood disability (DSD, DWCPD & UNICEF, 2012). Thus, data collected on childhood disability in South Africa is believed to be underestimated, problematic, and often incomparable with little information about the nature and prevalence disability in South Africa being known (ACPF, 2011; Vergunst, 2016).

### **1.1.2. Defining Neurodevelopmental Disabilities and Cerebral Palsy.**

Neurodevelopmental disabilities are a group of chronic disorders of assorted origin that share an essential core feature of disturbance in the attainment and expression of early developmental skills (Shevell, 2009). Previously, the domains at which the disabilities occurred, such as motor, speech and language, or daily living activities were used to classify these disorders. However, it has come to be understood that these domains are not mutually exclusive and they often overlap (Shevell, 2009).

Neurodevelopmental disabilities are believed to be a common problem in child health with a lifelong morbidity that requires additional specialised medical and health interventions within the domains of medical, rehabilitation, educational, vocational, and supportive needs (Shevell, 2009).

Neurodevelopmental disabilities are divided into subtypes of symptom complexes that assist in conceptualising recognizable, distinctive, and distinguishable diagnoses (Shevall, 2006). These subtypes also aim to provide a template for medical and rehabilitation evaluation in order to comprehend the disorders' pathogenesis, determine the healthcare service requirements, and form future expectations and outcomes (Shevall, 2006). One of the most common neurodevelopmental subtypes found in children is cerebral palsy (Shevall, 2009). Cerebral palsy can be understood as an umbrella term that encompasses a variety of permanent heterogeneous neurodevelopmental disorders of the development of movement and posture (Rosenabum, Paneth, Levitan, Goldstein, & Bax, 2006). These disorders are noted for causing activity limitations that are ascribed to non-progressive disturbances that occur in the child's prenatal brain development or postnatal infant brain (Rosenabum, et al., 2006). In addition to motor disorders, children with cerebral palsy often also present with disturbances of sensation, perception, cognition, communication, and behaviour due to epilepsy or secondary musculoskeletal difficulties (Rosenabum, et al., 2007).

## **1.2 Prevalence of Childhood Disability in South Africa**

South Africa is considered to be an upper middle-income developing country with a relatively strong economy compared to those of other developing African countries (World Bank, 2016). Although two-thirds of the world's least developed nations are in sub-Saharan Africa, South Africa has pockets of developed contexts in an overall developing context resulting in a comparatively well-developed infrastructure (Swanepoel, Störbeck & Friedland, 2009). Despite South Africa being considered a relatively wealthy country, huge disparities continue to exist huge between the rich and poor stemming from the Apartheid era, whereby black people continue to experience disproportionately higher levels of poverty and unemployment (ACPF, 2011). Access to infrastructure has also been found to be characterised by

inequality according to race and socioeconomic status (Swanepoel, Störbeck & Friedland, 2009).

It is estimated that over 2.1 million children in South Africa can be regarded as being disabled (DSD, DWCPD & UNICEF, 2012). The primary causes of disability in South Africa have been found to have their roots in poverty with families in the lowest socioeconomic bracket being observed to be 2.5 times more likely to have a disabled child (Lansdown, 2002). According to Swartz and Watermeyer (2006) disabled South Africans are amongst the poorest, most discriminated against, systematically excluded, and economically and socially marginalised people in the country.

Despite progress being made in terms of legislation and policy reform for children with disabilities since South Africa's democracy in 1994, the realities for children with disabilities have not changed much since. Children with disabilities are one of the most neglected groups in both the public and private spheres with enormous economic, political and social barriers that have an adverse impact on their physical, social and intellectual development and well-being (ACPF, 2011). This is believed to stem from the public's generally negative attitude, misconceptions, prejudices and stereotyping towards persons with disabilities (Nkeli & Associates, 2008; as cited in ACPF, 2011; Swartz & Watermeyer, 2006). As a result, children with disabilities in South Africa often experience multiple deprivations, a lack of basic needs, and invisibility in the policy agenda (ACPF, 2011).

### **1.3 Healthcare and Rehabilitative Services in South Africa**

In South Africa, substantial resources are allocated to social services for children particularly in the sectors of healthcare, social development and education. However, the impact thereof is limited as the public system is overburdened and understaffed with over 85% of the population relying on it (ACPF, 2011; Swanepoel, Störbeck & Friedland, 2009). In particular, the general state of the public healthcare system is poor, characterized by unsanitary and overcrowded hospitals with long waiting periods, and a shortage of staff and medicine (AFCP, 2011). A study conducted in 2007 found that one-third of public medical posts were unfilled resulting in an outrageous 1:4750 ratio of doctors to citizens (Geddes, 2010). Dell and Khan

(2017) found that surgical resources in South African hospitals were far below international recommendations, leading to an increase in premature death and disability.

Children with disabilities are particularly affected by this underprovided system as resources and tools to identify and track disabilities are deficient and general healthcare services for children with disabilities remain fragmented and unequal (AFCP, 2011). Therapeutic and rehabilitation services for children with disabilities in rural areas are usually only available on a monthly basis and only a third of children in need of long term rehabilitation in South Africa receive it (Couper, 2002, as cited in Saloojee, 2008). It has also been noted that there is difficulty in corroboration between caregivers and therapists that is believed to be based on disparate socioeconomic status, education levels, language, and culture that stem from the Apartheid era (Moja, 2004; as cited in Saloojee, 2008). Caregivers and their children are often disempowered passive recipients of therapy programmes whilst therapists often struggle to understand why therapy attendance is erratic and compliance with the home programme low (Saloojee, 2008).

### **1.3.1 Healthcare and Rehabilitative services in the Eastern Cape of South Africa.**

The Eastern Cape of South Africa is considered to be one of the country's poorest provinces with much of its population receiving inadequate and inequitable access to resources (Woolard, 2002). Hospitals in the Eastern Cape are reportedly understaffed, with weak primary healthcare and some calling upon the province to declare it a healthcare crisis ("Eastern Cape- Health Care Crisis", 2017). Research has found that aside from the inadequate and inequitable distribution of healthcare resources, many persons also reported additional barriers to accessing health care services such as: vast distances, high transport costs, long queues and disempowering care (Vergunst, 2016).

Grahamstown, the small town situated in the Eastern Cape where the research took place, is marked by vast disparities and inequities that stem from its rich history as a colonial settlement in the 1800's (Moller, 2001). On one side of the town exists a privatized economy driven by a well-known University and various private schools in the area. However, on the other side of town exists a greatly disparate scene in the expansive locations where overcrowding, poor service delivery, and failing

infrastructure are commonplace (Moller, 2001).

Anecdotal reports found that the town is served by only one hospital, which is a public and private partnership. The hospital is inequitably situated in close proximity to the financial hub of the city and it is not easily accessible to the areas marked by poor socio-economic factors. The hospital has only 251 beds available for in-patients which serves a population of over 70 000 people, thus, they often have to refer critical patients to hospitals in the nearby cities. Services at the hospital are free to pregnant or breastfeeding women and children under the age of 6 years old.

Children found to have developmental delays or disabilities are referred from the hospital to one of the various outpatient clinics situated in the rural areas. The clinics each host a monthly developmental clinic that is run in collaboration with the Department of Health (DOH), the local hospital, and a local branch of a national non-profit organisation (NPO) for persons with physical disabilities. Here, a team of therapists assesses children with developmental delays and disabilities, providing them with stimulation, exercises and a home programme for caregivers to continue to implement from home for the rest of the month while they do not have access to the services.

In conceptualising the service-learning programme, anecdotal reports from therapists working in the clinics showed that they too recognised similar downfalls in their services to those discussed above. Clinic attendance by caregivers and the children with disabilities/delays was reported to be erratic and compliance with the provided home programme was low resulting in a lack of continuity in assessing and treating children adequately. Caregivers also complained about the lack of financial means, inadequate resources, high transport costs, and long queues at the clinics, which prevented them from accessing the clinic services. Therapists also reported that many of the caregivers were experiencing low mood which could often be attributed to a lack of resources and a lack of support.

In order to address these issues, the clinic stakeholders approached the local University's Department of Psychology to help establish a service-learning programme that utilizes students to provide additional support to caregivers and their children (Mouton & Wildschut, 2015).

## **1.4 The Service-learning Programme**

### **1.4.1 Conceptualising the Service-Learning Programme**

Anecdotal accounts of the conceptualisation of the service-learning programme provide insight into the programme's formation and growth over the years. In 2010, the NPO director, who also served as the local hospital's Rehabilitation Manager, initiated the programme by contacting the department of Psychology at the local university. The programme initially involved third year and honours students volunteering to visit a special care unit at a local primary school. The unit catered for a maximum of twelve children from a disadvantaged background between the ages of three and eleven years old with a variety of developmental delays and disabilities.

At this time, members of the clinic, the NPO and the University Psychology Department met and were able to identify some key challenges they identified caregivers and their children with disabilities to be facing in the community, as mentioned above. By identifying these challenges, the community partners were able to inform the aims of the programme and establish a more effective outline for caregivers and their children with disabilities in 2011. The decision was made to shift the initiative so that the student volunteers visited the caregivers and their children in their own homes once a week over a nine month period with the aims of offering support, encouraging parent child interaction, and providing sensory or motor stimulation through appropriate play. The students were also able to provide descriptive feedback to the NPO social workers and the clinic therapists during a compulsory monthly supervision meeting regarding the families' well-being and progress, such as, whether the home programme was being implemented, whether there was evidence of neglect or abuse, or whether caregivers appeared to have low mood.

The service-learning programme was again re-examined by the members of NPO, the clinic and the university at the end of 2015 after difficulties were experienced with the student volunteers and ethical questions were raised. The volunteer programme's supervisors were experiencing a high drop out rate with students due to the extensive period that the volunteering took place over. They also found it difficult to provide thorough training to the student volunteers and adequate

support and supervision to guide them. Thus, the programme was once again re-envisioned to take into account these worries.

### **1.4.2 Intervention Programme- Service-Learning 2016**

In order to provide students with a greater capacity for learning and more structured supervision, it was decided that the current community engagement project outlined above would become a service-learning programme that would form part of an Honours course in Psychology for 2016. During the eight-week course, students were provided with on-going training and supervision to engage them theoretically with the literature on disability studies, early intervention, and attachment theory, amongst other things. Appendix 1, Figure A outlines the course content that was covered during the eight-week lecture cycle. During this period of learning, the students were also paired up and visited a caregiver and their child with disabilities once a week at the caregiver's home. The aims of the service-learning programme were to: provide social support for caregivers to address stress and isolation; provide advice for caregivers in line with recommendations of therapists; promote adherence to the home programme; encourage caregiver-child interaction to promote bonding, and increase caregivers' capacities to provide their child with learning experiences through play.

**1.4.2.1 Sampling for the Service-Learning Programme.** The participants for the service-learning programme were purposively selected through the Developmental Clinic in accordance with strict inclusion criteria. These criteria included:

- Children between the ages of 6 months and 5 years-old
- Living in the disadvantaged peri-urban area in a town in the Eastern Cape, South Africa
- Children and caregivers that have never before participated in the service-learning programme
- Attending the clinic for no more than a year and no less than six months
- Diagnosed with Cerebral Palsy with a Gross Motor Functioning Classification System (Palisano, Rosenbaum, Bartlett & Livingston, 2007) of Level I, II or III (Appendix 2, Figure A).

- Child and caregiver available to participate in the 8 week service-learning programme and willing to participate in the research

The therapists at the clinic evaluated their records to identify possible candidates from the clinic to partake in the service-learning programme, keeping in mind the above listed inclusion criteria. Unfortunately, only a few dyads were identified that fit the specific inclusion criteria. Thus, the inclusion criteria were extended to include all levels of GMFCS functioning from levels I-V. This resulted in a greater pool of candidates being identified.

Candidates who fitted the inclusion criteria were approached by one of the NPO's Social Workers through home visits and telephone calls and offered the opportunity to partake in the service-learning programme and the research voluntarily. The participants were offered an information leaflet (Appendix 1, Figure B) that outlined their participation in the service-learning programme. The participants could then voluntarily choose to participate in the service-learning programme by signing an agreement of participation (Appendix 1, Figure C). Participants who wished to participate in service-learning and not the research were not disadvantaged.

### **1.5 Rationale for Research**

Little research has been carried out on childhood disability within the disadvantaged setting, particularly within the Eastern Cape of South Africa. In particular, the service-learning programme has previously only been assessed informally through casual correspondence with the caregivers and the students involved. Thus, this research project forms part of a larger research project, which aims to formally evaluate the service-learning programme from various perspectives. This research aims to evaluate the programme's impact on the caregivers and their children, and their experiences of the processes involved in their engagement with the programme. The aim of the research is to investigate the outcomes alongside the views, experiences, and perceptions of caregivers, in order to establish whether the intervention services offered are effective, relevant and appropriate (Saloojee, 2011).

### **1.6 Thesis Structure**

The layout of the thesis will begin with a review of the literature around disability studies in low and middle-income countries. This will include a review of the literature around disability and intervention services in the disadvantaged setting, and a theoretical review of the literature that forms the basis for the service-learning programme, including, the role of the parent in intervention services, the theory of affect attunement, and attachment theory.

This will be followed by a chapter on the methodological approaches used in conducting this research, particularly, a descriptive case series design. Details of the research questions, research design, participants, data collection, and data analysis will be outlined here. Ethical considerations will also be taken into consideration in this chapter.

The data will then be presented on a case-by-case basis as per the case series design which calls for the presentation of all the data captured for each individual before moving on to the next. There are three cases and thus, each case will be presented as a separate chapter. These chapters will include an introduction to the case, presentation of the initial baseline data prior to the service-learning programme, presentation of the post service-learning programme data, and an overall discussion and conclusion for each individual case.

The final chapter will include a discussion of the various cases and the findings for the study. Thereafter, a conclusion will be presented that explores the strengths and limitations and possible directions for future studies.

## CHAPTER 2

### Literature Review

This research is broadly situated within the intersections of traditionally separate areas of study. The research is predominantly situated within the area of childhood disability studies, specifically, the literature related to the implementation and assessment of early intervention programmes that impact the development and well-being of children with disabilities and their caregivers in developing countries. There is also a notable critical underpinning to this research that draws on critical psychological literature to address the experiences of caregivers and their children with disabilities within a disabling society.

In order to assess early intervention programmes through research it is vital to understand the premises upon which they are based that provide them with their theoretical foundation for the implementation and attainment of specific goals and outcomes. Several theories, areas of research and literature underpin and provide a rationale for the service-learning programme that the research evaluates. The programme is principally situated within the areas of service-learning and community engagement, which looks at the role that higher learning institutions can play in providing intervention services to communities. Another large principle of the research entails the involvement of the caregiver in the intervention services.

This chapter situates the study within these various areas, looking at the established literature around childhood disability, service-learning and the importance of caregiver-child attachment. The research investigates the impact of the service-learning intervention from both a quantitative and a qualitative perspective. Firstly, literature relevant to prevalence of childhood disability within South Africa is reviewed in order to contextualise the service-learning programme and the proposed research. Thereafter, literature on community based interventions and service-learning is assessed and the effectiveness of these interventions is also appraised. Evidence on the importance of involving the caregiver in the intervention service is then discussed with regards to attachment theory. Finally, a critical appraisal towards disability studies in the South African context is offered as an underpinning to highlight the necessity of the proposed research.

## **2.1 Childhood Disability in South Africa**

### **2.1.1 Prevalence of Childhood Disability**

Expanding on the introduction chapter, prevalence studies on childhood disability in South Africa have found that the estimated population of over 2.1 million children with disabilities is considerably large, with an overrepresentation in poverty stricken areas where access to services is low (DSD, DWCPD & UNICEF, 2012). This figure is still considered to be an underestimation of the actual amount of children living with disabilities in South Africa (Burg, 2016).

An overview of inequality and poverty in South Africa by Woolard (2002) found that the poor had a disproportionately higher rate of disability, with children born into low-income households being twice more likely to have a disability. Lansdown (2002) also found that disability in South Africa has its roots in poverty with families in the lowest socioeconomic bracket being two and a half times more likely to have a disabled child. Donald, Kakooza, Wammanda, Mallewa et al. (2014) suggest that the prevalence of disabilities and comorbidities related to cerebral palsy are of a higher proportion and of a greater severity in poorly resourced countries, such as South Africa, when compared to that of European countries. This is believed to be due to poor care during birth, delayed presentation to healthcare services, and poor early intervention services (Burg, 2016).

### **2.1.2 Early Childhood Development Interventions**

There has been an increased recognition of the need for early identification and intervention of children with developmental delays and disabilities (Committee on children with disabilities, 2001). Research has shown that early identification of developmental problems and disabilities in infants and young children is considered an important factor in leading to effective therapy, improving outcomes, and helping the family obtain resources for successful functioning (Glascoe & Dworkin, 1995). However, it is well recognized that a gap exists between the needs of children with disabilities and the services available to them, particularly in resource constrained settings (Thornburn et al, 1992b; Pongraai et al., 1996; Couper 2002; as cited in Saloojee, Phohole, Saloojee & IJsselmuiden, 2007).

Access to healthcare is recognised in South Africa as an ethical and human rights obligation. However, considerable inequities still remain, largely due to

discrepancies in resource allocation (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Gilson & McIntyre, 2007). Access barriers also include vast distances and high travel costs, especially in rural areas (Harris, et al., 2011), high out of pocket payments for care (Goudge et al., 2009), long queues (Nteta, Mokgatle-Nthabu, & Oguntibeju, 2010), and disempowered patients (Schneider, et al., 2010). According to Harris et al. (2011), these barriers are the result of uneven social-power relationships. Their study on access to health care in South Africa concurs with previous South Africa studies, confirming that poor, uninsured, black South Africans and rural groups have poorer access to health care than any other members of South African society (Coovadia et al., 2009; Gilson & McIntyre, 2007; Goudge et al., 2009; Schneider et al., 2010).

A study conducted by Saloojee et al. (2007) on a population of 156 caregivers of children with disabilities living in a peri-urban area in South Africa found that: more than one half of the children in their study were denied access to school; less than one half received social grants they were eligible for; and only one quarter of the children in need of rehabilitation therapy received it. A longitudinal situation analysis by DSD, DWCPD and UNICEF (2012) reported on various studies that found that only a quarter of children aged 0-6 years with a Care Dependency Grant attended crèche; only 42% of children with disabilities were receiving rehabilitation; and only 33% of children in need of assistive devices had received them. Venter (2007) comments that in terms of services in South Africa the majority of children with disabilities tend to receive no, inadequate, or inappropriate interventions.

Several studies have identified barriers towards optimal care of children with disabilities in South Africa. Donald, Samia, Kakooza-Mwesige and Bearden (2014) identified the following barriers to best care for children with cerebral palsy in South Africa: a lack of access to medical services, healthcare facilities and specialists; a shortage of trained healthcare workers and rehab personnel; a dearth of adaptive equipment such as wheelchairs; and high levels of stigma attached to children with disabilities that deters caregivers from seeking help unless the disability is life threatening.

Ultimately, indications and observations have pointed to services that are limited and restricted to urban areas (Swanepoel, et al., 2009). Rehabilitation professionals such as physiotherapy, occupational therapy, speech therapy,

psychology, orthotics and prosthetics, are considered ‘scarce skills’ in South Africa’s public sector and the shortage thereof is believed to impact most directly on children with disabilities in terms of early identification and intervention (DSD, DWCPD & UNICEF, 2012).

Despite the high prevalence rates and notable deficit in interventions services for children with disabilities, research has remained scarce with a focus on epidemiology while the areas of prevention and health promotion in childhood disability have remained under-researched (Maulik & Darmstadt, 2007). Amongst the studies that have conducted research on services, there seem to be common factors that affect the use and availability of disability interventions and services. Thus, the importance of services capable of responding to the complex social causes of disability in marginalised communities has been highlighted (Nxumalo, Goudge & Thomas, 2013). Doctors, therapists and researchers working in low resource settings are becoming increasingly aware of the need to provide alternative service provisions to children with disabilities. Donald et al. (2014) suggest that the advancement of adaptable low-cost materials, community health care workers, the development of parent support groups, and multidisciplinary outreach programmes may serve as a means to bridge the gap in healthcare services for children with disabilities in South Africa. Couper (2002) states that the large number of children with disabilities will continue unless service providers, working together, can develop appropriate rehabilitation and intervention programmes that are multifaceted, multidisciplinary and sustainable.

## **2.2 Community Outreach and Service-learning**

### **2.2.1 Community Outreach and Rehabilitation Services**

The South African Department of Social Development includes outreach services as one of the seven categories in their Prevention and Early Intervention Programme. Outreach services are aimed at reaching out to particularly vulnerable children and families in order to meet the needs of children within the context of family and community (DSD, DWCPD & UNICEF, 2012). As an extension to hospital-based services, a balanced addition of community-based outreach has been found to be the most effective form of service-delivery and care provision (Saxena,

Thornicroft, Knapp & Whitford, 2007).

In addition to community based outreach, community based rehabilitation involves measures taken at the community level to use and build on the resources of the community as a whole. (World Health Organization, 1981). Community based rehabilitation was developed in order to address the prevailing shortage of healthcare workers (El Arifeen, Christou, Reichenbach, Osman, Azad, Islam et al., 2013). The main premise of community based rehabilitation involves breaking down the rehabilitation process and engaging people without a professional background in the rehabilitation process to increase the delivery of basic healthcare services (Finkenflugel, Wolffers & Huijsman, 2005). Community-based rehabilitation has been advocated as a complementary, accessible and inclusive approach to meeting the needs of children with disabilities at the community level (World Health Organisation, UNESCO, International Labour Organization, & International Disability Development Consortium, 2010).

Some provincial departments in South Africa have entered into public-private partnerships in attempt to implement community-based intervention programmes. However, it has been found that these attempts often lack a cohesive and strategic national position. Saxena et al. (2007) suggest that in order for community-based services to thrive, training, assistance and supervision by professionals is a necessary requirement. This is reiterated by Nxumalo, et al. (2013) who state that significant investment in resources, training and support could enable community healthcare workers to address barriers to care. However, this is often difficult due to a lack of funding, insufficient skills and a lack of support. Thus community outreach and rehabilitation services in South Africa remain for the most part diverse, fragmented, unstructured and unregulated (Nxumalo, et al., 2013).

Currently, the health sector in South Africa is focused on the formalization and integration of community-based services as a means to strengthen district level public healthcare services. An important aspect of this is conducting research and extending on existing outreach services that have been successful in order to strengthen community outreach and make it a viable option for the prevention and promotion of healthcare, adherence and psychosocial support, with a particular focus on maternal and child health (Schneider & Barron, 2008).

### **2.2.2 International Development of Service-learning**

A field that has been highlighted in the endeavour to provide sustainable community-based outreach is that of service-learning. Boyer (1997) suggests that higher education has a responsibility to develop scholarship that is connected and integrated with community outreach by preparing students to be active citizens that are better equipped to bridge expanding cross-cultural and economic differences (Hatcher & Erasmus, 2008). Historically, the core functions of western universities have been teaching, research and community engagement, with the former two often superseding community engagement (Fourie, 2003). In order to address this, the field of service-learning has emerged and become prominent within the United States since the 1990's. Service-learning can be defined as "a course based, credit-bearing educational experience in which students (a) participate in an organized activity that meets identified community needs, and (b) reflect on the service activity in such a way as to gain further understanding of course content, a broader appreciation of the discipline, and an enhanced sense of personal values, and civic responsibility" (Bringle & Hatcher, 1995, p.112).

### **2.2.3 Service-learning in the South African Context**

In 1999 in South Africa, service-learning was initiated by the Joint Education Trust (JET) through the Community-Higher Education Service Partnerships (CHESP) initiative which funded the corresponding development and implementation of service-learning programmes in South Africa (Lazarus, Erasmus, Hendricks, Nduna, & Slamati, 2008). Service-learning was introduced in South Africa in order to engage students in higher education institutes in a more meaningful manner whereby the committed resources better benefitted the communities. However, service-learning was introduced as a well defined pedagogy guided by American literature and academics and has thus garnered much critique across cultural contexts, particularly when applied in the unique South African framework of racial oppression and inequality (Hatcher & Erasmus, 2008; Tonkin, 2004). Fourie (2003) notes that it is of great importance that the needs and goals of the community are a priority in the design and implementation of service-learning programmes due to the historical inequities that existed in South Africa, particularly in the context of higher education. However, analysis of various service-learning programmes in South Africa has often revealed that the needs of students are emphasized above the needs of the community

(Fourie, 2003).

Although there is scepticism about the application of an American pedagogy to South Africa, various mandates and accountability structures have been set up to promote the development of service-learning programmes in South Africa to continually adapt and strengthen service-learning to the unique South African context (Hatcher & Erasmus, 2008). Fourie (2003) identified six critical conditions that should be taken into account when developing sustainable service-learning programmes in the South African context: (1) There needs to be a strong focus on community needs and goals; (2) the community needs to be involved in the identification of needs, planning, implementation and the evaluation of programmes on a continual basis; (3) effective partnerships need to be formed and maintained by various stakeholders; (4) there needs to be acceptance and understanding of the complexities related to community development; (5) There needs to be a focus on involving and empowering disadvantaged groups; (6) Integrated and iterative processes of learning should be undertaken to see the community as a source of learning by utilising local epistemologies and cosmologies.

Aspects of the American pedagogy of service-learning have been altered to include these critical conditions experienced in its application to better encapsulate and understand service-learning from a South African perspective. The JET has reinforced aspects of the definition of service-learning stating, “service-learning is focused on the development priorities of communities through interaction between and application of knowledge, skills, and experience in partnership between community, academics, students and service providers within the community for the benefit of all participants” (Joint Education Trust, 2001, pg. 5). This definition signified a shift from the American pedagogy by emphasizing the importance of the developmental priorities of communities, steering away from the deficit approach, and the inclusion of service providers in a triadic partnership (Hatcher & Erasmus, 2008).

The service-learning programme at the centre of this research project was developed from a community outreach programme into a service-learning course that formed part of a post-graduate honours degree in Psychology. The evolution of the programme into a service-learning programme allowed for a more focused intervention with greater structure and supervision from professionals that are

involved in academia, the community and public healthcare services. This called on both cognitive and affective resources from students who were required to utilise what they are learning in class by applying it to community problems, all whilst reflecting on their experiences in order to achieve real objectives for the community, and a deeper understanding and skills for themselves (Eyler & Giles, 1999; as cited in Mouton & Wildschut, 2005).

Research on service-learning has often focused on the development and implementation of programmes with a largely quantitative literature around the effects and the processes involved (Deeley, 2010). There has been a focus on acquiring the communities' input when developing service-learning programmes, however there is a paucity of research on the experiences of caregivers and their children receiving interventions through service learning, particularly from a critical perspective (Carpenter, 2011; Geller, Zuckerman, & Seidel, 2014). This research aimed to evaluate the service-learning programme from a critical perspective in order to understand the effects and the experiences of the caregivers and children involved in the service-learning programme.

### **2.3. Role of the Caregiver in Interventions**

It has been echoed that an important focus in developing and implementing a service-learning programme is the need to identify the community's needs and goals, as well as involving the community in the intervention (Fourie, 2008). In establishing the service-learning programme, community gatekeepers and public health-care workers were consulted to gain a deeper understanding of the current service provisions and the experiences of service providers, students and those receiving the services in order to ascertain the community needs and goals. One of the requirements that arose during the conceptualisation of the service-learning programme was the importance of the role of the primary caregivers of children with disabilities in the intervention services.

It is well documented that parenting stress is an important factor to consider when providing services for children with disabilities. Parental stress is associated with low parenting satisfaction, higher symptomatology, abusive behaviour, and insecure attachment (Smith et al., 2001). Families of children with disabilities often

face additional stressors due to the problematic parent-child relationship, the added burden and the additional financial implications of caring for a child with disabilities. Having a child with disabilities often places an added demand on family resources and adversely affects perceptions of family functioning (Dyson, 1997; as cited in Smith et al., 2001). It is suggested that in treating children with disabilities, professionals should consider ways of managing family stress levels and involve caregivers in the intervention services to have the most effective outcome (Dunst, Leet, & Trivette, 1988; McDowell, et al.s, 1995).

Traditionally, intervention services focus on the child and unwittingly exclude the caregiver, resulting in a strained partnership and a lack of collaboration with service providers. Saloojee (2008) explains the difficulty experienced in collaboration in South Africa to often be a result of disparate socioeconomic status, education levels, language, and culture that largely stems from the unequal power dynamics instilled during the Apartheid era (Moja, 2014; as cited in Saloojee, 2008). This leads to therapists applying a more one on one therapeutic stance with the child and not involving the caregiver which results in the caregivers becoming disempowered passive recipients of therapy programmes whilst therapists often struggle to understand why therapy attendance is erratic and compliance with the home programme low (Saloojee, 2008). Thus, a main focus of the service-learning programme was to help establish an intervention that utilises students to provide support not only to children with disabilities but to their caregivers through their inclusion (Mouton & Wildschut, 2005).

Dunst (2007, p.161) defines early intervention as “the experience and opportunities afforded to infants and toddlers with disabilities by the children’s parents and other primary caregivers.” This definition explicitly involves the caregivers of children with disabilities as their primary source of learning and therefore suggests that early interventions should be directed at increasing parents’ capacity to engage their children and provide them with learning experiences. It has been found that early identification and intervention are optimally performed by the primary caregivers of disabled children, who play a vital role in promoting the child’s acquisition of behaviour competencies that shape and influence their pro social interactions towards their surroundings (Glascoe, & Dworkin, 1995; Shonkoff & Phillips, 2000, as cited in Dunst, 2007).

Rosenbaum (2011) states that engaging caregivers with respect and providing continuity of care and appropriate information are key elements in supplying services to children with disabilities. Research on service provision has shown that when services are more family-centred, caregivers report better satisfaction, mental health and less stress in dealing with service providers.

### **2.3.1 Attachment Theory**

This importance of involving caregivers in intervention services stems from literature on attachment that has found that a caregiver who is more sensitive and responsive towards their child is more attuned with the child's needs, which results in a secure attachment and a greater improvement in the child's development (Dunst, 2007). Attachment behaviours are triggered when a vulnerable child experiences distress, such as anxiety, fear, confusion, or abandonment, and signals for the caregiver. The caregiver who is responsive to these signals and acts on them and in turn provides a secure base and a place of safety for the child (Howe, 2006). Whether in the context of feeding, close bodily contact, or face-to-face contact, caregiver-child interaction has been found to provide the child with an opportunity to build a working model of expectations for how accessible and responsive she might be, which in turn develops the child's own responses in terms of to their perceived danger, security and anxiety (Ainsworth, 1979).

Research on parent-child attachment identifies three distinct patterns of attachment, namely secure, insecure and insecure ambivalent, each of which is associated with different developmental outcomes (Ainsworth, Blehar, Waters & Wall, 1978). The fundamental assumption in attachment research is that sensitive responses by the parent to the child's needs result in a child who demonstrates secure attachment, while a lack of sensitivities results in an insecure attachment (Lamb, Thompson, Gardner, Charnov & Estes, 1984). A child whose primary attachment style is classified as secure experiences their caregiver as being sensitively attuned to their needs resulting in satisfactory relationships and greater social competence (Howe, 2006). In contrast, a child who exhibits an insecure avoidant attachment experiences their caregiver as being anxious and rejecting of them and therefore they adapt by excluding feelings of attachment and avoiding comfort seeking behaviour due to the anxiety it evokes in them (Howe, 2006). Children who have an insecure ambivalent attachment style experience their caregiver as inconsistent with poor

recognition of their needs which provokes great anxiety making the child maximise their distress and attachment behaviour to increase their chances of being noticed resulting in an anxious preoccupation with others' emotional availability and a demanding approach to relationships (Howe, 2006).

The ability of caregivers to provide care that promotes secure attachment and good developmental outcomes in children can be severely compromised by adverse conditions, including, poverty, maternal mental health and stress (Howe, 2006; Cooper, Swartz, Stein, McPherson & Murray, 2009). This is of particular concern in developing countries, such as South Africa, where there are high rates of poverty, maternal stress and depression (Cooper, et al., 2009). This is further complicated when raising children with disabilities who may be in need of particularly sensitive caregiving that adds to the caregivers challenge of sensitively attuning and providing for the child (Howe, 2006). This may be in part due to atypical development and facial, postural and vocal dissimilarities that make it more difficult for parents to read their signals and needs, and respond appropriately. In resource poor environments, the additional burden of care required from caregivers of children with disabilities has been found to place them at an increased risk of maternal morbidity and poor attachment styles (Howe, 2006).

This understanding of the importance of early intervention and the significance of utilising caregivers in the intervention process has led to the argument against the tendency of health professions to take over the parent function in early interventions. Rather, interventions should aim at increasing the parent's capacity to provide their children with learning experiences by helping the parent develop an understanding of the social and emotional development, and behavioural and interactional consequences of their child's disabilities (Hewett & West, 1998, as cited in Dunst, 2007). We therefore have to think of various support structures and resources that could be used in interventions to assist families and caregivers at risk (Rosenbaum & Gorter, 2011).

Benedict, Wulff, & White (1992) found that offering social support to primary caregivers resulted in a reduction of their experienced stress and by including them in the intervention there was an increased improvement in the parent-child interaction, both of which led to better chances of forming a secure attachment with their child, resulting in better care of the child and better cognitive development (Maulik &

Darmstadt, 2009). Cooper et al. (2009) carried out a small case series study in Khayelitsha, an informal settlement in the Western Cape, whereby mothers from the community were trained to give support to mothers of young children. Results showed that the intervention significantly benefited the mother-child relationship at both six and 12 month follow up with the mothers in the intervention group being significantly more sensitive to their child's needs and less intrusive in their interactions than the mothers in the control group (Cooper et al., 2009).

### **2.3.2 Role of the Caregiver in the Service-Learning Programme**

In conceptualising the service-learning programme at the centre of this research, the understanding of community needs and the knowledge of the importance of involving the caregiver in the interaction were taken into account. Therefore, the service-learning programme aimed to provide an intervention that utilises students to help parents to develop an understanding of the social and emotional development and the behavioural and interactional consequences of their child's disability.

Early support programmes, such as the service-learning programme, could play a role in helping parents develop an understanding of the social and emotional developmental and behavioural and interactional consequences of their child's disability. Such an approach recognises that it is not disability per se that predicts increased risk of maltreatment or insecure attachment. Rather, it is the interaction between firstly, the state of mind of the caregiver and secondly the type of disability in terms of its capacity to activate heightened arousal in the caregiver that works against their ability to understand the mental state of oneself and others (Howe, 2006). Similarly, Benedict et al (1992) suggest that social support may reduce stress experienced by parents of children with disabilities reducing the risk of the development of an insecure attachment. Mobarak et al (2000) argue for the need of informal sources of support for mothers to mediate maternal stress.

A recent review of community based interventions to optimise early development in low resource settings (Maulik & Darmstadt, 2009), found that whatever the form of intervention (play, reading, music, massage) it improved the parent child interaction which led to better care for the child and to better cognitive development. This finding supports projects such as service-learning which does not involve the provision of high level therapy but rather low level interventions delivered

by student .

McConachie et al. (2000) describe a study that established evidence of effectiveness of an outreach program for young children with cerebral palsy in Bangladesh which involved brief training of mothers and the provision of pictorial manuals illustrating positions, activities and home-made aids for children with impairments. Measures used included the development of adaptive skills in children, self report measures of maternal adaptation, maternal stress and parental knowledge, all demonstrating an increase after the intervention. Significantly, the study compared the distance training model describe above with other more intensive interventions ( a daily mother-child group) and less intensive interventions (once off health advice group) and found “participation increased stress for a considerable proportion of mothers, particularly those coming to the urban clinic” (p. 775). The authors argue that this finding points to a possible emotional cost for mothers attempting to participate in distant services leading to a strong recommendation for community-based rehabilitation services including the use of home visits employed in the service-learning project.

Saxena et al., (2007) point to evidence suggesting that in order to support community based services, training, assistance and supervision by specialist mental health staff is required. The article points to a number of problems including human resources referring to the scarcity of mental health professionals due to training facilities and migratory depletion, as well as financial resources arguing that “innovative, concerted and sustained efforts are needed to remove these obstacles and achieve better mental health” (p. 886). Such sentiments provide support for employing service-learning projects such as service-learning in higher education contexts to develop effective interventions in the area of childhood disability.

#### **2.4 A Critical Appraisal of Disability Studies**

Although much research has been conducted around the topics of childhood disability, service-learning and attachment theory internationally, there have been few studies that are set within the context of developing and disadvantaged countries, such as South Africa. In general, the field of disability studies was constructed from

knowledge of the global North, without reference to the theorists, or the social experience, of the global South (Meekosha, 2010).

In non-urban settings within South Africa there is a scarcity of available resources, inequities in the distribution of resources, and inefficiencies of the use of resources to aid children with disabilities in a meaningful way resulting in severely limited access to knowledge and activities directed towards childhood disabilities, (Saxena et.al., 2007). Therapeutic and rehabilitation services for children with disabilities are usually only available on a monthly basis at public service hospital (Saloojee, 2008). This is due to the high client: staff ratio and the difficulties families have with finding and paying for transport to these facilities, which are few and far between (Saloojee, 2008). Studies have shown that only a third of children in need of long term rehabilitation in South Africa actually receive it (Couper, 2002; Saloojee et al., in press; as cited in Saloojee, 2008).

Contemporary debates in disability studies in the Northern Hemisphere have tended to ignore the lived experience of disabled people in much of the global South (Meekosha, 2010). Thus, an important consideration in designing and implementing early interventions for children with disabilities in low resource areas is to contemplate the cultural beliefs and practices on childcare and the beliefs around childhood disability in particular (Maulik & Darmstadt, 2009). Ghai (2002) reviews the Western universalising discourse of disability by arguing that it ignores the challenging realities of disabled people's lives in countries fraught with social and economic marginalisation. McRuer's (2007) deconstruction of the World Bank's disability inclusive development agenda demonstrates how debates around disability tend to focus on independent living, care and human rights, which can often be considered irrelevant to those whose foremost objective is survival.

Therefore, the proposed research aims to investigate the beliefs and practices by giving voice to the global South in focusing on caregivers' experiences and thereby contributing to an understanding of the cultural appropriateness of service-learning within the South African context.

## **2.5 Summary of the Literature**

The literature reviewed above provides a strong rationale for the current

service-learning programme, as well as the importance of conducting critical disability studies within the South African context of the global South. Evidence is provided to show that Africa has a disproportionately higher rate of disability being seen in children from disadvantaged context. There continue to exist considerable inequities in access to healthcare as a result of unequal social-power relationships that result in discrepancies in resource allocation and barriers to access.

In order to address these inequities, community-based outreach services have been proposed as an effective extension to hospital-based services in order to provide a complimentary, accessible and inclusive approach to meeting the needs of children with disabilities at the community level. It is proposed that higher education has a responsibility to develop scholarship that is connected and integrated with community outreach. Therefore, service-learning is suggested as a way of creating a partnership between community, academics, students and service providers within the community for the benefit of all participants. It also aims to prepare students to be active citizens that are better equipped to bridge expanding cross-cultural and economic differences. Instead of focussing on a deficit model, service-learning aims to assist in highlighting the strengths within the community.

Therefore, the service-learning programme at the core of this research is based on the important premise of attachment theory that advocates for the involvement of the caregiver within the intervention services. The aim of this is to empower the caregiver as an active and imperative resource in her child's development.

However, an important consideration in designing and implementing early intervention services and service-learning programmes for children with disabilities in low resource areas in the global South is to contemplate that the premises upon which service-learning and attachment theory are based are Westernised ideologies from the global North. These ideologies often perpetuate unequal social-power relations and continue to reproduce unhelpful stereotypes. Therefore, the cultural beliefs and practices on childcare and the beliefs and experiences of childhood disabilities are important to deliberate in providing a voice for critical disability studies within the global South, This voice should aim to represent and think about disability within African contexts in order to reflect on the complexities of representation and end the perpetuation of unhelpful stereotypes.

## CHAPTER 3

### Research Methodology

This chapter describes the methodology used in the study. It begins with an outline of the aims of the study and a breakdown of the research questions. This is followed by a description of the chosen research design and data collection tools. Thereafter, the sampling methods, research time line, mixed methods data collection procedures, and the procedures of data analysis are outlined in detail. Thereafter, the validity and reliability of the study are discussed. The chapter concludes with an exploration of the ethical considerations taken into account during this study.

#### 3.1 Research Aims

This research formed part of a larger research project, which aimed to evaluate the service-learning programme from various perspectives. The belief is that without looking at the outcomes of a service-learning programme alongside the views, experiences, and perceptions of those involved in the programme, it is difficult to know whether the intervention services offered are effective, relevant and appropriate (Saloojee, 2011). It is imperative to establish an understanding of the effectiveness of the programme and the processes that make up the programme as this will have key implications for developing services through research. Furthermore, it will assist in developing further community-based interventions that are relevant and empowering within the local communities and better able to further their needs (Mkhize, 2004). Thus, this research aimed to evaluate the programme's impact on the caregivers and their children with disabilities, and the processes involved in their engagement with the programme. Specifically, the research aimed to look at the impact of the service-learning programme on; the caregivers' well-being, the child's functioning, the parent-child relationship, and the caregivers' experience of care received from both the clinic and the service-learning programme. The research also aimed to assess what sense could be made of the impact of the programme in light of the caregivers' subjective experiences of the programme.

The information garnered from this study provides feedback to the course-coordinator of the service-learning programme to inform future applications thereof, as well as to explore possibilities for further research. The data also provides feedback to the clinic workers, including Occupational Therapists and Physiotherapists, as well as volunteers from the NPO in order to assist them in understanding how their services are perceived and may be better improved.

### **3.1.1 Research Questions**

1. What is the impact of the service-learning programme on the caregivers and their children who participate in the programme?
  - a) What is the impact of the intervention on the caregiver's well-being?
  - b) What is the impact of the programme on the child's functioning?
  - c) What is the impact of the programme on the parent-child relationship?
  - d) What is the impact of the programme on the caregiver's experience of care received from service providers?
  - e) Are there trends and patterns of change that can be identified?
2. What sense can be made of the impact of the programme in light of the caregivers' subjective experiences of the programme?

## **3.2 Research Design**

### **3.2.1 Case Series Design**

Due to the small population of only eight caregiver-child dyads taking part in the service-learning programme, a descriptive case-series design was used to assess the impact of the service-learning programme on a small sub-population of the participants receiving the same intervention. A case-series design can be defined as "a group of patients with similar diagnoses or undergoing the same procedure followed over time" (Carey & Boden; 2003, p.1631). Thus, a case-series can be seen as a longitudinal study that involves the researcher observing a particular set of variables in a group of participants at two or more intervals over a period of time (UK Essays, 2013). Although this alternative form of research is often overlooked due to its lack of a randomized control group, it is still believed to yield respectable inferences about efficacy, effectiveness, and mechanisms of change when applied properly (Barlow & Hansen, 1984; Kazdin, 1982; as cited in Borckardt & Nash, 2002). The case-series

can provide an initial indication of interventions efficacy or the description of any novel problems and complications. However it cannot be used to draw inferences regarding the effect of the intervention (Carey & Boden, 2003).

Using the case series design, an individual in-depth evaluation of three caregiver-child dyads participating in the service-learning programme was conducted over a period of twenty-one weeks. In order to create a comprehensive and rich understanding of each case, a mixed methods approach to data collection was used to make use of both subjective and objective, quantitative and qualitative data (Hanson, Creswell, Plano-Clark, Petska, & Creswell, 2005). Quantitative and qualitative methodologies are both believed to be useful and have their own individual strengths and weaknesses. The goal of using mixed methods research is to draw on the strengths, whilst minimising the weaknesses of single method studies (Johnson & Onwuegbuzie, 2004). A mixed method design integrates the use of more than one method of design, data collection and data analysis within a single study in an attempt to provide a workable solution for more complex problems of interest. This approach is believed to illicit a broader purpose of breadth, depth of understanding and corroboration that provides a greater confidence in the conclusions generated (Johnson, Onwuegbuzie & Turner, 2007).

Repeated observations, testing and interviews took place in order to obtain the topography of change during the course of the study- before and after the addition of the service-learning programme (Borckardt & Nash, 2002). Case-series designs are particularly concerned with the baseline phase prior to intervention because it describes the extent of the clinical problem without the intervention (Borckardt & Nash; 2002). Therefore, data was collected at two periods prior to the start of the service-learning programme to establish a baseline understanding of the clinical problem prior to the addition of the service-learning programme and again at the end of the service-learning programme.

This method allows for an intensive analysis of the individuals over time and conditions, and recognizes the uniqueness of delivering healthcare services within the disadvantaged South African setting (Borckardt, & Nash; 2002).

### 3.2.2 Data Collection Tools

The following mixed quantitative and qualitative methods of observation, testing and interviewing were used to collect data relating to the various outcome measures portrayed in the research questions.

#### 3.2.2.1 Quantitative Procedures.

**Demographic Questionnaire.** A demographic questionnaire (Appendix 3, Figure B) was administered to all participants at the start of the research to ascertain the caregiver and child's socio-demographic characteristics. This in-depth questionnaire (adapted from Saloojee, 2008) gave some insight into other contributing factors that could be impact on the outcomes of the intervention. The demographic questionnaire was translated into isiXhosa by a translator and administered to the caregiver by an isiXhosa speaking research assistant at the first baseline phase.

**Caregiver well-being.** The South African Clinical Outcomes in Routine Evaluation-Outcome Measures (CORE-OM) (Appendix 3, Figure C) is a measure of distress and dysfunction (Campbell & Young, 2013). The CORE-OM is a client self-report questionnaire that is administered before or after a therapeutic intervention and takes only 5-10 minutes to do. The CORE-OM has 34 questions that clients are asked to respond to about their feelings over the past week, using a 5-point scale ranging from 'not at all' to 'most or all of the time' (CORE IMS, 2015). The 34 items cover four dimensions; subjective well-being, problems and symptoms, life functioning, and risk or harm (CORE IMS, 2015). The CORE-OM has been translated into over twenty languages including an isiXhosa version that has been piloted on a sample from an Eastern Cape, historically` disadvantaged university where participants were all first language isiXhosa speakers (Campbell & Young, 2013). The translation process of the CORE-OM has been reviewed by an array of student members of the target population, psychologists, and other isiXhosa speaking professionals in order to investigate general readability and ease of use of the tool, as well as administrative instructions, response formats and item content (Campbell & Young, 2013). It has been shown to have good reliability and validity when used amongst first language isiXhosa speakers in the Eastern Cape.

**Child functioning and level of impairment.** The Paediatric Evaluation of

Disabilities Inventory- Computer Adaptive Test (PEDI-CAT) is a standardised paediatric functional assessment instrument that is used to assess key functional capabilities and performance in disabled children between birth and 20 years old (National Disability Authority, 2012; Naar-King, Ellis, & Frey, 2004). It was initially designed for children with Cerebral Palsy but can be used on children with varying physical and combined physical and cognitive disabilities (Naar-King, Ellis, & Frey, 2004). The PEDI-CAT measures both functional performance and capability in four domains: self-care, mobility, social function, and responsibility. Examples of the questions that are in each domain can be seen in Appendix 3, Figure D.

***The process of care.*** The Measure of Process of Care (MPOC-8 SA) (Appendix 3, Figure E) is an eight item self-report scale that has been adapted from the Measure of Process of Care (MPOC-20) by Gillian Saloojee (Saloojee, 2008). The MPOC assesses the caregivers' experiences of family-centred intervention service providers and describes caregivers' perceptions of the care they and their children receive from the therapy service (King et al., 2004a as cited in Saloojee, 2008). Although the MPOC-20, as developed in Canada, does not have reliability and validity within disadvantaged settings in South Africa, Saloojee (2008) suggests that an eight item version of the MPOC, with just two factors instead of five, does appear to have possibilities for use in a South African population. The MPOC-8 SA focuses on the factors of respectful and supportive care, and providing information and advice to caregivers.

***Caregiver-child relationship and interaction.*** The Marschak Interaction Method (MIM) is a play-based technique used to observe the interaction between adults and children while they perform a series of structured tasks together (Booth, Christensen & Lindaman, 2011). This structured observational technique is used to assess the quality of the caregiver-child interaction. It has been recognized that optimal childhood development is associated with responsive parental communication styles and therefore it is important to address the interactive behaviour between children and adults, particularly in children with disabilities where caregivers may have more difficulty attuning to their children's unique communication styles (Olsson, 2004). The dyadic interaction is evaluated on the following four domains: structure, engage, nurture, and challenge.

The caregiver's interaction is evaluated for how well they can: (1) Structure the environment, provide safety, set clear and appropriate limits, and co-regulate the child's experience. (2) Engage the child in interaction that leads to optimal arousal, and joyful connection. (3) Respond in an empathic, nurturing manner that calms and soothes the child when needed and conveys a sense of self-worth. (4) Create appropriate challenges that give a sense of pleasure and mastery. (Booth, Christensen & Lindaman, 2011)

The child's interaction is evaluated on how well they can: (1) Accept structure from the adult rather than taking charge themselves. (2) Engage with the adult, rather than being avoidant or overtly independent. (3) Accept nurturing and care from the adult, opposed to looking to oneself for comfort. (4) Respond to and be open to take on appropriate challenges rather than being helpless or clingy, or being too competitive and placing high demands on oneself. (Booth, Christensen & Lindaman, 2011)

The caregivers and their children were placed in a room with a play area. The researcher and research assistant observed them through a one-way mirror and video recorded the interaction. A list of seven set tasks (Appendix 3, Figure F) was developed by the researchers and adapted from the MIM to take their disabilities into account. This list of tasks was read out to the caregiver-child dyad in the room over the intercom system by the isiXhosa speaking research assistant. The caregiver was given enough time to complete the task at their own pace before having the next task read out to her.

#### **3.2.2.2 Qualitative Procedure.**

*Interpretative Phenomenological Analysis.* A qualitative Interpretative Phenomenological Analysis (IPA) was used to gain personal insights into the caregiver's experiences' of the service-learning programme. The aim of IPA is to explore in detail the processes through which participants make sense of their own experiences by looking at the respondent's account of the processes they have been through and seeking to utilise an assumed existing universal inclination towards self-reflection (Brocki & Wearden, 2006). The use of the qualitative IPA aims to expand on the quantitative data, and further enrich the understanding of the caregivers' well-

being, the functioning of the child, the process of care, and the caregiver-child relationship from the caregiver's own perspective.

Two one-hour semi-structured interviews were conducted face to face by the isiXhosa speaking research assistant, one prior to the intervention and then again after the intervention. These interviews were voice recorded. The interview schedule (Appendix 3, Figure G) asked questions that were open-ended and non-directive in order to give the participants the ability to tell their own story in their own words, a central premise of IPA (Smith, Flowers & Osborn, 1997). In addition, any developing understanding could be immediately exposed to new observations and be extended, elaborated, qualified, or revised as necessary (Macran, Stiles, & Smith, 1999).

### **3.3 Data Collection Procedure**

#### **3.3.1 Researchers**

In order collect the data in the most accurate and informed manner, a research team was developed to recruit participants, conduct interviews and administer tests in the participants' first language of isiXhosa, as well as interpret and translate for the non-isiXhosa speaking researchers. The rationale behind using a collaborative research team was made in order to take into consideration how unshared language, communication and verbal understanding, as well as social characteristics, such as race, social class, age, and gender, impinge on the research process and play a part in the dynamics of the interviewing process itself (Edwards, 1998). Making use of an interpreter is believed to be fraught with difficulties as it adopts a tradition, un-reflexive stance that ignores the disparities of power within the context of the research setting. In acknowledgment of the language barriers and social imbalances, the researcher chose to conduct the majority of the research with an isiXhosa research assistant as opposed to through the research assistant. This allowed for the research assistant's role and interaction with the caregiver's to be highlighted and made explicit (Edwards, 1998).

The research team was made up of the researcher, Nicole Cooke, who organized, set up and oversaw the entire research process. She was assisted by Sinazo Williams, an isiXhosa speaking research assistant who oversaw the explaining and signing of confidentiality and consent forms, the administration of quantitative tests,

the conducting the IPA interviews, as well as acting as a translator between the participants and the researchers, particularly during the administration of the PEDI-CAT.

Two Occupational Therapists from the Settler's Day Hospital, Jolene Tarr, and Robyn Cooper, acted as external researchers in assisting the researcher to administer the PEDI-CAT with the assistance of Sinazo as the translator. Their in depth knowledge of childhood disability and functioning assisted the researchers in acquiring more accurate results.

Assistance was also sought from Zuki Gubevu, a volunteer auxiliary social worker from the NPO, to help with the recruitment of participants to the service-learning programme and the research. The assistant is a local resident with a good rapport amongst the caregivers as she herself has a disabled child. She acted as a gatekeeper into the community and assisted us in gaining access to each participant.

### **3.3.2 Participants**

As outlined in Chapter 1, the participant dyads for the service-learning programme were purposively selected through the clinic's database in order to obtain eleven caregiver-child dyads that pertained to the specific inclusion criteria set out by the course coordinator. The inclusion criteria were set out in order to find a more closely defined group for whom the intervention was significant (Chapman & Smith, 2002). These inclusion criteria also defined the population for the research. The specific inclusion criteria were: (1) Children had to be between the ages of 6 months and 5 years old due to this being an early childhood intervention. (2) The child had to be diagnosed with Cerebral Palsy with an indication of their Gross Motor Functioning Classification System (Palisano, Rosenbaum, Bartlett & Livingston, 2007). (3) Lastly, the child had to have never before participated in any earlier form of the service-learning programme in previous years.

#### **3.3.2.1 Sampling**

Caregiver-child dyads were purposively invited to participate in the research study from the small group of eight caregiver-child dyads partaking in the service-learning programme. Purposive sampling techniques involve selecting certain cases based on a specific purpose rather than randomly (Tashakkori & Teddlie, 2003). Specifically, purposive sampling of unique cases was employed for this research

study, as the specific group of cases was a major focus of the research investigation as opposed to a more general problem (Teddle & Yu, 2007).

Upon recruitment to the service-learning programme by the NPO's Social Worker, the caregivers were presented with an information leaflet (Appendix 2, Figure B) and timeline of important dates (Appendix 2, Figure C) that outlined the research and the extent of their participation in detail and invited them to participate. This letter was also verbally explained to each of the service-learning programmes' participants in person by a local isiXhosa translator and auxiliary social worker from the NPO. It was also explicitly outlined that all participation in the service-learning programme and research is voluntary and participants who do not wish to participate in the research will still continue to receive equal services from the clinic, the NPO and the service-learning programme.

Upon the caregivers expressing interest to join the research, the researcher and research assistant visited each caregiver at their house where they personally met the caregiver and child and further explained the research process, answering any questions or concerns the caregivers had.

Four caregiver-child dyads agreed to participate in the research; however, one caregiver child dyad was unable to continue participating in the service-learning programme and dropped out during the second data collection period. Therefore, the sample was made up of three caregiver-child dyads. The caregivers consisted of two mothers and a grandmother who were all full-time primary caregivers to their children with disabilities. The children were all boys and ranged in age from 8 months to 4 years and 10 months at the start of the programme. They had all been diagnosed with Cerebral Palsy, one child had a GMFCS Levels of 2 and the other two children had a GMFCS level of 5. The participants came from varied extensions of the extensive Grahamstown township area and none of them had previously participated in the service-learning programme. The demographic details and case history of each caregiver-child dyad will be further discussed in detail in their relative chapters.

### **3.3.2.2 Pilot Study**

The researcher and research assistants employed a pilot study on one caregiver and her twin children with cerebral palsy prior to commencing with the main research study. The caregiver was recruited through the clinic. She was not eligible to

participate in the service-learning programme as she had already participated in the service-learning programme in a previous year. However, she met the other inclusion criteria as set out by the course co-ordinator.

The pilot study was carried out in order to pre-test the various measures, ensuring that they made sense and were correctly translated, as well as providing the researchers with some experience in administering the various measures (Bryman, 2012). Below, are some of the issues the researchers came across and changed after conducting the pilot test.

Firstly, the researcher realized that conducting the research inside the caregivers' homes would be a problem due to the limited space and the lack of confidentiality. Thus, transport was organized and a research room was set up to do the data collection in a confidential, private space at the Rhodes University Psychology Department.

During the course of the research study it was also noted that to administer all of the tests, observations and interviews at one sitting was quite time consuming and exhausting for the caregivers and their children, as well as the researchers. Due to this it was decided that the research should be split into two days and researchers should be aware to schedule the interviews at times that fit into the dyads daily patterns so as not to interfere with sleep or feeding times.

The pilot participant also seemed to become confused by the different scales used for the various tests, such as the MPOC-8 (SA), CORE-OM and PEDI-CAT. In order to make these scales clearer for the caregiver, the researcher created a visual representations for each of the scales (Appendix 3, Figure H). These representations could then be used to help the caregiver transition from using one scale to the other with greater ease and understanding.

Thus, the pilot study was integral in assisting the researchers in establish a research protocol, identify what resources were needed and the possible time constraints involved in carrying out the research.

### **3.3.4 Location**

The data was initially set to be captured in the participants' houses, however, due to space constraints and the lack of privacy and confidentiality within these households, the researchers made the decision to localize the data collection in a

private location. Thus, all of the data was collected at the University Psychology Department where a double room with one-way glass mirror was set up for the researchers to administer the tests and conduct the interviews. The one-way mirror allowed for the principal researcher to observe the data collection process whilst offering the research assistant and the participant the space to connect and talk openly without feeling overwhelmed by the presence of an additional researcher.

The room was made to be as comfortable and welcoming to the participants as possible. Attached in Appendix 3, Figure I is a view of the room as it was set up for the data collection of the PEDI-CAT. Therapy mats and beanbags were used to make the floor activities more comfortable for the participants and an array of interactive toys were placed on a low table nearby to keep the children occupied and entertained. The participants were also provided with water, juice and biscuits to ensure they weren't thirsty or hungry.

The participants were transported by car to and from the data collection location by the researchers who collected them from their houses and returned them once they were done.

### **3.3.5 Research Timeline and Collection Procedures**

The longitudinal case series design chosen for this study was implemented over a period of twenty-one weeks with repeated observations and testing of each participant at intervals in order to obtain the topography of change during the course of the study- before and after the addition of the service-learning programme (Borckardt & Nash, 2002). The table attached in Appendix 3, Figure A outlines the three data collection phases and details the various tests carried out at each data collection period.

Two data collection periods took place prior to the commencement of the service-learning programme in order to create a baseline phase prior to the intervention. The baseline phase describes the extent of the clinical problem without the intervention and allows the researchers to estimate the extent of the problem, whether the problem is getting better or worse without intervention, the stability of the problem, and the existence of simple patterns in the data (Borckardt & Nash, 2002). This in depth standard descriptive information of the participants at the baseline phase allowed for a well-described study population that was clearly defined

and could be further evaluated (Carey & Boden, 2003). A final data collection took place after the service-learning programme had ended.

Each data collection was conducted over a two-day period with each caregiver-child dyad so as not to cause fatigue in the participants and interrupt their day-to-day duties. In this way, the researcher only needed to access the participants for a maximum of two to three hours a day, including travel time. The participants could also opt to have a day off between data collections if they were too busy or tired to attend.

Typically, the first day of data collection centred around the caregiver, focusing on signing consent forms, conducting the IPA interview, and filling in the CORE-OM and MPOC-8 SA tests. The child did not have to attend these sessions with the caregiver but if they did, the principal researcher was able to help care for them during the interview process. The second day of data collection centred around the caregiver and the child with the MIM Video analysis and PEDI-CAT taking place. The specific data collection procedures for each data collection period are outlined below in more detail.

**Data Collection 1 (Baseline).** On the first day of the first data collection period the participants were required to sign various consent forms, including: (1) a confidentiality agreement between the caregiver and researchers (Appendix 4, Figure F), (2) a parental/guardian consent form for a minor to take part in the research (Appendix 4, Figure G), and (3) an audio and video recording permission and release form for the audio recorded interviews and MIM videos (Appendix 4, Figure H). The isiXhosa speaking research assistant took her time to thoroughly read through and explain all of the points on these documents to the participants so that they understood what the research required of them, that the research was confidential, and that the process was completely voluntary, meaning they could drop out whenever they wanted to without their services being affected. Thereafter, the research assistant conducted a Demographic Questionnaire with the participant to ascertain information about their socio-demographic features. This was also a great introduction for the research assistant to start getting to know the participant. Finally, the research assistant administered the MPOC-8 SA and the CORE-OM.

On the second day of the first data collection period, the caregiver-child dyads were video-recorded doing the MIM activities set out for them. Thereafter, the external researchers, with the help of the caregiver and research assistants' translations, conducted the PEDI-CAT to assess the child's functioning.

**Data Collection 2 (Baseline).** The first day of the second data collection period differed slightly from that of the first data collection period. The research assistant went over the confidentiality agreements signed by the caregiver to verbally reiterate the confidential nature of the research and assure the participants of their rights, however, these forms did not need to be signed again. The researcher then asked the participant if there had been any changes in terms of the demographic information collected during the first data collection period. Thereafter, the data collection began with the IPA Interview which was voice recorded. Finally, the MPOC-8 SA and the CORE-OM were administered.

The second day of the second data collection period was similar to that of the first data collection period with the MIM being videoed and the external researchers administering the PEDI-CAT.

**Data Collection 3 (Post Intervention).** The final data collection process followed the same format as that of the second data collection. However, caregivers were now asked to evaluate both the clinic and service-learning programme when responding to questions. This was particularly apparent in the IPA interview schedule which was slightly different to that used in the pre intervention as it now took into account. A comparison of both interview schedules can be seen in Appendix 3, Figure G.

### 3.3.6 Compensation

The caregiver-child dyads were compensated for their participation in the research to thank them for their time and effort. The compensation came in the form of a Shoprite Checkers Gift Card to the value of R100.00 that was given to the participants at each data collection period (R300.00 vouchers in total). Shoprite Checkers is a local convenience store that is popular amongst residents of Grahamstown. The choice was made to award them with gift cards as this gave the caregivers autonomy to obtain something they really needed or wanted, rather than the researcher assuming what that might be.

### 3.4 Data Analysis

#### 3.4.1 Quantitative Data Analysis

**3.4.1.1 CORE-OM.** An overall score of between 0 and 136 will be gained from the CORE-OM by adding the response values of all 34 items, resulting in a measure of current psychological global distress ranging from healthy to severe (Mellor-Clark et al., 1999; as cited in Campbell & Young, 2014). A total mean item score can then be obtained by dividing the total score by the number of complete responses and a clinical score can be obtained by multiplying the mean item score by 10, resulting in a score between the range of 0 and 40 (Evans et al., 2002; CORE Information Management System, 2007; as cited in Campbell & Young, 2014).

It is believed that individuals who produce a clinic score of 10 or above are experiencing significant psychological distress and require intervention (Campbell & young, 2014). Clinical scores below 10 fall into the non-clinical population, experiencing low levels of psychological distress occasionally but tending to function in a healthy range overall (Campbell & Young, 2014). Barkham, Mellor-Clark, Connell & Cahill (2006) provide a scale of levels of severity related to clinical scores whereby a clinical score of 10-14 indicates mild psychological distress, 15-19 indicates moderate distress, 20- 24 indicates moderate to severe distress, and a score of 25 or above indicates severe distress.

**3.4.1.2 PEDI-CAT.** The scaled scores provided for each domain in the PEDI-CAT were used to track the child's functional progress during the baseline phase of the study and after the service-learning programme. Scaled scores represent the child's current status along a continuum of function represented by the items in the domain being assessed (Haley, Coster, Dumas, Fragala-Pinkham & Moed, 2012). An increase in score means that the child's skill or responsibility in that domain has improved as differences in scaled scores represent the absolute amount of change that has occurred from one assessment occasion to another (Haley et al., 2012).

The PEDI-CAT also produces a fit score that was used to provide information about whether the responses to the questions were expected. The fit score is a standardizing log-likelihood polytomous item to test the persons fit for each scaled score (Haley et al., 2012). If the pattern of the score is highly unexpected and miss-

fitting the fit score will become large ( $> +2.00$ ) and should be interpreted with caution (Haley et al., 2012). A further inspection of miss fitting items may indicate unique challenges or supports that affect the child's performance (Haley et al., 2012).

**3.4.1.3 MPOC-8 SA.** The MPOC-8 SA consists of a 7 point Likert scale with an assignment of 7 for satisfaction to 'a very great extent' and 0 'not applicable'. Therefore, the greatest satisfaction with the intervention is a score of 56 and the least satisfied is a score of 0, with varying scores of satisfaction between these. Basic descriptive statistics is used to analyse the change in the Likert scale scores from the pre-test of the caregiver's satisfaction with the Developmental Clinic and the post-test after the addition of the service-learning programme to the Developmental Clinic. This score will be expressed as a percentage of satisfaction with the services. A higher percentage indicates high satisfaction with the services whereas a smaller percentage indicates low satisfaction with the services.

**3.4.1.4 MIM Video Analysis.** The videos were analysed by the researcher as per the Marschak Interaction Method Pre School/School Age, Prenatal, Infant and Adolescent Manual (Booth et al., 2011). Each video was viewed in its entirety and then each task was observed individually. The researcher used an observation recording form (Booth et al., 2011) and a shorthand key of observations (Appendix 3, Figure J) to annotate the interactions observed. Thereafter, a clinical MIM report was written up by the researcher outlining the interaction observed during each task. After analysing each task individually, the researcher observed the overall interaction in terms of the four domains of structure, engagement, nurture and challenge. Finally, the researcher gave an overall summary of the interactions observed.

Once the MIM clinical report was completed, the researcher filled out an Assessment of Emotional Interaction Style (Salo & Makela, 2006). The scale is divided into five different dimensions relating to those of the MIM: (1) Structure and challenge, (2) Emotional reciprocity and initiative, (3) Nurture, (4) Playfulness, and (5) Internal representation (Elinder, Johansson Larsson, Lindberg, Stenling, Williamsson & Wohlert, 2008). The caregiver and child are assessed on the first four dimensions and only the child is assessed on the last. These dimensions are rated on a scale of 1-5 with half points being allowed. Points in the lower part of the scale represent a poor interaction style whilst points of 4 and 5 indicate a good interaction between caregiver and child (Elinder et al., 2008). These scores were used to describe

the quality of the interaction and examined for changes between pre and post-test results. This approach involves visiting and revisiting the data, constructing and reconstructing of the relationship, and finally the identification of patterns, themes and trends in affect attunement (Olsson, 2004).

### **3.4.2 Qualitative Data Analysis**

**2.4.2.1 IPA.** IPA consists of a systemic qualitative, script-by-script, inductive analysis of the transcripts that aims to detail the perceptions and understandings of each individual case (Smith & Osborn, 2007). Once an in-depth understanding of each individual transcript is gained, IPA would normally aim to seek a broader, generalised across-case understanding of the group as a whole (Smith & Osborn, 2007). However, due to the small sample the case-series design did not allow for this. Instead, a within-case analysis was performed to gain a broader understanding of the change across the two series of each individual's interview scripts.

The audiotaped isiXhosa interviews were fully transcribed, including the researchers questions, indications of pause, mishearing's, repeated words, hesitation words, and speech dynamics in order to make the analysis as accurate as possible (Smith & Osborn, 2007; Biggerstaff & Thomson, 2008). The transcripts were then translated from isiXhosa into English by a translator and reviewed by the research assistant in order to compare translations for quality and accuracy.

The researcher read the English transcripts several times before annotating each individual case with free associations and possible themes (Smith & Osborn, 2007). After each case had been individually analysed for emergent themes and sub-themes, the identification of emergent patterns between the first series and second series interviews took place. This further analysis attempted to find convergence or divergence between the series to inform the experiences of the caregivers over the eleven-week period prior to engaging in the service-learning programme and again after the programme had ended.

In this way an in-depth and rich understanding was be gained from each of the participants through individual detailed examinations of each case that were pursued until a degree of closure was obtained (Smith, 2004).

### **3.4.3 Overall Analysis.**

Each case will be presented individually in separate chapters utilising the data captured for each individual and combining the quantitative and qualitative in an in-depth mixed methods approach. A conclusion chapter then draws on each individual case in terms of the other cases and overall findings.

## **3.5 Ethical Considerations**

Prior to engaging in this research project, the community partners involved in the service-learning programme were presented with the research proposals and offered the opportunity to give their input. The community partners expressed great willingness to support and assist with the research. Jolene Tarr, an Occupational Therapist at the Settler's Day Hospital, put herself forward as an external investigator on the project to assist with data collection methods (Appendix 4, Figure E).

With the support of the community partners, an application was made to the supervising university's relevant ethics committees, including the Research Proposal and Ethics Review Committee (RPERC) and Rhodes University Ethical Standards Committee (RUESC). The proposal was granted ethical approval by RPERC (Appendix 4, Figure A) and RUESC (Appendix 4, Figure B) ensuring that the ethical standards protocol set out by the researcher was in accordance with the national policy and guidelines to ensure that the research activities involving humans were performed reasonably and met the highest ethical standards. Further ethical approval was sought from the Department of Health via an online application, as well as letters to the Head of the Settlers Day Hospital (Appendix 4, Figure C). Ethical approval from the Department of Health was granted (Appendix 4, Figure D).

This study was conducted on what is considered to be a vulnerable human population of caregivers and their young children with disabilities (this is due to the children being unable to give their informed consent to participate in the research). The researchers identified that there were risks involved in dyads participating in the research, particularly around the emotional impact of them being involved in the research, the attention drawn to the family from the community, and the possible consequences on the services they received. The utmost care was put into the ethical considerations to reduce the risks and do as little harm as possible.

The ethical concerns highlighted related to the principles of informed consent and confidentiality. Upon recruitment to the service-learning programme, caregivers were offered an information leaflet (Appendix 2, Figure B) that outlined the research in full, without any deception. The time was also taken by the recruiter, the researcher and research assistant to visit each participant dyad on separate occasions to discuss any questions they had around their possible participation. Caregivers who chose not to participate in the research were not excluded or disadvantaged, and continued to receive equal services from the clinic, the NPO and the service-learning programme.

Upon recruitment to the research, the caregivers had to sign various consent forms including: (1) an informed consent, (2) a parental/guardian consent form, and (3) a video and audio recording consent and release form. The consent forms addressed multiple areas of possible concern, including: the studies purpose, the procedures, the risks and benefits, confidentiality, consent for minor children to partake in the research, agreement to be audio and video recorded, and the voluntary nature of the research.

One of the risks identified in partaking in the research was that caregivers might become distressed during the research process due to the emotional nature of the topics discussed during interviews. Provisions were made by the researchers to allow the participants to access free psychological counselling at the University Psychology Clinic should they have felt they needed additional support during the research process.

Furthermore, all of the community partners involved in the research process were also required to sign confidentiality agreements with the researchers to protect the identities and confidentiality of the participants. The translator hired to translate and transcribe the interviews was also required to sign a confidentiality agreement. The data shared with her was also required to be kept in a password protected folder that only she was allowed to access and it had to be deleted immediately once she was finished with the translation work.

The researchers endeavoured to be as understanding, sensitive and supportive as possible to the participants during the research process. The confidentiality agreements and procedures were reiterated at every data collection point to ensure the participants knew their rights and understood the voluntary nature of the research. If

any participant became excessively upset, the research was stopped and they were given time to re-gather and decide if they would like to continue with the research.

Although full anonymity could not be assured due to the researchers and research assistants knowing the participants; great care was taken throughout the research process to protect participants' personal identifying details and uphold their anonymity as best as possible. In line with this, the following result chapters make use of pseudonyms assigned to the participants by the researcher and any identifying factors in the direct quotes are excluded in order to reduce the chance of the participant being identified.

## CHAPTER 4:

### Research Findings: Andiswa and Bongani

What follows is an account of the first case study; this chapter reports on findings from research carried out with one particular caregiver-child dyad that partook in the service-learning programme, Andiswa and Bongani. The chapter includes an introduction to the participants that informs the reader of their demographic details, the presenting problems and reasons for being included in the service-learning programme. This will be followed by the presentation of the data collected during the study. The data will be presented in relation to the specific research questions outlined in chapter 3. Both the quantitative and qualitative data pertaining to each question will be outlined. The chapter ends with a summary of the questions and overall findings in relation to this specific case.

#### 4.1 Case Description

The case description and demographic information pertaining to Andiswa and Bongani was obtained through the collection of data from various sources, including: the Demographic Questionnaire (Appendix 5, Section 1, Figure A), hospital records from the Clinic, and Andiswa's interpersonal accounts from IPA interviews. This information is detailed below.

##### 4.1.1 Demographic Information

Bongani, a black male, was born into an isiXhosa speaking family in the Eastern Cape in June 2011. He was 4 years and 10 months at the start of the research. Bongani's disability only became apparent at the age of two years when he was diagnosed with epilepsy and GMFCS Level II cerebral palsy.

Andiswa is a 58 year old, isiXhosa-speaking, black woman. She is Bongani's grandmother and according to her accounts, she has been involved in caring for him from a young age as an auxiliary caregiver to aid his mother who neglected her children. Andiswa became Bongani's primary caregiver in 2015 when his mother tragically passed away.

Andiswa and Bongani live in an impoverished township area of an Eastern Cape town. Their house is a small informal structure made predominantly from corrugated iron and bricks. They have access to electricity and their main water source is from a tap in their garden. Two additional adults, Andiswa's daughters, and four children, including Bongani's younger sibling, also occupy the house with them.

Throughout the research process, Andiswa remained unemployed yet seeking work. She currently relies on income from a child support grant, a personal disability grant, Bongani's disability grant and maintenance from Bongani's father, which equates to a total income in the bracket of R 3 000.00- R5 000.00 per month. This revenue is the main source of income for the entire household.

#### **4.1.2 Background Information**

It was reported that Bongani had a normal birthing process and was developing typically with only slight delays, however, these weren't yet concerning.

At the age of two years and four months, Bongani experienced a bout of uncontrollable seizures for which he was hospitalised and diagnosed with epilepsy. Thereafter, Bongani began exhibiting behavioural problems and delays in feeding himself. He attended crèche for a month but was asked to leave due to complaints from teachers regarding his behaviour. Due to this, Bongani began attending a local clinic for developmental delays and disabilities at three years old. Here, he was diagnosed with a mild hemiplegic cerebral palsy with weakness in his left arm and leg. Further investigation revealed that Bongani also had necrosis of the brain tissue, which has left him intellectually disabled.

During Bongani's monthly clinic visits, it was also uncovered that he had a social history of neglect and parental alcohol abuse. His grandmother, Andiswa, offered to take over Bongani's care from his maternal mother but she refused. A few months later, Bongani's mother was murdered with her children inside the house-the extent to which they witnessed the brutality is unknown. Andiswa took over the care of Bongani and his sibling and is now their primary caregiver.

Following these difficult times of adjustment, Bongani and Andiswa did not attend the clinic for much of 2015. During that year, Bongani also experienced more bouts of epilepsy that doctors struggled to control.

In December 2015 Andiswa and Bongani began attending the clinic again, however, their attendance remained inconsistent. Andiswa was invited to participate voluntarily in the service-learning programme to help encourage attendance and offer additional support. Andiswa consented to participating in this research.

#### **4.1.3 Presenting Problem**

At the start of the research, Bongani continued to exhibit a mild left hemiplegic cerebral palsy with weakness in his left arm and leg as diagnosed by the clinic. His Gross Motor Function Classification System (GMFCS) level was rated as a level 2 with his mobility being generally good. Bongani was able to walk and move freely without the weakness being overtly apparent, however, he often stumbled and fell and he needed assistance with tasks such as climbing stairs, jumping, and running. The weakness was more apparent in Bongani's upper body with him favouring the right arm for activities and neglecting the left arm.

Bongani exhibited significantly impaired intellectual and adaptive functioning because of his brain injury. This has resulted in him having major delays in his ability to communicate, concentrate, process information and control impulses. At the beginning of the research process, Bongani only knew a few words and simple sentences that he used in a repetitive manner to express his felt needs. He was unable to control his wants or focus on tasks for long periods.

Bongani also expressed himself physically with violent behaviour, particularly through hitting and pushing people, beating the floor and windows, and throwing objects.

### **4.2 Participation in the Research**

Andiswa and Bongani participated in all three of the data collection processes in May, July, and September of 2016. During the first data collection process, it became apparent that Andiswa was significantly distressed and she was referred to local psychological services for free counselling. Although Andiswa booked a session, she never took up the opportunity to attend counselling citing practical constraints. However, she elected to continue with her participation in the research.

### 4.3 Research Findings

The research findings will be presented in terms of the specific research questions in order to integrate the quantitative and qualitative accounts of the data in a rich, descriptive manner that hopes to offer insight into the effects of the intervention programme on the caregiver's well-being, the child's functioning, the caregiver-child relationship and the caregiver's experience of care received. This will be done by presenting the quantitative data from tests specific to the question and then discussing the qualitative themes that emerged from the IPA interviews that relate to the specific question. A brief discussion will ensue to comment on the integration of the quantitative and qualitative results. After answering each of the specific questions, a final discussion will summarise the effect of the service-learning programme in addition to the clinic services, on Andiswa and Bongani.

The result tables for Andiswa and Bongani referenced in this chapter can be found in Appendix 5. The Appendix is divided into three sections, firstly, the quantitative result tables for the CORE-OM, PEDI-CAT, EIS and MPOC-8 SA can be found in Section 1. This is followed by Section 2, which holds the Marschak Interaction Method Clinical Reports that relate to the EIS results. Lastly, the attached table in Section 3 outlines all of the themes extracted from the pre and post interpretative phenomenological analysis of the qualitative interview data collected around Andiswa's experience of being a caregiver to Bongani.

#### 4.3.1 What is the impact of the intervention on the caregiver's well-being?

**4.3.1.1 Quantitative: Clinical Outcomes in Routine Evaluation- Outcomes Measure (CORE-OM).** The attached table in Appendix 5: Section 1, Figure B, shows the results of the CORE-OM questionnaire for Andiswa over the three data collection periods, which aims to ascertain the caregiver's well-being and level of distress.

**Baseline results.** During the first data collection process, Andiswa's distress level was recorded at a clinical score of 11.8, which is clinically significant and implies she was experiencing mild psychological distress that required intervention. Andiswa exhibited particularly high levels of symptom severity with her problems score of 20 and her well-being score of 12,5. Despite the high level of symptoms and

moderate well-being score, Andiswa's life functioning score was not clinically significant and she did not seem to be at risk.

Her second data collection results of 7,9 indicated a substantial decrease in distress level without the addition of the intervention or attending the clinic. The score of 7,9 indicated that Andiswa was no longer considered clinically distressed. On the individual scales it was apparent that Andiswa's well-being score had increased to 15 but she showed signs of at risk behaviour. However, her symptom severity had substantially decreased by 12 points to a clinical score of 8. Therefore, it could be surmised that although Andiswa's well-being was poorer, she was exhibiting far fewer symptoms.

**Post-Intervention results.** After the intervention, results showed that Andiswa's level of distress remained relatively stable in comparison to the scores collected at the second baseline with only a slight decrease in her distress level from 7,9 to 7,1.

Although Andiswa's overall scores decreased and she was no longer considered significantly distressed, it was noted that her scores for the domain of well-being increased steadily at each data collection point making it the highest after the intervention programme was ended. This is atypical to what Young & Edwards (2013) describe would happen in therapy where a decrease would first be seen in well-being, followed by a decrease in symptom severity and lastly, a decrease in life functioning.

**4.3.1.2 Qualitative IPA Interview.** Below, are some of the themes that arose in Andiswa's baseline and post intervention interviews regarding the emotions, struggles and joys she experienced as a caregiver to Bongani. The themes specific to Andiswa's well-being are outlined in Appendix 5: Section 3, Figure H.

**Baseline interview.** Some of the main themes that arose during the baseline interview with regards to Andiswa's well-being were around the traumatic experiences of having a child with ill health and disabilities and the immense responsibility of caring for a child with disabilities that often left her feeling isolated, exhausted and sad. These are presented and discussed below:

*Overcoming Traumatic Experiences.* Andiswa experienced many traumatic health scares with Bongani while he was growing up that were largely out of her

control, as her daughter would not give her custody over Bongani. Andiswa had to fight to be a part of Bongani's life and to protect him from the neglect and serious health concerns he faced. This all culminated in Andiswa being awarded custody when Bongani's mother was murdered, another extremely traumatic experience that Andiswa struggles to come to terms with.

“His mother didn't care very much about giving him his treatment for the fits I remember one day she arrived here with the child I think it was around 2am...she had been out drinking, she used to drink a lot. She left the child with me only to find that the child hadn't eaten...When I tried to pick him up he had started having fits. We immediately called the ambulance...They tried resuscitating him on the way to the hospital.” (Page 4)

“They decided to admit the child (to hospital in a distant city) but they still could not take him to ICU because it was full. So they asked me if I would manage sitting on a chair the entire time and I said I was going to be fine as well as feeding him through those tubes. I stayed there with that child day in and day out...I wouldn't sleep at all because the child was still in a coma.” (Page 5 and 6)

*Unrelenting Responsibility.* Andiswa experienced Bongani as being a constant responsibility that she felt solely accountable for and burdened with. She felt the responsibility in two senses, firstly, in her everyday life, caring for Bongani, keeping him safe and preventing further health scares. This was seemingly a stressful responsibility that she took solely upon herself, not trusting anyone else to fulfil these duties. This left Andiswa with a constant sense of worry and fear about Bongani and placed her under pressure to provide the best care possible for him. This is demonstrated in the following quotes:

“He is the kind of child who must always be right in front of you, if 5 minutes passes and you can't see him you must make sure to try and find him

immediately, he disappears in the blink of an eye. That's the kind of child he is, one that you always have to have your eye on him at all times." (Page 2)

"He also takes medication at specific times...it has to be three times a day no matter what, every single day. So I can't let someone else take care of him because they might forget about the medication or maybe lie and said that they have given it to home even if they have not. That's why I prefer having him right here in front of me." (Page 3)

Secondly, Andiswa experienced caregiving as a long-term responsibility that she had to accept and come to terms with. She felt as if there was no one else who could take care of Bongani like she did and in order to make sure he would not be mistreated, she felt that she alone would have to care for Bongani for the rest of her life. There was also a sense that Andiswa felt trapped in this position and had no other choice, though she draws on her religious faith to provide her with a sense of strength.

"There is no other way; I have to accept it because there is no other person who will take care of him except for me. So I have to tell myself that he is my child, he will be mine for the rest of my life no matter who says what. Where else would he go? I have to tell myself that no matter what happens, even if he gets sick, he is mine and I have to take care of him, so I have to accept that he is my responsibility, no one else would be able to take care of him except me." (Page 13 and 14)

"I have to encourage myself because I have no other choice, there is no one else who will help me. I must accept that all of this depends on me. Sometimes I tell myself that it doesn't matter what happens with this child, how he sometimes also disturbs me mentally, his mother is not coming back, he is now mine and will always be mine till the end. I must always remind myself that he is my responsibility and there is no one who is going to help me. There is no neighbour who will come and help me with this child. So I must accept

that my challenges are my challenges and must take them to God in prayer and trust that he will help me through it all.” (Page 11)

*Isolation and Exhaustion.* Andiswa experienced the burden of caring for Bongani and all of her other children and grandchildren to be extremely exhausting and very isolating. She described feeling alone in doing all of the work, which left her tired and sad.

“No what made me a bit sad was the amount of work I have to put in alone. I have times when I feel so tired but I have to work because these children are dependent on me and my daughter has a one month old child.” (Page 10)

“So I’ve been places because of that child, my body is tired and sore because of that child, but what can I do? I do get tired, but I think to myself what would I do with him because he is mine now, he is my responsibility and there’s no one else to take care of him.” (Page 14)

*Post intervention interview.* The themes that arose during the post interview with Andiswa around her well-being were similar to those that arose from the interview during the baseline phase. She continued to experience caring for a child with disabilities as a huge responsibility with constraints that often left her sad, worried and tired with a great fear for what the future holds. However, she also placed additional emphasis on her support structures and spirituality as proponents that helped her come to accept Bongani’s disabilities, and assist her in coping with the difficulties she faces. These themes are discussed below:

“*I am the one who feels for him and thinks for him*”. Andiswa reiterated the immense responsibility she has in taking care of Bongani as his primary caregiver. She stated that she is the one person who has to think and feel for him, which includes watching him all the time in order to ensure he does not get hurt or come in harm’s way.

“When I look at him, I don’t think he realises that he is disabled, he just does whatever he wants and does not even realise it when he is in danger. For instance, if there is a car driving past, he wants to go straight to that moving car so I have to constantly keep an eye on him.” (Page 1)

“He can even lean against that heater, he doesn’t realise that it is hot, he will only get a shock when he gets burned, and you will see that he got burnt but even so, he won’t seem to be experiencing any pain, no I will be the one who thinks maybe I should give him some Panado and ointment to alleviate the pain and also take him to the clinic so that he can get some medication because I can see that he is hurt, but he does not realise that he is hurt.” (Page 2)

*No support at home.* Andiswa also experienced the responsibility of caring for Bongani as solely hers, with little support from her daughter at home, which troubled her immensely as she was unable to trust or rely on her. This disturbed her as she felt that her daughter was the only person she had that could stand up for her and help her.

“Most of the time I end up missing a lot of things, I cannot go because I do not trust her, she doesn’t like being at home. Those are the kinds of things that hurt me and the situation with my child.” (Page 8)

“She is also my child and she is giving me problems because it’s just the two of us, there is no one else that can defend me apart from her.” (Page 9)

*Fear of the future.* It was also apparent that Andiswa feared for the future of her children knowing that she is getting older and may not be around forever to care for them. This filled her with worry and concern for what would happen to the children. Andiswa was particularly concerned for Bongani due to his disability and worried about him being accepted and cared for by someone else. She wished for God

to make him a normal child, without a disability, so that even if he was naughty or difficult, he would be better able to care for and aid himself.

“All I ever really think about is this child. I pray to God to change him to be a normal child even if his mental state doesn’t change but at least to, because I will not live forever. It could be that God will take me while he is still sick and I will leave him in that state. I don’t mean to say that God shouldn’t take me but all I ask for is that, before he takes me, can he wait for my children to grow up first. When they are all grown up, He can do whatever he wants, but can he please wait for me to raise them up until they are old enough. So that whoever takes care of them after me, they can find them older and able to do things for themselves, that is my prayer.” (Page 8)

“I pray the same prayer; that even if I am sick or tired or hurting, all I ask for is for God to never take me so that I don’t leave my children behind. Because I would never rest in peace, I would be constantly thinking about my children.” (Page 8)

*Financial Constraints.* Andiswa also felt somewhat limited in her ability to provide Bongani with new learning experiences, such as going to the shops or having a picnic due to the immense financial pressure she is under. This left her feeling resentful and frustrated.

“If for instance I was a white person who has money, maybe I would even take him to a park, just to take him out. Maybe take him along with other children.” (Page 3)

“There is not time, there is no money and all those things need money.” (Page 4)

*Sick and tired but resilient.* Andiswa conveyed that she felt both sick and tired due to the immense responsibilities she has and her worries around Bongani. However, she also expressed her need to be resilient, as she understood her responsibility towards caring for Bongani and felt a duty to fulfil it despite how she felt.

“Otherwise, I feel alright just tired, I am tired physically and mentally but I cannot give up. I have to be strong and just tell myself that I am on my own and I have to face my situation. Yes, because all of this is up to me, if I get tired and give up then who we will take over this job? I have to persevere until the end.” (Page 5)

“I am sick, I am sick because his disability is bothering me...” (Page 8)

Andiswa felt that her ability to be resilient and find acceptance came from the external support she received, particularly from her church congregation, her spirituality, and the parent support group she attended. The sub-themes related to this are discussed below:

*Feeling valued and understood.* Andiswa presented as an extrovert, drawing much of her happiness and enjoyment from spending time with other people, particularly people in her congregation. Andiswa described receiving a lot of support from her church congregation that gave her a sense of value and a feeling of being understood. Her role in sharing messages and offering support to others, even at funerals, left her happy as she had a purpose to fulfil and she was helping others. She also felt as if the members of her congregation were able to understand the immense responsibilities she has at home and accept her without judgement, despite her perceived flaws. She viewed her congregation as friends and drew much happiness and power from sharing with them.

“I do feel valued just by virtue of being asked to go share a message where there’s been someone’s passing. So even there I get encouraged, it means I’m

not forgotten, people still recognise me as another human being amongst them. And that I have a contribution to make at church, to the family that has lost someone, just to give them encouragement today. It means that I will get to share their pain with them and they also know the pain I am carrying. But it also means that I should put aside my pain and focus on theirs.” (Page 5)

“I was happy last week because the whole week we had funerals. So I was busy with those funerals, going up and down to the different families... No the bereavements didn't disturb me because we cover one another.” (Page 6)

“So I think that is how my life has changed because even church members are a support to me, they understand my situation. When I cannot make it to church, they understand because they know that I have this responsibility that God has given me. They cannot force me to go to church because they know my burden. All we need to do is to support her at all times and not think because she is not attending church, that she is lazy, but understand that she has that responsibility.” (Page 11)

“I think (what makes me happy) it's mainly spending some time with friends, doing things we enjoy, whatever they may be, but just being happy spending time together indoors and so on...and chatting with people so that one is not constantly by themselves thinking about all sorts of things. It's very nice if I had started to think about things and then maybe you walk in and we start chatting and then someone else joins, it distracts you from your thoughts. Some people may even develop suicidal thoughts, or think about the fact that they do not have money, about the burden of running and taking care of an entire household by themselves. But if someone walks in and maybe reminds you of a word that was shared at church, that helps me forget whatever I was thinking about.” (Page 6 and 7)

*Spirituality.* Andiswa describes drawing a lot of strength, acceptance and understanding of her situation from her religious beliefs in God. Although she spoke of her religion and beliefs during the baseline interview, she reiterated it more strongly during the post-intervention interview. She particularly felt that although she was encumbered, God would not give her a burden that she could not deal with which gave her a sense of resilience as she felt that He was there for her to guide her through it and sustain her.

“He has also been able to sustain me and help me through a lot of things even though I may not see Him. But spiritually, he helps me a lot and he will not come to me in person and say here, all I will see are just actions that are happening.” (Page 6)

“Because in everything we do, we shouldn’t forget God [deep sigh, starts crying] it’s easy to think that you are the only one going through something but there are others going through some pain, maybe someone has lost a loved one but God would never give you a burden you cannot carry.” (Page 5)

*Parent Support Group.* Andiswa received additional support from the parent support group for caregivers of children with disabilities that she started attending. The support group helped with her sense of loneliness by showing her that she was not the only one experiencing the difficulties of raising a child with disabilities. The support group also helped her come to terms with having a child with disabilities and accepting it.

“Now there are a lot of parents and we all support each other. We have accepted our children as a gift from God it doesn’t matter what happened.” (Page 10)

“Now the support group has taught me that it’s important for us as parents to support each other when it comes to our children. Maybe one parent was

struggling to accept their child but since they joined the group of mothers, they realise that they are not the only ones there are a lot of other parents who have a disabled child as well. So that parent ends up accepting it because now she knows she is not alone.” (Page 11)

**4.3.1.3 Discussion.** From the results of the quantitative and qualitative data, it is apparent that Andiswa’s overall level of distress decreased substantially between the baseline phases and then again slightly after the addition of the service-learning programme. This decrease was predominantly due to an improved score in the problems domain indicating that Andiswa was experiencing fewer symptoms of her poor well-being as well as a greater functional ability. However, the improvement in Andiswa’s levels of distress after the addition of the service-learning programme was insubstantial indicating that the service-learning programme did not have a significant impact on improving her well-being. Despite this, the consistent score indicates that the service-learning programme may have assisted in maintaining the substantial improvement seen in her distress levels between Baseline 1 and Baseline 2.

From the IPA interviews, we can see that Andiswa continued to experience the same burden of unrelenting responsibility that left her sick, tired and worried. This was also reflected in the CORE-OM scores, which echoed a continual increase in the domain of well-being over the research process with the poorest score being recorded after the intervention.

A decrease in symptom severity could also be attributed to the additional support structures Andiswa cited during the post intervention IPA interview, including her involvement with her church congregation, her spiritual beliefs, and her participation in the caregiver support group.

There is also the possibility that the research may have been perceived as an intervention in itself, creating a passage of catharsis for Andiswa to openly talk about her past traumas and current problems and contributing to the initial drop in the baseline phase.

#### **4.3.2 What is the impact of the programme on the child’s functioning?**

**4.3.2.1 Quantitative: The Paediatric Evaluation of Disability Inventory-computer adaptive test.** Scaled scores represent the child’s current status along a continuum of functions in the various domains and are based on a 20 to 80 point

scale. An increase in score indicates that the child's performance or skill in a domain has increased, whilst a decrease in scale score indicates a possible regression.

Bongani's scores for the PEDI-CAT can be seen in Appendix 5: Section 1, Figure C.

**Baseline results.** Bongani's results for the PEDI-CAT remained somewhat consistent with only slight and mostly insignificant fluctuations. For the domains of Daily Activities, Social Cognitive and Responsibility, his scores decreased during the baseline period. Daily activities decreased by two points from 50 to 48; Social/Cognitive decreased by 1 point from 56 to 55; and Responsibility decreased by 4 points from 39 to 35. The only area that saw an increase was in the domain of motor functioning, which increased by 3 points during the baseline phase from 59 to a score of 62.

**Post results.** Scores from Bongani's post intervention assessment again showed only slight fluctuations. Bongani's scores for domains of Daily Activities and Social/Cognitive further decreased from the baseline data. Daily Activities decreased by a further 2 points from 48 to 46; while the domain of social/cognitive further decreased by 1 point from 55 to 54. Bongani's responsibility domain increased by 2 points from 35 to 37 post intervention, however, this increase remained 2 points lower than the initial data collected. The only domain that saw initial increases, mobility, remained consistent between the second and post intervention data collections with a score of 62.

Thus, one can surmise that the service-learning programme in addition to the Clinic had little to no effect on Bongani's functional abilities.

**4.3.2.2 Qualitative IPA Interview.** Below, are some of the themes that arose in Andiswa's baseline and post intervention interviews regarding her experience of Bongani's functional abilities. These themes are outlined in Appendix 5: Section 3, Figure I.

**Baseline interview.** During the baseline data collection, Andiswa was still seemingly trying to gain an understanding of Bongani's disability. She also related his disabilities to naughtiness and expressed hope that the disability would go away in the future.

*Understanding the disability.* Andiswa seemed to be unsure of what disabilities Bongani had and what exactly had caused them but she had developed her own understanding thereof, believing it had come from the coma he once went into due to epileptic fits and related very much to his physical health and well-being. She also understands disability as being different from other children particularly in his inability to know the difference between wrong and right decisions. She stated:

“He was in a coma during those three days and I think that how he got to have this arm that doesn’t work and I have noticed that even mentally he is not alright.” (Page 1)

“His disability is mental and then with this mental disability he was also in a coma. He has fits, so the fits lead him into a coma.” (Page 1)

“Bongani doesn’t know much, he is just a mentally disabled child, he can’t tell the difference between right and wrong. Let me just say he is unlike a normal child.” (Page 2)

*Disability as naughtiness.* Andiswa experienced Bongani’s disability as naughtiness, with Bongani not listening to her and disobeying instructions. She felt that she needed to correct his behaviour as she didn’t want to raise a child that is naughty. Andiswa expressed that the best way to do this is to be strict on him and spank him whenever he does something wrong, instilling a fearful respect for her.

“It’s very easy to tell that he is not a normal child, when you tell him to stop doing something he shouldn’t be doing- he does exactly what you are telling him not to do.” (Page 2)

“He is very naughty but he is scared of me because I don’t baby him. If he does something wrong I spank him and tell him what he has done wrong”  
(Page 14)

“I don’t want to raise a naughty child.” (Page 14)

*Hope for the future.* Andiswa also showed hope and optimism towards the future with regards to Bongani’s disabilities. She saw Bongani’s disability as something that might bring her a blessing one-day. She also felt that if she treated Bongani like a non-disabled child he might become less disabled and be fine in the future.

“God gave him to me because I believe that there is more he is still to bless me with through that child. That’s why I say it’s important for me to accept him the way he is and not focus too much on the fact that he is disabled, maybe greater things are yet to come. I must treat him like other children and forget sometimes that he is disabled maybe in the end he will be fine, I have that hope that he will be well, it doesn’t matter when.” (Page 16 and 17)

*Post intervention interview.* In the post intervention interview, Andiswa continued to question the cause of Bongani’s disabilities and felt a need to find a solution to them as she feared for his future. She also continued to view his disabilities as a behavioural problem, however, she was also able to empathise with Bongani and show an understanding of his lack of control of the behaviours she perceived as naughty due to his disability. Andiswa also described functional improvements in Bongani that she attributed to their involvement in the service-learning programme. These themes are further illustrated below:

*Disability as a behavioural issue.* Andiswa continued to view Bongani’s disability as a behavioural problem, describing his disability as naughtiness.

“So I am the one that knows that he is not well, so I can say that his disability is more mental. It has damaged his brain because he is very naughty, he climbs on things and does all sorts of things, I don’t know how I can really describe him. He is a child and yes he is disabled but he doesn’t realise that, he believes that he is just like other children.” (Page 1 and 2)

“And if he was not a naughty child, I would take a walk with him and go to town, go to Shoprite and drive him ride on the trolley there, just for fun” (Page 4)

*Empathy.* Although Andiswa continued to view Bongani’s disability as naughtiness, in the interview she was better able to express empathy and an understanding that he is not necessarily aware of his actions or able to control these behaviours. It is possible that her interview narrative reflects improved insight into Bongani’s disability, which has increased Andiswa’s ability to better understand Bongani’s needs. Her narratives in the interview suggested that she was making provisions to better fulfil Bongani’s needs. This was apparent in Andiswa’s realisation that Bongani was still a child who enjoyed exploring and going out into the world without being constantly reprimanded or monitored- just as any young child would. Her increased insight and empathy into these factors helped her make provisions to try and better accommodate Bongani, by taking him to town more often and putting up a fence around the house so that Bongani could have more freedom to roam around without getting in harm’s way.

“He doesn’t know what he is like, that he is different from other children, he is just who he is. So I am the one that knows that he is not well.” (Page 1)

“He is a child and yes he is disabled but he doesn’t realise that, he believes that he is just like other children. If he could talk maybe he would say, “why am I like this whereas others are like that or why am I constantly under someone’s eye when others are free to do what they like; you close the door

and whenever I go somewhere, someone always comes looking for me but you don't do that with the others?" If he could talk but then since he cannot talk, but he does want to do what other children are doing even though he cannot because of whatever controls in his brain." (Page 1 and 2)

"And not be stuck in the house because he does need to go out sometimes. Can you see I even have a gate now so that he cannot go out and get hit by a car because I didn't see him leave, I would be the one in trouble for that, that's why I want my yard to be closed at all times. But he does need a chance to go out and take a walk sometimes." (Page 4)

*Longing to find answers.* Andiswa continued to hope for a cure for Bongani's disabilities, however, there was a sense that she now experienced this need with desperation and a fear of the future. She felt that she still did not fully understand what caused Bongani's disabilities and therefore, she needed to get definite answers and closure as to whether he would be like this for the rest of his life or if there was possibly a cure.

"But I did ask the doctors and they explained to me that the problem with the child is mental. That is why I mentioned to Julia that I would love for him to get treatment from Fort England. So that the doctor at Fort England can tell me exactly what is wrong with his brain because I wouldn't leave Fort England without knowing what is wrong after the doctors have assessed him. Maybe it has some dot or something but the doctor must tell me whether or not it is curable so that I know and I am aware that my child will be like that his whole life. If maybe he says it's a dot, what is going to happen, maybe the brain what what [surgeon] will remove it or whatever they will do or if they cannot remove it and he will be like that his whole life. I want to know that so that I am not in the dark even though my child has been to see doctors, I do have a right to ask the doctors." (Page 9)

“I need to ask the doctor, just to find out what help is possible. He will respond, a honest doctor might even tell me the truth that maybe treatment will be administered for 2 years or before 2 years it will be treated. So I need to get that information from him, from the doctor’s consultation room so that I am also satisfied with the report.” (Page 9 and 10)

*Functional improvements.* Andiswa experienced Bongani as having improved functional abilities after the service-learning programme. She expressed that she had noticed improvements in Bongani’s ability to feed himself, play ball, and listen to her, stating that he was much better than he was before the service-learning programme.

“He is better now than how he was before, there are certain things that I have noticed he’s improved on since we met you, there are certain things, he is better than before. Especially because if you remember when I was here, he could eat for himself using his spoon. And also when I throw a ball at him he can catch it. So there are certain things he can now do, he is much better now.” (Page 1)

“Before he could not eat by himself or even catch a ball, he really was not fine but now I am happy with how he is doing, he is so much better compared to what he was like before. He is so much better now, so much so he even listens better, yes he is still a bit naughty, that has not changed much but he is better than what he was before.” (Page 1)

*Improvements attributed to service-learning programme.* Andiswa attributes the functional improvements she has noticed in Bongani to the work of the students from the service-learning programme, saying they worked with him and focussed on teaching him specific functions, as well as encouraging her to get out with him and provide him with new learning experiences.

“I think maybe it is because I’ve been working with all of you and not sitting at home with him. Whenever we get the chance, we go to town and he gets the time to practise the things you teach him and get some fresh air. He is not stuck in the house like I was with him before. He gets to go out in town and around here he also walk up and down, constantly wanting to go to the toilet.” (Page 3)

“They helped me because the child learned how to catch, you see that catching, now he knows how to catch because they trained him how to catch. They taught him and showed him, they really worked on him.” (Page 15)

“And sometimes he throws them (toys) away but now they know that he does that so whenever he does that, they tell him to pick them up. Just like when his toys would be all over the place, they taught him how to collect them.” (Page 15)

**4.3.2.3 Discussion.** The quantitative scores from the PEDI-CAT indicated that the service-learning programme in addition to the Clinic had little to no effect on Bongani’s functional abilities with an overall marginal decrease in scores from the initial baseline collection being observed at both the baseline phase and after the service-learning intervention. However, the quantitative data was contrasted by the qualitative data that outlined Andiswa’s personal experience of Bongani’s disabilities and her perception of positive changes in his disabilities. Andiswa also attributed these changes not only to her participation in the service-learning programme and the clinic but also to their participation in the research. Her narratives also suggested some change in the way she saw Bongani – as a child with thoughts and feelings of his own.

In the qualitative data, it is apparent that Andiswa still views Bongani’s disabilities as naughtiness after the intervention, however, there is a sense that she is better able to empathise with him and understand his experiences and needs. She also stated that she had seen notable improvements in some of his functional abilities, such

as self-feeding, playing ball and tidying up. Andiswa also perceived a decrease in Bongani's naughtiness with him listening to her better.

However, these reported positive changes did not reflect on the quantitative PEDI-CAT outcomes with no significant improvements being observed in the various domains or overall score. This may indicate a lack of sensitivity to these changes in the instrument used.

### **4.3.3 What is the impact of the programme on the caregiver-child relationship?**

**4.3.3.1 Quantitative: Emotional Interaction Style- Assessment of the Marschak Interaction Method.** The summarised score table for Andiswa and Bongani's Emotional Interaction Style Assessment can be seen in Appendix 5: Section 1, Figure D and the MIM Clinical Reports can be found in Appendix 5: Section 2.

**Baseline results.** During the initial baseline collection, Andiswa and Bongani scored a relatively low score of 22,5 for their EIS assessment of the MIM indicating an inadequate/variable relationship. The clinical report summary cited the relationship as being "quite chaotic and characterized by an authoritarian style with Andiswa demanding a lot of Bongani and Bongani rebelling against her." Scores were particularly low for the domain of nurturance, especially with Bongani who scored a reciprocity score of 1,5. It was noted that Bongani seemed "quite distressed by their interaction and would try and get away from Andiswa's physical touch or presence by running away or even kicking out at her." This was possibly because of Andiswa being said to be "emotionally unavailable to truly connect with Bongani and thus she was unable to be empathically aware and attuned to his needs...ignoring his requests and not encouraging and praising (of him)."

The second data collection period saw a slight improvement from the initial baseline phase to a score of 23, which was somewhat negligible and still indicated an inadequate/variable relationship between the caregiver-child dyad. There were slight improvements in the domain of Structure and Challenge, particularly with Bongani showing better cooperation. However, there were notable decreases in the domains of Nurturance and Playfulness, as well as a decrease in Andiswa's Emotional Reciprocity score. The clinical report noted that Andiswa "came across as quite

depressed, having episodes where she became frustrated, overtly sad and complained of pain which closed her off to any possible interaction with Bongani.” Due to her emotional unavailability, Andiswa’s interaction with Bongani became “very demanding and (she) did not offer praise, or positivity...(being) physically forceful and impatient- taking away toys from Bongani.” Thus Bongani seemed to “avoid physical contact (and)... expressed himself by physically hitting things”. However, it was noted that they “both seemed to appreciate having each other but they seemed unsure of how to act in a harmonious, loving and empathic manner.”

**Post results.** After the intervention Andiswa and Bongani presented with an improved EIS score of 29. This indicated an improvement in their perceived caregiver-child relationship, however, the score remained somewhat low and only indicates their relationship was variable. Andiswa was able to supply Bongani with a good amount of structure and engagement and Bongani was able to cooperate better. They also obtained fairly good scores of 3 and 3,5 for Emotional Reciprocity and Playfulness respectively. This was reiterated in the clinical report summary: “Andiswa and Bongani seem to have a fairly good but cautious relationship with one another. It is apparent they care for each other, with Bongani listening to Andiswa and interacting with her in a positive manner at time and Andiswa praising and encouraging him”. However, they continued to score in the lower range of 2,5 and 2 for the domain of Nurture with the report stating, “Bongani was also careful around her and mistrusting of her actions. Andiswa showed moments of having a short temper and become easily frustrated which made her emotionally unavailable and forceful with Bongani and caused him to retreat from her.”

The EIS Scores of the MIM showed little improvement during the baseline phase, which suggests that the Clinics may not have had an impact on Andiswa and Bongani’s relationship prior to the intervention programme. However, after the intervention an improvement was seen in the caregiver-child relationships as indicated by a better EIS Score in the post intervention MIM compared to the scores from the baseline data collections. This suggests that the service-learning programme in addition to the Clinics may have had an impact on the caregiver-child relationship as reflected in the scores. Although problem behaviours still continued to exist at the post data-collection, these seemed to be reduced from the baseline phase and Andiswa was better able to structure and engage Bongani who then cooperated better.

**4.3.3.2 Qualitative IPA Interview.** Below, are some of the themes that arose in Andiswa's baseline and post intervention interview regarding her relationship with Bongani. These themes are summarised in Appendix 5: Section 3, Figure J.

**Baseline interview.** During the baseline interview, Andiswa explained that her and Bongani got along well but because he was so naughty she often had to spank him to teach him what he was doing wrong, taking on a disciplinarian role in their interactions. Andiswa expressed that she felt Bongani knew when he was doing something wrong and reported that he feared her, running away when she came towards him. Andiswa also explained that Bongani was quite stubborn and refused to stop doing things he shouldn't be doing, retaliating physically with hitting and kicking. This gave insight into their interaction style and relationship with one another and suggested that Andiswa tends to take on a strict, authoritarian role with Bongani, turning to physical discipline to get him to behave and obey her.

“He is very naughty but he is scared of me because I don't baby him. If he does something wrong, I spank him and tell him what he has done is wrong. So even now, he knows when he has done something wrong, he runs as soon as he sees me.” (Page 14)

“We get along but he also knows that when he is wrong he is wrong. I don't want to raise a naughty child because one day I will leave him with other people and he will not cope.” (Page 14)

“I also tell them not to spank him when he is wrong, they should let me be the one who spansks him.” (Page 14)

“He doesn't want anyone stopping him... if you try and stop him he will start crying, he will even hit you with whatever he has even though you were trying to take it away from him for his own safety. (Page 16)

**Post intervention interview.** During the post intervention interview, Andiswa stated that she and Bongani had a good relationship, however, she expressed still feeling that his naughtiness impacted on their relationship and caused her to avoid doing tasks with him in fear of how he might react. The post intervention interview suggested that Andiswa continued to take on an Authoritarian role, disciplining Bongani for his ill behaviours, however, the interview also pointed to ways in which she was better able to empathise with him.

**Empathy.** The theme of empathy emerged as Andiswa's interview included narratives where she seemed better able to place herself in Bongani's thoughts and understand what he might be feeling. This seemed to impact on her views around disciplining Bongani through spanking him with her stating that she has realised he does not understand that he has done something wrong. Although she still took on an authoritarian role, spanking Bongani, Andiswa's interview pointed to moments where she was better able to consider the root of the behaviour, reflect on whether this form of discipline was necessary and what the impact thereof might be.

“We do have a relationship, we get along very well but since he is a naughty child; he is really naughty, he is naughty he wants to get out of the gate and run away, he doesn't even realise when there is danger. So sometimes we fight about that and I spank him so that he can know, but I also gather that he doesn't even understand that he has done something wrong and that's why I'm spanking him, so I end up stopping.” (Page 12)

“I could see that he was so excited, but still very naughty at the same time. So when my sister wanted to spank him, I refused because it was going to spoil the visit for him.” (Page 13)

**4.3.3.3 Discussion.** Looking at both the quantitative EIS scores and the IPA interviews from before and after the intervention it can be surmised that the service-learning programme had a positive impact on the caregiver-child relationship between Andiswa and Bongani.

Although Andiswa still considered Bongani a naughty child, she was seemingly better able to empathise with Bongani after the service-learning programme, which resulted in a better understanding of his behaviours and disabilities.

In line with this, the MIM observation report and EIS score from the post intervention data collection conveyed that although there were still signs of problematic behaviours, there was a marked improvement in Andiswa's ability to structure and engage Bongani who then collaborated better with her.

#### **4.3.4 What is the impact of the programme on the caregiver's experience of care received from service providers?**

*4.3.4.1 Quantitative: The Measure of Process of Care- 8 South Africa.* The attached table in Appendix 5: Section 1, Figure E shows the scores for the MPOC-8 SA which aimed to measure Andiswa's experience of care received from the clinic services prior to the intervention and then her experience of care received from the service-learning programme in addition to the clinic services after the intervention. The scores obtained from the test are then expressed as percentages in order to understand the score in terms of the percentage of satisfaction with the services.

*Baseline data.* At the first data collection process Andiswa rated her satisfaction with the clinic services at 46,42% satisfied which is a relatively low level of satisfaction with the services. During this survey Andiswa tended to lean towards the extremes and was either highly satisfied scoring 7 or not satisfied at all scoring 1. Andiswa was particularly satisfied with how the clinic staff gave of their time and treated her like an individual and a parent. However, she was highly unsatisfied with the lack of information available about her child's disability and she felt that she was not given a chance to express her concerns and that she did not receive suggestions from the therapists on how to better handle her concerns.

At the second baseline data collection Andiswa expressed her satisfaction with the services as 73,21% which is very high in contrast to the first baseline collection. Her answers were less extreme but tended to lean towards the positive side of the scale. Andiswa had changed her opinion quite drastically on a few of the questions. Although she still felt there wasn't any information available on her own child's

disability she now felt there were general information pamphlets available. Andiswa also felt that at the second data collection point the clinics gave her a chance to explain her concerns and to a very great extent offered her suggestions and ideas on how to handle these concerns. This was radically contrasting to her initial answers.

Interestingly, it was noted that Andiswa did not attend the clinic during this period, which highlights the possibility that the research may have been seen as an intervention in itself. Alternatively, Andiswa may have also perceived the researchers as part of the clinic services, or as invested in the clinic services, and therefore, the findings may have also been influenced by social desirability.

**Post Data.** During the last data collection period, Andiswa rated her satisfaction with the service-learning programme in addition to the clinic at 48,21% satisfied. This percentage of satisfaction drops significantly compared to the second data collection period but increases slightly compared to the first scores obtained. Andiswa was particularly unsatisfied that she was not being treated as an individual, she felt she wasn't able to express her concerns and she wasn't given any suggestions to address these concerns. Andiswa also felt that there was no information available to her regarding her child's disability, nor were there pamphlets available regarding disability in general.

**4.3.4.2 Qualitative IPA Interview.** Below, are some of the themes that arose in Andiswa's baseline and post intervention interviews about the services she received from the clinic prior to the intervention and again after the intervention which asked her to reflect on the services received from the clinic as well as the home visiting programme. These themes are summarised in Appendix 5: Section 3, Figure K.

**Baseline interview.** Andiswa offered insight into the services she was receiving from the clinic prior to the intervention programme. Andiswa felt there were both positive and negative aspects to the services. The negative aspects she experienced centred on barriers to accessing healthcare services. The barriers to access she experienced included:

**Transport Difficulties.** Andiswa found it difficult to get to and from the clinic stating it was problematic to walk long distances with a child who had a motor disability and had become too big for her to carry. Walking to the Clinic was also weather permitting. This required her to seek additional transport in the form of taxis

that are costly, and often do not understand or have the patience to wait for a child with disabilities. Andiswa stated the following regarding transport difficulties:

“Getting there is very difficult because if it’s raining I can’t go there with him because I have to take a taxi from [street name] and then walk up from [street name] with him and he is so big.” (Page 19)

“It’s transport to get the child to the clinic and this child is very naughty, if he gets into a taxi, he doesn’t want to get off. So some taxi drivers do not have the patience and they are disrespectful.” (Page 19)

“It would be much better maybe if I were to get transport, so that I can take both of them with me, but now it is very difficult to walk with them.” (Page 19)

*Clinic dates not suitable.* Another barrier to access that Andiswa experienced was that the monthly clinic dates were prescribed to her and often coincided with other events or activities that she had to attend. She also experienced difficulties in finding appropriate people to babysit her other children during these periods. This was also an additional cost for Andiswa to cover in order to attend the clinic on a monthly basis.

“Unfortunately, my dates always coincide with other things, like my children being sick, or maybe he has to go to the clinic.” (Page 18)

“Even when the child gets sick I have to personally rush him to Settlers and I can’t leave him there by himself, I have to sleep there. What about the younger one now who is left behind at home, because I cannot take her with me? So I usually have to ask my daughter to take care of the little one as well. Even my brother, if I have to go to PE with the other child, my brother does

take care of the younger one at home. Otherwise she would be a huge responsibility if I had to take her with me to PE.” (Page 10)

“They gave me a date but sometimes I cannot go because there is no one to look after the smaller one.” (Page 18)

*Child too naughty to take to clinic.* The final barrier to access that Andiswa experienced was her own apprehension around taking Bongani to the clinics due to his trying behaviour. Andiswa felt he was very difficult to control in these scenarios and caused havoc amongst the hospital and clinic staff, who she acknowledged deal with him well. However, she still felt concerned and hesitant about having to cope with these behaviours in such a setting.

“I always end up having to run after him while we wait for the nurses. He is very naughty but the nurses understand him now, they play with him but not for long.” (Page 18)

Andiswa also experienced some positive aspects in her interactions at the clinics. She particularly enjoyed the support and acknowledgment she received from both the therapists and the other caregivers. The following positive themes emerged:

*Respect and kindness from therapists.* Andiswa stated that she found the clinic therapists to be very respectful, taking time to listen to her concerns and answer all of her questions. She felt that they really loved their jobs and the children they worked with. She felt they took really good care of Bongani and never tired, even when he was exhibiting difficult behaviour.

“Yes, they really respect us and they love the children, they play with them. They love them because I’ve been there twice.” (Page 18)

“The dieticians from the clinic are always very helpful they take the child and they also answer all of my questions.” (Page 19)

“They don’t get tired, they even say that they can tell that I am really doing my best to help him as well.” (Page 20)

*Support from other parents.* The other positive aspect that Andiswa enjoyed about the clinic was that she had the opportunity to meet a lot of other caregivers of children with disabilities who offered her support and encouragement.

“I get a lot of help there because I get to meet other mothers who take their children as well and they also encourage me to be strong and keep going there.” (Page 18)

*Post intervention interview.* During the post intervention interview, Andiswa described her experience of the service-learning programme in addition to the clinic services. She reported her experience of the service-learning programme as very positive. She attributed functional improvements in Bongani to the programme and in addition, she found the service-learning programme to be status boosting for her, it gave her a break, and it eased structural barriers such as transport difficulties. Andiswa also expressed that the students were able to act as intermediaries with the clinic to assist her in changing her clinic location from the township based clinic to the local hospital. In addition to her experience of the service-learning programme, Andiswa expressed her satisfaction with the clinics in both locations. This is further delineated in the themes below:

*Visits as status boosting.* Andiswa expressed her personal enjoyment in partaking in the service-learning programme, stating that for her it was extremely status boosting amongst the community. She experienced being visited by white people and students as extremely prestigious, which brought her additional respect from others in the community.

“Oh that was very nice such that even in the community I’m viewed with more respect and high regard now. Because they see this white lady and the students from [University name], I even invite the children from around the community to come and play here, yho I’m highly regarded now.” (Page 15)

“Even when this child was admitted at [Hospital name] they visited us and brought him some yoghurt and even at the hospital I was the first one to be visited by white people and by [University’s name] students. I also noticed that even in that ward I was being viewed with high regard as well.” (Page 15)

“Gosh, what do I say, oh they were, I don’t know how to describe it. If I could climb up a mountain and shout out my gratitude, I don’t know, what they did for me, and I didn’t even expect that I would meet people who are like that with my child. But I thought to myself that, God knows everything and controls everything. Even in the township people would ask where we got them from. Because even when I said I was waiting for some people, another lady who spent the night here was asking me who these people were and where they were from. So I told her that they are here for my child. And I always say that God is still taking me very far with this child just like I said it to you. So when the students came, it was because of this child and everyone is always amazed and wonder why I get visits from such decent people but it is because of this child but I also get recognised because of it.” (page 16)

*Easing transport difficulties.* Andiswa also experienced the service-learning programme as easing structural barriers she experienced such as transport difficulties. She expressed that this was a tremendously helpful aspect of the visits for her.

“So it was very nice, they would even use their transport to take me and the child to the clinic sometimes and bring us back.” (Page 15)

“And sometimes I would catch a lift to town with them if I have to go to town. They were so helpful.” (Page 16)

*Gave her a break.* Andiswa experienced the service-learning programme as providing her with a break from caring for Bongani. She felt she was able to leave Bongani with the students to play which gave her some time to do the things she needed to do around the house without having to worry about him.

“It was also helpful to as well because I would get a break. While they are busy with him, I would sit here or if there is anything that needs to be done, I do that. So it was very helpful.” (Page 16)

“Because they were so helpful to me as well, they gave me a break.” (Page 16)

*Mediating between caregiver and clinics.* Andiswa experienced the students from the service-learning programme as helpful at the clinic as they were able to assist her with Bongani and act as intermediaries between her and the clinic staff. Although she reported always feeling welcome and respected at the clinic, she described feeling even more so with the assistance and presence of the students. Andiswa reported that the students were also able to assist her in finding a more suitable clinic to attend which alleviated some of her grievances mentioned in the baseline interview, such as transport difficulties and suitable clinic dates.

“Oh they were the ones who were going up and down with the child. Even when we went there (to the clinic) with them and they attended to us so well there especially because I was with them, they were busy helping me.” (Page 17)

“Oh they were the ones who were going up and down with the child even when he was supposed to meet with the physiotherapist, they were the ones

who took him, it was so nice. I felt even more welcome there as much as I always feel welcome.” (Page 17)

“So my connection with them was very nice, I was held in high regard. But I don’t mean that I was not respected or highly regarded before, but I mean they contributed to that even with the changes from [name] to [name] clinic. They were also satisfied and happy because they had seen the other clinic that it was full of sick people, children who had gone for their weight, mothers, fathers and so on and the clinic is very small.” (Page 17)

*Difficult to let go.* Andiswa experienced the service-learning programme as being too short and expressed that she was shocked at how soon it had come to an end. She felt as if she had really bonded with the students from the service-learning programme and still hoped to remain in contact with them.

“I have their numbers I have kept them and I have told them that I will call them one day just to say hi. But they must also call me one day and maybe I will be at the hospital with the child. We have now bonded, we are friends and nothing can separate us unless they leave the university and then we lose contact but for now, we are one. They treated me really well.” (Page 15)

“And so when they told me that they had finished their 9 weeks I was shocked, I thought it was too soon. I even told them that it went by very fast because I thought they were still going to keep coming but they told me that their time was up.” (Page 16)

*Research as an intervention.* Andiswa seemed to group the researchers with the students together and there is a possibility that she viewed the researchers in a similar way to the students

“And also meeting with you because with these, like you may have noticed when he saw you he jumped at you because he was so excited they thought it was the [students name]. So they enjoy seeing other people that they do not know. I mean even this child, when he saw you he ran to you, can you see that he knows you?” (Page 4)

“I don’t even want to spoil it, it changed my life for the better, that’s why I keep saying that you are all welcome here and even in the community because they can see you when you come here and they know that you are coming to see me. Even the area where you park the car, they know you and they know the car...they always look after the care and no one can touch it because they know that you are here to see me. So it was very nice and I don’t want to spoil it. So that’s why I am saying that, we are parting ways, I said this to the students\* as well, that we are parting ways but I don’t know what we are going to do now. Maybe God will again make something else happen, whatever that may be. Just like you, maybe you will remember me again and come back or send someone else, I don’t know.” (Page 18)

**4.3.4.3 Discussion.** A combined analysis of the quantitative and qualitative data to understand Andiswa’s experience of the care she received from both the clinic and the service-learning programme showed disparate outcomes.

The quantitative data from the MPOC-8 SA showed a high level of satisfaction with the clinic at the baseline phase, despite Andiswa and Bongani’s low attendance rate during this period. The increase in satisfaction between baseline 1 and 2 from 46,42% to 73,21% was particularly interesting in that Andiswa and Bongani did not attend the clinic during this period, and the only noted interaction during this period was in connection with the research team. In the IPA interview Andiswa cited both positive and negative aspects to attending the clinic. The negative aspects focussed on structural barriers that spoke to their low attendance, such as difficulties traveling to the clinic, clinic dates not being suitable, and Bongani being too naughty to attend the clinic. However, when they did attend the clinic, Andiswa stated that she was treated with respect and kindness by the therapists and felt supported by the other parents she met there.

The post intervention results of the MPOC-8 SA showed a drastic decrease in Andiswa's satisfaction with the services with the addition of the service-learning programme. However, the IPA interview showed incongruent results with Andiswa asserting mostly positive remarks about the service-learning programme. Andiswa found the service-learning programme to be status boosting for her amongst community member bringing her more respect. She also stated she experienced it as giving her a break from caring for Bongani, and it eased some of the structural problems she had experienced in accessing healthcare services as stated in the baseline interview. Although she still continued to experience worries about accessing healthcare services, the students were able to act as intermediaries between Andiswa and the clinic to help her change her clinic location to one that Andiswa felt better suited her and Bongani. Andiswa also stated that she was still well respected and welcomed at the clinic as much as she had been prior to the intervention, however, she felt that the students garnered her additional respect and help from the therapists.

Despite these positive remarks, the quantitative results were less than satisfactory. A possibility of this may be the hurt and abandonment that Andiswa was experiencing due to the abrupt ending of the service-learning programme which she felt had passed too quickly. This left her questioning what would happen in the future.

**4.3.5 Are there trends and patterns of change that can be identified? What sense can be made of the impact of the programme in light of the caregivers' subjective experiences of the programme?**

In summary, the results of the quantitative and qualitative data collected for Andiswa and Bongani aimed to provide a rich understanding of their experiences of participating in the service-learning programme in addition to the clinic and the possible effects that these intervention services had on them. In particular, the research aimed to garner information on the effects of the interventions on Andiswa's well-being and level of distress, Bongani's functional abilities, the relationship between Andiswa and Bongani, and Andiswa's experience of care received from the intervention services. Viewing the data holistically, we can see that the general trend

was that the service-learning programme in addition to the clinic had only slight effects on this caregiver-child dyad.

Positive effects of the intervention were seen in Andiswa's lower levels of distress and in the improved quality of the caregiver-child relationship. Andiswa's level of distress, as measured by the CORE-OM, showed consistent decreases in level of distress with improved scores between each data collection phase, with the lowest score being recorded after the addition of the service-learning programme. However, the most significant improvement in Andiswa's level of distress was seen between the two baseline phases. One could attribute this to her participation in the clinic, however, Andiswa and Bongani did not attend the clinic during this period. This brings into question whether her participation in the research was possibly experienced as an intervention in itself. Andiswa stated after the first IPA interview at the second baseline collection, "At least I feel much better now, it's so nice to talk about things. I feel so much better now. I am so grateful to you for all the support, even the pain of his mother's death will also go away eventually". This quote shows that she felt supported by the researchers and found catharsis in speaking about her experiences. The decrease in score between baseline 1 and 2 was maintained after the addition of the service-learning programme with a further slight improvement in Andiswa's overall well-being. Although the improvement after the addition of the service-learning programme was not significant, it is possible that the service-learning programme played a role in maintaining the initial improvements seen at the baseline phase. Despite Andiswa's decrease in her overall score for distress levels on the CORE-OM, her score in the domain of Well-being continued to increase throughout the research indicating an increasingly poorer state of health and happiness. This was also evident in the IPA interviews with the themes from the post intervention indicating that Andiswa continued to experience many of the same worries and stressors despite the intervention. However, Andiswa indicated themes of support from her congregation, spirituality and a parent support group in addition to the service-learning programme that may have assisted her in decreasing her perceived psychological symptoms and improved her life functioning resulting in the positive effect on her levels of distress as seen in the post intervention CORE-OM. However, these effects were only marginal between the second and third data collection period which indicates the service-learning programme may have only had a slight positive

impact on Andiswa's levels of distress, however, it had a negative effect on her well-being.

The other recorded positive outcome after the addition of the service-learning programme was the caregiver-child relationship, which saw improvements in the interaction between Andiswa and Bongani. Improvements were seen with increased scores on the EIS with positive remarks from the MIM Clinical Report. The IPA interview themes showed that although Andiswa still considered Bongani to be a naughty child with behavioural problems, she was better able to empathise with him and understand his lack of control over his actions, which resulted in her being more patient and less hasty to punish him physically for these behaviours. These results indicate that although problem behaviours continued to exist, Andiswa's perception was that they had decreased significantly after the addition of the service-learning programme, which implies that the service-learning programme had a positive effect on the caregiver-child relationship between Andiswa and Bongani.

The programme seemed to have little to no effect on Bongani's functional abilities, with the scores for the PEDI-CAT showing mixed results with an increase in the domains of Responsibility, decreases in the domains of Social/Cognitive and Daily Activities, and the domain of Mobility remaining the same after the addition of the service-learning programme. These fluctuations were marginal and could not be considered significant enough to indicate the service-learning programme as having a negative impact on Bongani's functional abilities. However, the qualitative interview contradicted these findings as Andiswa described experiencing improvements in Bongani's abilities and behaviour, such as self-feeding, playing ball and tidying up. Andiswa attributed these improvements to the work of the students from the service-learning programme indicating that the programme may have had a positive impact on Bongani's functional abilities or at the very least positively impacted on Andiswa's perception of Bongani's abilities.

Looking at Andiswa's experience of the care she received from the service-learning programme in addition to the Clinic, showed disparate outcomes between the quantitative and qualitative results. The quantitative data from the MPOC-8 SA showed a high level of satisfaction with the clinic at the baseline phase, despite Andiswa and Bongani's low attendance, and a low level of satisfaction with the services after the addition of the service-learning programme. However, the IPA

interviews contradict these findings. In the baseline IPA interview Andiswa cited both positive and negative aspects to attending the clinic. The negative aspects focussed on structural in accessing the clinic, however, Andiswa cited that when they managed to attend the clinic she was treated with respect and kindness by the therapists and felt supported by the other parents she met there. This resulted in her experiencing the clinic with much satisfaction as was recorded by the MPOC-8 SA. However, the post-intervention IPA interview showed incongruent results with Andiswa's MPOC-8 SA score asserting only positive remarks about the service-learning programme. Andiswa found the service-learning programme to be status boosting, it gave her a break from caring for Bongani, and it eased some of the structural barriers she had stated in the baseline interview. Although she still continued to experience worries about accessing healthcare services, she reported that the students were also able to act as intermediaries between Andiswa and the clinic staff. Andiswa also cited positive remarks about the clinic stating that she was still well respected and welcomed as much as she had been prior to the intervention, however, she felt that the students garnered her additional respect and help from the therapists. Despite these positive remarks, the quantitative results for her satisfaction with the services were less than satisfactory. A possibility of this may be the hurt and abandonment that Andiswa was experiencing due to the abrupt ending of the service-learning programme which she felt had passed too quickly.

Overall, the results from Andiswa and Bongani showed many discrepancies, particularly between the quantitative and qualitative findings. However, it can be surmised that Andiswa and Bongani's participation in the service-learning programme had a positive impact on the caregiver-child relationship and Andiswa's overall level of distress, albeit marginal. The qualitative findings from the IPA interviews showed a greater extent of satisfaction, enjoyment and positive results from taking place in the service-learning programme than the quantitative results. It is interesting to note the role of the research as a perceived intervention and the influence this may have had on the results. Another possibility for this disparate outcome may be that the reasons given by Andiswa for her satisfaction with the service-learning programme and its effects were not necessarily in line with the service-learning programmes goals that informed the quantitative measures. Thus, the high satisfaction and positive impact of the services seemed to come from aspects that were not necessarily measured in the

quantitative tests, such as the service-learning programme bringing Andiswa personal esteem, giving her a break from caring for Bongani, and Bongani's observed functional improvements.

## CHAPTER 5

### Research Findings: Zintle and Lizo

This chapter outlines the results of the second caregiver-child dyad that took part in the research, Zintle and Lizo. The chapter includes an introduction to the participants that informs the reader of their demographic details and reasons for being recruited into the service-learning programme. This will be followed by the presentation of the data collected during the study. The data will be presented in relation to the specific research questions outlined in chapter 3, as in the previous chapter. Both the quantitative and qualitative data pertaining to each question will be outlined in answer to the question. The chapter ends with a summary of the questions and overall findings that came from them.

#### 5.1. Case Introduction

##### 5.1.1 Demographic Information

Information from the Demographic Questionnaire (Appendix 6: Section 1, Figure A) is presented herein. Lizo, a black male baby, was born in September 2015 via induced labour due to his mother's ill health. Lizo's disability is congenital and soon after birth he was diagnosed with GMFCS level 5 hypertonic cerebral palsy. At the time of the first data collection, Lizo was 8 months old and exhibited severe disabilities, the extent of which were not yet fully understood by his mother.

Zintle, Lizo's biological mother and full-time caregiver, can be considered an older parent at the age of 44 years old. Zintle is a black isiXhosa speaking woman who is married and has three additional children, two of whom are already adults themselves. For the duration of the study, Zintle was unemployed but seeking work. Her only personal source of income was from a disability grant of R800,00 that she claimed for Lizo. Zintle is supported financially and emotionally by her husband who assists her in raising Lizo. The total family income is between R 3 000,00 – R 5 000,00 per month which predominantly comes from Zintle's husband's work.

The family lives in the underprivileged township in an Eastern Cape town. They live in a well-sized house made from plastered brick with a corrugated iron roof

and a fenced off yard. They have access to electricity but their main source of water comes from a tap in the yard.

### **5.1.2 Background Information**

Lizo's birthing process was reportedly long and difficult. Zintle developed gestational hypertension or preeclampsia and doctors had to induce her labour. The second stage of labour took very long and doctors eventually had to vacuum extract Lizo, which has left his head misshapen.

Lizo was diagnosed with hypoxic ischemic encephalopathy which is a brain injury caused by a lack of oxygen during the birthing process resulting in brain damage. After birth, it was noted that Lizo was very rigid, stiff and restless. Lizo was immediately transported to the closest neonatal intensive care ward to consult with a specialist doctor. Here, Lizo was diagnosed with GMFCS Level 5 spastic quadriplegic cerebral palsy. Lizo has also been diagnosed with epilepsy. Zintle was told that due to the severity of his condition, Lizo would probably have limited functioning throughout his life.

Lizo started attending the clinic in March 2016 at 6 months of age. He was still very small for his age and his body was extremely rigid and tense due to the increased muscle tone. During his monthly visits, it also became apparent that Lizo might have problems with his eyesight as he constantly looks upwards and to the right. Lizo continued to exhibit a GMFCS level 5 cerebral palsy with increased muscle tone and low functioning. The hypertonia left Lizo in a constant uncomfortable extensor state in which he was unable to relax the muscles in his upper body, particularly in his neck and trunk. Lizo presented as severely developmentally delayed and could not sit, crawl, or babble as a baby of his age typically would.

## **5.2 Participation in the Research**

Zintle and Lizo participated in all three of the data collection phases willingly without any difficulties or interruptions.

### 5.3 Research Findings

The research findings will be presented in terms of the specific research questions in order to integrate the quantitative and qualitative accounts of the data in a rich, descriptive manner that hopes to offer insight into the effects of the intervention programme on the caregiver's well-being, the child's functioning, the caregiver-child relationship and the caregivers' experience of care received. This will be done by presenting the quantitative data from tests specific to the question and then discussing the qualitative themes that emerged from the IPA interviews that relate to the specific question. A brief discussion will ensue to comment on the integration of the quantitative and qualitative results. After answering each of the specific questions, a final discussion will summarise the effect of the service-learning programme in addition to the clinic services, on Zintle and Lizo.

The result tables for Zintle and Lizo referenced in this chapter can be found in Appendix 6. The Appendix is divided into three sections, firstly, the quantitative result tables for the CORE-OM, PEDI-CAT, EIS and MPOC-8 SA can be found in Section 1. This is followed by Section 2, which holds the Marschak Interaction Method Clinical Reports that relate to the EIS results. Lastly, the attached table in Section 3 outlines all of the themes extracted from the pre and post interpretative phenomenological analysis of the qualitative interview data collected around Zintle's experience of being a caregiver to Lizo and their participation in the intervention services.

#### 5.3.1 What is the impact of the intervention on the caregiver's well-being?

**5.3.1.1 Quantitative: Clinical Outcomes in Routine Evaluation- Outcomes Measure (CORE-OM).** The attached table in Appendix 6: Section 1, Figure B shows the results of the CORE-OM questionnaire for Zintle, which aims to ascertain the caregiver's well-being and level of distress.

**Baseline results.** During the first data collection period, Zintle's distress level was recorded just below that of significant distress at 9,7. Although this was not considered clinically significant, Zintle showed significantly high scores for the domains of Well-being (17,5) and Life Functioning (12,5), making her at risk to become clinically distressed.

During the second baseline collection, Zintle's score increased slightly to 10, which was clinically significant and indicated a mild level of distress. This score resulted from an increase in Zintle's symptoms with an increase in her Problems domain from 9,2 to 12,5. Zintle's scores for Well-being and Functioning remained significantly high at scores of 17,5 and 10 respectively.

***Post-Intervention results.*** After the intervention, Zintle's overall CORE-OM score was recorded at 5,6 which was a drastic reduction in her distress levels from the second data collection at baseline. She was no longer considered clinically distressed or at risk for clinical distress. This was a significant decrease from baseline data with a 4,4 point decline in distress levels. The reduction resulted from a decrease in the domains of Well-being, Problems and Functioning. Zintle's Well-being improved the most with a reduction of 10 points from 17,5 prior to the intervention to 7,5 post intervention. She also exhibited fewer symptoms with a Problem score of 6,7 and felt she was Functioning better with a score of 6,7.

Thus, the quantitative data indicates that the service-learning programme in addition to the clinic may have had a significant effect on reducing Zintle's levels of distress. However, the clinic alone seemingly had no effect on reducing her distress levels prior to the service-learning intervention.

#### ***5.3.1.2 Qualitative: Interpretative Phenomenological Analysis (IPA)***

***Interviews.*** Below, are some of the themes that arose from Zintle's baseline and post-intervention IPA interviews with regards to her experience of being a caregiver to a child with disabilities and the effect it has had on her well-being and levels of distress. An overview of the themes from the baseline and post-intervention interviews can be seen in Appendix 6: Section 3, Figure F and G.

***Baseline interview.*** Some of the themes and emotions that arose during Zintle's initial baseline interview with regards to her well-being and level of distress were: shock and disbelief, hurt, unfairness, resilience, helplessness and loneliness. These will be discussed in detail below.

*"I did not expect to have a child like this".* Zintle expressed the trauma she experienced having a child with disabilities and how unprepared she felt for it. She stated it was shocking for her to find out that Lizo was not able to do anything for

himself even though he looked physically like a typical baby, which left her in a state of disbelief.

“It was a very difficult journey because I had not expected to have a child like that.” (Page 9)

“I was really shocked that he would not be able to do anything for himself even though he had all the limbs, everything, so I was really shocked.” (Page 10)

Zintle also expressed the hurt, sadness and worry she felt from knowing her child had such severe disabilities. She explained how deeply painful it had been and described the sadness that had ensued knowing her child was different. She also placed emphasis on certain disabilities, such as blindness, being more devastating to accept than others. Zintle explains how this hurt even manifested physically with her blood pressure increasing to dangerously high levels.

“I was deeply hurting, I was always crying, it hurt a lot. I was always crying and wondering what could be causing my baby not to cry, what could be blocking him. My blood pressure even increased during this time because I was so worried.” (Page 10)

“Oh I was not ok at all because of the way he was, I was really not ok.” (Page 14)

“It made me feel so sad because they (family) really wanted to hold him but they also understood that he was different, so it was painful seeing that.” (Page 16)

“What breaks my heart the most is that he will be blind, that one really breaks my heart. The fact that he will not be able to walk does not bother me much but the being blind it’s so much harder to accept. He alone has all the disabilities, being unable to walk and unable to see, it really makes me sad.”  
(Page 4)

*Alone with the responsibility.* Zintle expressed how she felt solely responsible for Lizo’s care and could not trust others to provide the same care or help her. She felt that this was quite disruptive as she could not leave Lizo with her husband or other children for long periods and found herself continually rushing home to be with him for fear of what might happen if they did something wrong.

“He will not be able to do anything for himself, he will depend on me, I will do everything for him.” (Page 9)

“I make sure I get back home as soon as I can because I don’t want them to do something they shouldn’t do (to the baby). If I told them to feed him his bottle, that’s what they must do and give him his porridge and nothing else. So I make a point to get home as soon as possible.” (Page 16)

“The other children I used to leave because they were nice and sweet they didn’t have any problems. I would leave them and come back whenever I wanted.” (Page 16)

Zintle also articulated how she felt she was suffering alone. She expressed that there was no one at home or in her life she felt she could talk to about the hurt and sadness she was carrying with her. Zintle also spoke about how she felt that she did not want to burden anyone with this, as she knew that they were experiencing the same difficult emotions. She also expressed how she spends a lot of time alone with Lizo during the day, which is when she overthinks and feels sad without anyone to share the experience with or express herself to.

“No, there was no one I was talking to at home. I was not talking to him (husband) because he was also going through the same thing as well.” (Page 12)

“It (being sad) usually happens when I spend the whole day with him. That’s what causes me to think a lot and break my heart.” (Page 3)

*Acceptance.* Zintle also spoke of her need to be resilient and strong for her family by trying to come to a place of acceptance. She acknowledges that she feels hurt and saddened by Lizo’s diagnosis but she realises that this will not resolve it and therefore, she tries to console her hurt and find happiness in his uniqueness by accepting him. She also exhibits good insight into the strong connection between her emotional well-being and the effect that it has on Lizo’s well-being. However, there is also an undertone of helplessness in Zintle’s narrative, realising that she cannot change Lizo’s diagnosis and her way of dealing with this realisation is to try and come to terms with it and accept him.

“No I just told myself that being sad won’t help instead it will affect him as well. So I have to be well so that he can be well.” (Page 3)

“I thought about it and realized that being heartbroken will not help, I must console myself.” (Page 11)

“It hurts, it doesn’t feel good at all but I always remind myself to accept it because there is nothing I can do about it.” (Page 3)

“It doesn’t help being sad about it or treat him differently because of his disability. I have accepted that he is like that and he is the only one who is like that, so that makes me happy.” (Page 7)

I was really shocked but then I also realised that there is nothing I can do about it except accept it. (Page 4)

*Post intervention interview.* Zintle continued to experience similar worries during her post intervention interview to those recorded during the baseline collection. She expressed that she was experiencing problems at home that worried her, as well as constraints that came with the demanding and tiring responsibility of being a caregiver to child with disabilities. Zintle also felt a need to be happy at all times so as not to transfer her emotions to others. These themes are further outlined below:

*Problems at home.* Zintle expressed that she was experiencing problems at home that really worried her and broke her heart. The worries centred on limitations she experienced for her family, as well as herself. Zintle was concerned for her older children who had inadequate opportunities to find employment and therefore remained financially dependent on her husband. This also impacted on Zintle who had to continuously ask her husband for money due to her own unemployment.

“Sometimes there are things at home that bother you, that break your heart and you realise that this particular thing is not sitting well with you, your heart is not at peace.” (Page 5)

“Sometimes it’s the children, the older children though, the fact that they are unemployed, it really breaks my heart. My children are all grown up but they are not working.” (Page 5)

“(Deep sigh, pause) It’s staying home, unemployed and not having money. The only person is my husband. You know what men can be like when they are the ones who are working, they want to keep all the money to themselves. And you have to be the one constantly asking for money for this and that. There are some men who do not mind giving you the money as the wife. But

some are unable to do that, you have to ask all the time and they don't give it to you easily." (Page 6)

"Such things hurt, they break your spirit. Sometimes Lizo has run out of nappies and I have to constantly tell him that Lizo has run out of nappies or Lizo's milk is finished. He doesn't know how to voluntarily give me money to use as I see fit and to get Lizo's things." (Page 6)

*Responsibilities.* Zintle articulated the immense responsibility of taking care of a child with disabilities, reiterating that it is a full time commitment that does not allow her to take a break. This responsibility has impacted on Zintle as she can no longer work and earn an income. She is also restricted in her movements and finds it difficult to go anywhere without Lizo, which has stopped her from doing some of the things she used to.

"Having a disabled child is difficult because you have to tell yourself that you have this disabled child now you see. You have to constantly take care of him and not get tired or fed up with him, you can't get tired of a disabled child." (Page 9)

"It's hard because you have to constantly take care of him so that he can also be happy being with his mother." (Page 9)

"A lot changed because I cannot work. Even when I have to go somewhere I have to think who could be a suitable person to take care of him, someone who will take good care of him and not mistreat him. Going to places is difficult such that I don't go to places anymore. Even funerals, I don't attend funerals because there is no one to leave him with." (Page 10)

*Need to be happy.* Zintle also expressed how having a child with disabilities encourages her to be happy all the time so that he can be happy too. She felt that it was inappropriate to express negative emotions as this would impact on Lizo's emotions, just as it had done when she was pregnant with him. Therefore, she chose to rather hide or ignore these negative emotions, feeling that she had to be resilient and show happiness. There seemed to be an underlying sense of guilt for feeling negatively about Lizo and therefore, Zintle appeared to negate these negative emotions and overcorrect with positive emotions.

“You have to be happy all the time so that he can also be happy because if he is not happy and at peace in his soul, he will not grow.” (Page 9)

“It was not looking good even when I was pregnant, you see because I was always, because I was fighting at home. I was always fighting with my husband, always hurting, I would cry a lot, all the time (laughs). Oh I really cried a lot, that's why they are saying Lizo is an emotional child, it's because I was always sad.” (Page 20)

*Family Support.* Zintle experienced happiness and support from spending time with people in her family, particularly her older daughters who continued to live with her at home. She found much enjoyment in spending time chatting with them, watching cartoons, reading the bible and seeing them play with Lizo.

“No, even yesterday I was happy because we went to visit my family, so I was with my family. We even spent the night there, they didn't want us to leave so we slept there. I am so happy.” (Page 5)

“It's spending time with Thandeka\* and Anele\* (older daughters), just chatting because when Anele\* comes back from school she doesn't usually go out to play. So I always spend time with her just talking and she plays with

Lizo, and that makes me happy, we watch television, cartoons (laughs).”  
(Page 9)

“I usually take the bible and read. Sometimes I ask Anele\* to read or to read me a story that she likes. Anele\* loves reading stories, I ask her to take her stories and read for me while I am with Lizo.” (Page 8)

**5.3.1.3 Discussion.** Looking at the quantitative and qualitative findings for Zintle’s level of distress and well-being, it is evident that the service-learning programme may have had a very positive effect on Zintle. This was apparent in her CORE-OM score, which decreased substantially after the addition of the service-learning programme, indicating improvement in her well-being, psychological problems, and life functioning that indicated Zintle was no longer clinically distressed.

Despite this drastic decrease in Zintle’s scores on the CORE-OM and apparent improvement in her distress levels after the addition of the service-learning programme, in the IPA interviews she continued to express that she was experiencing problems that concerned her and made her upset. These included problems at home, worries about her children, the finances and her own immense responsibilities in caring for a child with disabilities that inhibited her from gaining employment or doing the things she liked.

However, Zintle also felt that having a child with disabilities encouraged her to focus on being happy in order to keep everyone else happy, particularly Lizo. She felt that negative emotions adversely influenced her family, causing the sadness and ill health. Therefore, Zintle felt it better to avoid negative emotions in order for her to remain resilient and protect her family. It is possible that this approach aided Zintle in being happier and decreasing her levels of distress.

Zintle also expressed in the post intervention interview that she found a lot of joy in spending time with her family, particularly her older daughters. Spending time with them seemingly gave her the opportunity to do things she enjoyed, reading the bible, talking to them, and having stories read to her. This may have left Zintle feeling

less alone in her responsibilities and given her additional support that may have lowered her levels of distress.

These experiences, in addition to the service-learning programmes may have played a role in the improvement in Zintle's well-being, decreasing her levels of distress to a non-clinically significant level.

### **5.3.2 What is the impact of the programme on the child's functioning?**

**5.3.2.1 Quantitative: The Paediatric Evaluation of Disability Inventory-computer adaptive test.** The attached table in Appendix 6: Section 1, Figure C shows the scaled scores collected for Lizo from the PEDI-CAT. Scaled scores represent the child's current status along a continuum of function in the various domains and are based on a 20 to 80 point scale. An increase in score indicates that the child's performance or skill in a domain has increased, whilst a decrease in scale score indicates a possible regression.

**Baseline results.** Lizo's results from the baseline data showed increases between the two data collections in the domains of Daily Activities, Mobility, and Responsibility. Daily Activities increased slightly by 2 points from 38 to 40; Responsibility increased quite significantly by 4 points from 25 to 29; and the domain of Mobility increased the most substantially by 6 points from 33 to 39. The domain of Social/Cognitive showed a slight decrease in ability of 2 basis points from 41 to 39. Overall, it could be surmised that Lizo was showing general improvements in his functioning which may have been attributed to his attendance at the clinic and the therapy he received from the clinic services.

**Post results.** After the addition of the service-learning programme, Lizo showed an improvement for the scores of Mobility and Social/Cognitive but the domains of Daily Activities and Responsibility showed a decline in score from the second baseline collection. However, the decline in score was not lower than the initial baseline data collected with Daily Activities scoring 38 and Responsibility scoring 25. The increase in Lizo's Mobility score was only very slight with a 1 point increase to 40 from the second data collection but an overall increase of 7 points from the initial baseline data collection which is substantially improved. Although Lizo showed an initial 2 point decrease in the domain of Social/Cognitive during the

baseline phase, his score then increased substantially at the post data collection by 7 points to 46.

Thus, results from the PEDI-CAT show that the service-learning programme may have had a slight positive effect on Lizo's functioning in the Social/Cognitive domain which indicates an increase in his ability to interact and participate with others (Haley, Coster, Dumas, Fragala-Pinkham & Moed, 2012). However, the other domains all showed little changes.

**5.3.2.2 Qualitative: Interpretative Phenomenological Analysis (IPA) Interviews.** Below, are some of the themes that arose from Zintle's baseline and post-interventions IPA interviews regarding her experience of Lizo's functional abilities. The themes are outlined in Appendix 6: Section 3, Figure I.

**Baseline interview.** The themes pertaining to Zintle's experience of Lizo's functional abilities at the baseline data collection were around the immense growth and improvement Zintle had seen in Lizo since they started attending the clinic.

*He is growing up now.* The first improvement Zintle noted was that Lizo was growing at what she considered a more typical rate. She noticed he had grown bigger, and he had started to reach more milestones that made him seem more like a typical child to her. She had also noted functional changes in Lizo, such as a reduction in his hyper-extensive pattern that aided him in being able to sit. This gave Zintle a sense of peace and made her happy.

“No, it's his body that I have noticed, he is growing and becoming bigger, that's what I have noticed.” (Page 2)

“He is growing up now, he has really grown, things that he could not do when he was smaller he can now do.” (Page 14)

“It made me happy knowing that things he could not do before he can do now. So it made me feel happy, calmed my soul and gave me peace, the fact that he can now do some of the things other kids can do.” (Page 13)

“Lizo is growing up just fine. I have also noticed that his body is more flexible now. Previously, his body was a bit stiff but now it’s so much better. Even when you sit him down he sits just fine like a normal person. So some changes I have noticed include the fact that he is becoming more of a normal child as I know it...He will not be exactly like the other children but there are certain things he does that I am pleased with.” (Page 1)

*Improvements attributed to the clinic.* Zintle also attributed these changes in functioning to the clinic services, saying that the changes started when Lizo attended the clinic and that they had made the biggest difference in Lizo’s life. However, Zintle seemed somewhat vague about the exact clinic services she deemed most helpful or how these services had impacted Lizo positively.

“It’s the clinic because at the clinic they take him in and do whatever they do to him, that where the changes start.” (Page 2)

“It makes me so happy because I really do want to see him well and what they do to him (at the clinic) makes a difference in his life.” (Page 8)

“I can see that Lizo is no longer doing that, when his dad picked him up he sat properly, so I can see that the clinic really helps.” (Page 9)

***Post intervention interview.*** Zintle experienced Lizo’s functional abilities and growth as a difficult and slow process. However, she noted that Lizo was trying and this showed in small functional improvements. She also cited improved health in Lizo. She attributed these improvements to her own devotion to Lizo and the care she gave him, as well as to the Clinic that has taught her so much.

*Growth with difficulties.* Zintle experienced Lizo's development as being extremely slow and difficult. She noted that he continued to have severe delays in his functional abilities when compared with children his age, not being able to sit or crawl.

“Difficult, yes. Difficult because his growth is with difficulties. It's difficult, other kids grow up faster by he is much slower.” (Page 2)

“I mean when it comes to things like sitting and crawling, he does not do any of those things, a child start by sitting first and he cannot sit, he cannot do anything.” (Page 2)

*“He is trying now”.* Zintle seems to observe Lizo very closely and seems sensitive to small changes she experiences in his functioning. Despite Lizo's severe disabilities, Zintle described how Lizo had now started trying when presented with a challenge. She explained that although he may find these challenges hard, Lizo attempts to do what is being asked and he eventually manages to do it. Thus, Zintle experienced Lizo's development as improving and growing.

“Lizo currently is growing up just fine, uhm, he is the kind of child that, he is trying now compared to before. There are certain things I have observed that have changed, things that he is trying to do. Because sometimes you can find him smiling, that's one of the things he is doing. Yes, also using his hands, he is really trying to use his hands more. What he has not yet started using are his legs but he is using his hands. Sometimes when I lay him on his stomach with his arms and hands underneath, he really tries until he is able to remove and stretch his arms.” (Page 1)

“It's his development and growth, he is growing up well, yes he is growing up well; he is growing up well starting from then until now.” (Page 3)

*Health improvements.* Zintle also experienced health improvements in Lizo. During the baseline interview Zintle noted that Lizo had recently begun having seizures but during the post intervention interview she reported that Lizo's seizures had seemingly stopped as the treatment he had been prescribed had helped bring them under control. This seemed to be a huge relief for Zintle as her fear for Lizo's health had previously worried her.

“He is fine health wise, I am happy with how he is doing now, especially with the treatment he is taking. I can tell that it is really working.” (Page 2)

“He was not in good health before because he would sometimes have the fits but now he doesn't get those anymore.” (Page 2)

*Devotion.* Zintle experienced the improvements in Lizo as being due to her own devotion to him, saying that she had learnt a lot from the clinic but it was her own dedication to Lizo that helped her employ what she had learnt and give him the best care possible that has helped him improve.

“What helps him is the fact that I am devoted to him. I have accepted it and decided that I must raise him just like my other kids so that he can also feel good in his heart. “(Page 3)

“It's spending time with him, helping him do things, and seeing him trying to do what I have just helped him do , that makes me happy, yes (laughs).” (Page 9)

**5.3.2.3 Discussion.** The IPA interviews showed that Zintle experienced Lizo as continually growing and improving in his abilities and health with her reporting positive advances in his functional abilities at both the baseline and the post-

intervention data collections. However, Zintle also noted at the post-intervention interview that Lizo's improvements were slow and difficult due to him having limited abilities due to his disabilities.

This was in line with what the PEDI-CAT reported as only slight improvements and minor fluctuations were seen in Lizo's results. The fluctuations could be perceived as a generally positive trend as Lizo's initial and baseline data showed no significant decreases. The baseline phase saw only positive increases in all functional domains, while the post-intervention saw some decreases, however, these did not fall below the initial data collected indicating that the service-learning programme in addition to the clinic did not necessarily have a negative effect on Lizo's functional abilities. Improvements were seen in domains of Mobility and Social/Cognitive at the post-intervention data collection indicating that the service-learning programme in addition to the clinic may have had a positive impact on Lizo's functional abilities. Maintenance in functional abilities can in itself be seen as an accomplishment in a child with level 5 CP.

At the baseline interview, Zintle attributed all of the improvements she had seen in Lizo to their attendance at the clinic. She attributed these changes passively without regard for her role in the intervention, stating they take him and do whatever they do to him, which makes him better. However, after the addition of the intervention Zintle seemed to be able to identify the importance of her role in helping Lizo by attributing the functional improvements to her own dedication to Lizo through the help of the intervention services. Thus, the addition of the service-learning programme may have also had a positive effect on Zintle's identity as a caregiver, empowering her to see the positive changes she has instilled in Lizo.

### **5.3.3 What is the impact of the programme on the caregiver-child relationship?**

#### ***5.3.3.1 Quantitative: Emotional Interaction Style- Assessment of the Marschak Interaction Method.***

***Baseline results.*** The scores obtained for Zintle and Lizo's EIS are outlined in Appendix 6: Section 1, Figure D. At the initial baseline collection, Zintle and Lizo obtained an EIS score of 23,5 for the MIM observation of their interaction. This is a relatively average score and could be used to describe their relationship as somewhat

variable, showing times of good attunement as well as times of poor interaction. The score remained somewhat low due to Lizo's functional disabilities that inhibited him from responding to Zintle's efforts. This was particularly apparent in his poor scores for emotional reciprocity and playfulness that he was not able to show. Despite this, Zintle still provided a variable to good amount of structure, emotional reciprocity, nurture and playfulness. Some of these scores remained variable, as Zintle would "reprimand Lizo for crying, rather than acknowledging his emotions but she would still physically respond in a nurturing manner to restore his mood and reengage him." It was also found that although Zintle was an extremely positive and encouraging caregiver, "she still seemed to not have accepted Lizo's disability and still had large dreams for him that were more than likely unattainable (such as becoming a doctor)." Despite this, in the MIM Clinical Report 1 summarized that they "seemed to have a good relationship that is affectively attuned and in synchrony at most times. They looked very comfortable with one another and seemed to enjoy their interaction."

The second data collection period saw a slight improvement in the EIS score from initial baseline phase to a score of 26, which still indicated a variable relationship between the caregiver-child dyad. Lizo's scores for the different domains remained low due to the severity of his disabilities that prevent him from showing emotional reciprocity, initiative, and playfulness. However, Lizo did respond well to his mother's attempts to nurture him. Zintle improved marginally in all of her domains when compared with the previous EIS, showing scores of good for the domains of Structure and Challenge, Emotional Reciprocity, Nurture and Playfulness. The Clinic Report states, "Overall, they seemed to be very in tune with one another and comfortable with each other's presence and physical touch. They responded well to each other with Zintle providing good amounts of structure, engagement, nurturance and challenge. Zintle was a very expressive, empathically aware and caring parent who was able to acknowledge Lizo's feelings and react to them in an appropriate manner to restore his mood when he became distressed. Zintle was also open to challenging and teaching Lizo new skills and encouraging him to strive."

From the observations of the MIM, it seems as if Zintle and Lizo had a fairly good relationship prior to entering into the research, which was evident in the scores obtained from baseline 1 and 2. Their relationship may have also been somewhat

assisted by the intervention of the clinic, with their second MIM observation being recorded as slightly improved compared to the first.

**Post results.** After the intervention, Zintle and Lizo's EIS score decreased to 22, which is lower than both the scores recorded at the baseline phase, indicating an inadequate interaction style. Both Zintle and Lizo saw slight decreases in all of the domains with Lizo scoring particularly low, barely engaging or showing playfulness. However, Lizo was able to score well on nurturance, responding well to Zintle's attempts. The MIM Clinical Report showed that "Zintle was a highly energetic and engaging caregiver who aimed to challenge Lizo, encouraging him to strive. However, at times she did not affectively attune to Lizo's emotions causing him distress due to too much challenge or engagement. Zintle was able to realise this and she apologised to Lizo whilst providing him with nurturance and care to sooth him. Lizo responded well to Zintle and they were able to show a comfortable and loving relationship with good amounts of structure and nurturance."

Although the scores fluctuate, Zintle and Lizo's relationship was still recorded as being good with high levels of nurturance and structure that made them look comfortable together. However, there was a slight decrease in the EIS score between the baseline and post-intervention interviews which may have indicated a slightly adverse effect to their relationship with the addition of the service-learning programme. However, it is also important to consider that this score is susceptible to the influence of both the caregiver and child's mood during the observation. It is also possible that ending of the service-learning programme and the research may have impacted this.

### **5.3.3.2 Qualitative: Interpretative Phenomenological Analysis (IPA)**

**Interviews.** Below, are some of the themes that arose from Zintle's baseline and post-interventions IPA interviews with regards to her experiences of the relationship between her and her infant. The themes are outlined in Appendix 6: Section 3, Figure J.

**Baseline interview.** Some of the themes that arose during Zintle's initial baseline interview concerning her relationship with Lizo were that they had a strong, understanding connection between them, which was indicative of a good relationship.

However, Zintle also doubted herself at times and worried that she might misunderstand Lizo's needs.

*A strong connection between mother and child.* Zintle experienced the relationship between her and Lizo as being very good. She described feeling that despite Lizo's disabilities he knew who his mother was and would quieten down quickly when Zintle held him. This made Zintle pleased to know that Lizo recognised her and identified with her as he could tell her apart from others, therefore indicating a good bond between them. She placed emphasis on the importance of being physically close and bonded to Lizo and felt that he was able to recognise her through this.

“No, we get along. Whenever I hold him he can tell that he is held by his mother. I also talk to him so that he can distinguish my voice and know that I am his mother.” (Page 4)

“When we are about to sleep, especially during bedtime, I put him here, he sleeps there and when I try to remove him so I can put him on the bed, he can tell...He is like that sometimes, he just wants me to hold him.” (Page 5)

“I don't know how he can tell when it's his mother holding him. I talk to him and calm him down and he does keep quiet when I do that...It makes me so happy, even at home, when he cries and then I take him and he quickly quiets down....He knows when he is held by me and I often wonder how he can tell that his mom is holding him.” (Page 4/5)

*Pride in understanding child.* Zintle expressed how she felt proud of herself when she was able to identify Lizo's needs. Being able to understand Lizo made her feel happy as it showed she was able to connect with him and know him despite his disabilities.

“I feel happy and impressed by the fact that I understood what he was trying to say.” (Page 6)

*Worry about misunderstanding child.* However, Zintle also expressed that she worried and feared misunderstanding Lizo. She expressed the pain she felt in not being able to understand him at times due to his inability to communicate which left her guessing what it is that Lizo might want or need, or what exactly it was that made him happy. These concerns are not atypical of a caregiver of a young child, however, her trepidation seemed to be exacerbated by his disability which made her more concerned than she had been with her previous children.

“It is painful, not knowing whether he wants to or not, it’s painful. Maybe you do something to him only to realize that he does not want but he has no other way of telling you because he cannot speak.” (Page 17)

“There are times when I find him smiling and I won’t even know why he is smiling, what he is thinking, or feeling that causes him to smile so much. Even when I play with him I usually play with him and I notice that he smiles a lot even though I wouldn’t know what brought the smile about.” (Page 5)

*Post-intervention interview.* During the post-intervention interview, Zintle experienced her relationship with Lizo as being a strong bond of understanding. She expressed that she loves him and felt that she was able to understand him. However, Zintle also expressed her frustration and exhaustion she felt when she did not understand Lizo’s wants and needs which resulted in him constantly crying. She put this down to possibly spending too much time together and how important it was to have other people to step in at times to help give them both a break.

*“He is loved”.* Zintle expressed that Lizo was very much loved by everyone, but he was particularly loved by her. She voiced that nothing had changed and she always loved him, despite the difficulties she had in raising a child with disabilities.

“I love Lizo, nothing has changed, nothing has changed, I love him.”

(Page 11)

*I understand him.* Zintle felt that she was really starting to understand Lizo’s wants and needs. She felt that she was better able to learn and understand his subtle ways of communicating with her that indicated what he might want, such as food or to be moved. She seemed more confident in her ability to understand him. This made her feel a greater bond to Lizo.

“But now I can see, I can tell when he wants food, I have noticed certain signals he does when he is hungry; I know what kind of child he becomes when he is hungry or when he needs his nappy to be changed... I understand him, yes.” (Page 3)

“We get along very well (laughs). Such that even when I am sleeping at night, I put him very close to me so that I can see that he is right here. Sometimes I even let him sleep here; I completely forget that he is here. And then later on in the night I’ll hear him breathing heavy because he wants to be removed, so I move him and put him right next to me on his pillow, then he sleeps (laughs).” (Page 11)

*Getting tired of each other.* Although Zintle expressed that she experienced a good, strong bonded relationship with Lizo, she also felt exhausted and frustrated at times when she was not able to understand Lizo’s wants and needs which resulted in him constantly crying. She put this down to possibly spending too much time together and the importance of having additional support to step in and help give them both a break from each other. Zintle also seemed to be more trusting of others caring for Lizo.

“No he, sometimes he does not keep quiet when he is with me. So maybe Anele or Thandeka take him and tries to calm him down and he quickly calms down and keeps completely quiet (laughs). I don’t know if it’s, maybe because he would be tired of being with me or what, I don’t know. Such that even now Anele helps put him to sleep.” (Page 12)

“He also know how to (laughs) take chances and completely refuse to keep quiet to a point where I also get tired. So when I am very tired, I hand him over to his father and say there you go, I am tired, it’s your turn to experience what it is like (laughs). Because sometimes he cries and you won’t even know when he is crying and he will cry non-stop and that’s when I hand him over to his father... We don’t get along when he cries.” (Page 12)

**5.3.3.3 Discussion.** Zintle’s relationship with Lizo was observed in the MIM as being good with them being comfortable in their interactions together. Zintle was observed as being an expressive and empathically aware caregiver who structured, nurtured and challenged Lizo well throughout the research process. Their interaction was particularly good during the baseline phases with Zintle reiterating their strong bond in the IPA interview. She felt that she was able to understand Lizo and they got along well, however she was also very concerned about misunderstanding him and causing him more distress.

After the addition of the service-learning programme Zintle and Lizo’s relationship was recorded as being slightly poorer on the EIS with Zintle being observed as being a little too high energy and challenging for Lizo at times which upset him. This may have been due to observer effect whereby Zintle felt pressurised to perform. However, their relationship was still good with Zintle being able to recognise Lizo’s sadness and nurture him back to comfort. In the IPA interview Zintle reiterated the strong bond that existed between her and Lizo by saying he was very much loved by her and she understood him well. However, she also admitted that sometimes they both got tired of spending time together and this is when they clashed with Lizo crying endlessly and Zintle not being sure what to do.

Thus, it seemed as if the clinic might have had a positive effect on Zintle and Lizo's relationship prior to the start of the service-learning programme. However, the addition of the service-learning programme seemed to have a slightly negative effect on their relationship with Zintle experiencing bouts of exhaustion and frustration with Lizo when she did not know how to care for him.

### **5.3.4 What is the impact of the programme on the caregiver's experience of care received from service providers?**

**4.3.4.1 Quantitative: The Measure of Process of Care- 8 South Africa.** The attached table (Appendix 6: Section 1, Figure E) shows the scores for the MPOC-8 SA that aimed to measure Zintle's experience of care received from the Clinic prior to the intervention and then her experience of care received from the service-learning programme in addition to the clinic after the intervention. The scores obtained from the test are then expressed as percentages in order to understand the score in terms of the percentage of satisfaction with the services.

**Baseline data.** At the first data collection Zintle rated her satisfaction with the clinic at 55,36% satisfied which is an average level of satisfaction with the services.

At the second baseline data collection Zintle expressed her satisfaction with the services as 73,21% which is very high in contrast to the first baseline collection.

**Post Data.** During the last data collection period, Zintle rated her satisfaction with the service-learning programme in addition to the Clinic at 64,29% satisfied. This level of satisfaction was improved from the initial baseline phase; however, it was lower than the second baseline phase. This may have indicated that Zintle was not as satisfied with the service-learning programme as she was with the clinic. However, it is also important to consider that the ending of the service-learning programme, which left caregivers feeling deserted, may have influenced this score.

**5.3.4.2 Qualitative: Interpretative Phenomenological Analysis (IPA) Interviews.** Below, are some of the themes that arose from Zintle's baseline and post-interventions IPA interviews with regards to her experiences of the clinic and the

service-learning programme. A full list of themes regarding Zintle's well-being is outlined in Appendix 6: Section 3, Figure H.

**Baseline interview.** The themes that arose during Zintle's baseline interview with regards to her experience of the clinic were that she experienced them as guiding, acknowledging and encouraging her to better care for Lizo. She also found the support of the other parents to be helpful.

*Clinic providing guidance, acknowledgement and motivation.* Zintle expressed that attending the Clinic with Lizo had offered her guidance and insight into how best to assist him with his disability. She expressed that they did this by teaching her about his disability and showing her exercises to improve his functional abilities and ease his hyper extensive patterns. She seems to exhibit a good understanding of the clinic's function in the transference of skills that they aim to supply caregivers with.

"I do all the things that they tell me to do...I have noticed that it helps him a lot." (Page 7)

"They do whatever they have to do to him and they even give me things to do with him when I get home as well." (Page 2)

Another aspect that Zintle enjoyed about the Clinic was their acknowledgement and praise of her effort, which was encouraging for her to hear.

"And also when I get home from the clinic, I also continue what they did at the clinic. When I go back to the clinic they do notice the difference as well, they can tell that I also continue with what they started." (Page 7)

Attending the clinic also motivated Zintle as she could see the improvements it had in Lizo. This motivated her to want to help him too.

“It always motivates me to go to the clinic because Lizo has a tendency to do this, but there, they help him to do this. So I can see that it has helped him a lot and I must do it so I can help him too.” (Page 8)

*Clinic’s community of caregivers.* Zintle also experienced the community of caregivers and children with disabilities as helpful as she no longer felt alone seeing other children that were similar or worse off than Lizo.

“Another thing that helps is going to the clinic and being with other parents who have children that have the same problem. That helped because it made me realize that my child is just like any other kid and also because there are children who are far worse than my child.” (Page 9)

“It was seeing other parents who had children with the same problem going to the clinic that helped me a lot because I realized that there are other children who are like my child.” (Page 14)

***Post intervention interview.*** During the post intervention interview, Zintle continued to praise the Clinic, experiencing it as encouraging, a learning experience, and acknowledging of her efforts. These themes are discussed below:

*Encouragement.* Zintle felt very encouraged to continue attending the clinic by all the role players in the public health care system, including the nurses, who continually urged her and reminded her to attend therapy.

“They take him and check him and they always remind me to check the dates for his physiotherapy sessions so that I don’t miss is, they are always reminding me when it comes to his sessions... the nurses, without fail, they remind me not to miss his physiotherapy dates, they always urge me to bring him back for physio, and I always say I will.” (Page 17)

*Learning experience.* Zintle also experienced the clinic as a learning experience for her. She felt that every time she attended the clinic she learnt something new that she could take away and use to help Lizo at home. She also exhibited a very good understanding of the developmental trajectories for a child with disabilities.

“The physiotherapists take Lizo and stretch his legs. This time around they were teaching me how to lay him down on his stomach with his arms underneath the stomach so that he can learn how to turn over on his side. When his nose touches or is against the floor he will know that he needs to lift his head, so that’s what they were doing to him last week. And also because he cannot see with his eyes they made him a cardboard box, painted it black and put certain things in it. They took him and put him inside the box and they would take things out one by one and put a torch inside.” (Page 17/18)

“Uhm it taught me that I have to take care of Lizo and do all the things that I am told to help him do... Even if there is not significant change or he doesn’t do these things properly but at least he is trying.” (Page 18)

“Nothing has been unhelpful that would make me not go to the clinic, one has to go to the clinic so they can get help.” (Page 18)

*Acknowledgement.* Another aspect that Zintle enjoyed about the clinic was that she felt very much motivated and happy with the acknowledgement she received from the therapists who could tell she was employing the methods she had been taught to help Lizo. This made her feel as if she was making a difference to Lizo and helping him improve.

“It helps because I can see that there are certain things Lizo is now trying to do, I also try to help him do the same things when we’re at home. They also say that they can tell that I am also playing my part when we’re at home

because they can see some changes in Lizo when they meet with him again.”

(Page 18)

Zintle also experienced the addition of the service-learning programme as enjoyable and helpful for various reasons. The emerging themes centred around her enjoyment of spending time with the students, the break it offered her and the empowerment she felt in guiding them.

*Enjoyment in spending time with the students.* Zintle experienced enjoyment in spending time with the students and Lizo. She expressed that during their visits she felt free, and relaxed and they had a good time together. The visits gave her time to talk and possibly eased her loneliness by bringing her company at home.

“They would spend time with us. If Lizo is awake they would take him, spend time with him, talking to him and also talking to me and they would play with Lizo as well.” (Page 9)

“I was very happy to a point where I would even ask them what they were in a hurry for when they were leaving (laughs). Yes, I was very happy with them.” (Page 15)

“I learnt that they were good people. They would arrive, have a chat with me, play with the baby and have a good time.” (Page 15)

“It was spending time with them, talking to them. I was always free uhm whenever they would come and visit I would feel free and relaxed.” (Page 16)

*Gave her a break.* Zintle felt that she could trust the students with Lizo which gave her a break to do errands around the house while they played games and cared for him.

“No, it was nice because I was able to leave them playing with Lizo and go do some laundry. No, it was really nice because they were kind people.” (Page 14)

*Empowering- “I taught them”.* Zintle also experienced the service-learning programme as empowering as she was able to take the lead and teach the students about her child and how to work with him. This seemed to make her feel proud of her abilities and acknowledging of her understanding of Lizo and the care she is able to offer him.

“I taught them what I was taught at the clinic how to hold Lizo. I also taught them and showed them what they needed to do when they were with us at home.” (Page 16)

“They learnt that I understand Lizo; I know what he is like when he is hungry.. so that is what they learnt, that I understand him and that it wouldn’t be easy for someone else to take care of him because I know him better, I know what to do with him (laughs).” (Page 16)

*Research as an intervention.* Zintle may have also experienced the research as an intervention saying it helped her learn to speak about the problems she was facing more openly and talk about Lizo without shame and embarrassment which made her feel free.

“It has taught me how to speak about Lizo without shame or embarrassment, to speak freely about my child...I’m not someone who likes talking (laughs) but then it has taught me how to talk to people.” (Page 19)

‘No it was a release for, I feel free after I have spoken about something that is bothering me... Because it is what it is, I have to talk so that I can be free.’  
(Page 19)

**5.3.4.3 Discussion.** At the start of the research process, Zintle expressed that she had an average level of satisfaction on with the clinic on the MPOC-8 SA, however, this level of satisfaction increased remarkably at the second baseline collection with Zintle expressing far greater satisfaction with the clinic on the MPOC-8 SA. This level of satisfaction was reiterated by Zintle’s remarks in the IPA interview, which stated she found the clinic to be a source of great guidance, acknowledgement and motivation. She also found support from the clinic’s community of caregivers who she was able to share her experiences with and realise she was not alone in having a child with disabilities.

After the addition of the service-learning programme, Zintle rated her satisfaction with the services as above average on the MPOC-8 SA. However, her level of satisfaction had decreased from the second baseline collection, although it remained higher than the initial baseline collection. In the IPA interview collected post intervention, Zintle continued to express her enjoyment of the clinic, stating that they were encouraging, a great learning experience and acknowledging of her efforts to help Lizo improve. However, Zintle also experienced satisfaction in taking part in the service-learning programme. She expressed that she had experienced great enjoyment in having the students visit her and Lizo. Zintle also felt that the service-learning programme gave her a break from taking care of Lizo so she could do errands around the house. Zintle also seemed to experience the visits as empowering as she got to teach the students how to care for a child with disabilities.

Thus, it can be surmised that Zintle was most satisfied with the clinic at the second data collection phase; however, she was less satisfied with the Clinic at the start of the research. This brings into question whether the research process was possibly experienced as an intervention prior to the start of the service-learning programme with Zintle expressing that she had found it helpful to speak about her worries and talk openly about Lizo’s disabilities without shame. This and the

excitement for the start of the service-learning programme may have had an impact on her satisfaction of the services with such a huge spike in satisfaction being seen in the MPOC-8 SA at the second data collection point as compared with the first. The ending of the service-learning programme may have left Zintle feeling a somewhat deserted which may have also impacted on the scores post-intervention.

**5.3.5 Are there trends and patterns of change that can be identified? What sense can be made of the impact of the programme in light of the caregivers' subjective experiences of the programme?**

This research aimed to use the findings from the quantitative and qualitative data to assess the impact of the service-learning programme in addition to the Clinic on Zintle and Lizo in a rich, holistic manner. The research aimed to assess the effects of the service-learning programme on Zintle's well-being and levels of distress, Lizo's functional abilities, the relationship between Zintle and Lizo, and Zintle's satisfaction with the services. In summary, the addition of the service-learning programme seemed to be enjoyed by Zintle, however, the results of their participation in the programme, based on the quantitative findings, showed both positive and negative outcomes for their participation.

The service-learning programme seemed to have the greatest positive effect on Zintle's well-being and levels of distress. Prior to the service-learning programme, Zintle showed rising levels of distress on the CORE-OM with the second baseline collection indicating her distress levels were clinically significant of a mild level of distress requiring intervention. Without the addition of any known intervention, apart from the service-learning programme, Zintle's distress levels proceeded to drop drastically after the addition of the service-learning programme and she was no longer considered clinically distressed, nor was she at any immediate risk.

Despite the positive outcomes of the CORE-OM Zintle still continued to express that she was experiencing problems at home and struggling with the responsibilities of being a full time caregiver to a child with disabilities that inhibited her from gaining employment or doing things she enjoyed. Zintle seemed to be better able to express these negative emotions during the post-interview, however, it was apparent that Zintle still tended to focus on trying to remain positive and happy

despite her difficulties. In addition to this, it seems that after the addition of the service-learning programme, Zintle was better able to identify and own her role in providing care for Lizo that had helped him improve positively. The service-learning programme had seemingly assisted her in recognising the effort she put in to doing the therapies she had learnt as she taught them to the students. This helped Zintle recognise the importance of her own role and she may have been better able to acknowledge herself as a contributor to the positive effects seen in Lizo, as opposed to attributing it solely to the clinic.

It seems that that the clinic may have had a very positive effect on Lizo's functional abilities in the PEDI-CAT with Zintle attributing Lizo's improvements to their work. However, the addition of the service-learning programme also possibly contributed to certain increases in Lizo's functional abilities, with a significant increase seen in the domain of Social/ Cognitive on the PEDI-CAT, which indicated improvements in his abilities to interact and participate with others. This improvement was reiterated by Zintle who felt that she and Lizo both enjoyed spending time and interacting with the students from the service-learning programme. A slightly positive increase was also seen in Lizo's scores for mobility. However, Lizo remained very delayed throughout the research process.

The addition of the service-learning programme seemed to have a slightly negative impact on the caregiver-child relationship. In the IPA interview after the addition of the service-learning programme, Zintle spoke of her and Lizo as having a good relationship with much love and understanding which was a reiteration from the first interview. However, she also alluded to the difficulties she sometimes experienced when she and Lizo seemingly got tired of spending time together and she could not control his crying no matter what she tried. Zintle seemed to get a little frustrated and tired spending all of her time with Lizo; this was particularly due to his lack of reciprocation in their interactions. It may be that Zintle was also better able to express the difficulties she was facing in the post-interview, which can be a cathartic and healthy practice for caregivers. By expressing her difficulties Zintle also seemed to allow herself trust and rely on her support system to assist with Lizo's care.

Zintle also expressed less satisfaction with the services after the addition of the service-learning programme on the MPOC-8 SA. Despite this lower level of satisfaction, Zintle did not express anything negative about the clinic or the service-

learning programme in the IPA interviews. Zintle articulated that she really enjoyed participating in the service-learning programme, particularly spending time with the students. She also felt that the service-learning programme gave her an opportunity to take a break from the full time responsibility of caring for Lizo, which gave her a short time to do things she needed to do. Zintle also enjoyed teaching the students about Lizo and showing them what she had learnt from the clinic, which empowered her and showed the students that she knew how to care for a child with disabilities. Although Zintle enjoyed participating in the service-learning programme, she did not attribute any functional improvements to their visitations. However, Zintle felt that the Clinic was very helpful in helping her learn how to care for a child with disabilities and she attributed the functional improvements in Lizo to their attendance at the Clinic. Here, Zintle felt acknowledged, guided, and motivated to care for Lizo. She also experienced great support from the clinic's community of caregivers. However, it is important to consider that the abrupt ending of the service-learning programme may have left her feeling deserted and impacted negatively on her perceptions of the service.

Another aspect to consider was the role of the research and whether it may have affected the scores and outcomes measured. This was possibly seen with Zintle and Lizo in the second data collection during the baseline period where a substantial increase in certain scores was observed without the addition of any other service or a change to the Clinic. Zintle expressed that she experienced the research as helpful in getting her to be more comfortable with speaking about Lizo and his disabilities. She also felt that it was good to speak openly about the problems she was facing which made her feel free. This indicates that the research may have acted as an intervention in itself.

Therefore, it can be surmised that the addition of the service-learning programme had a possible positive effect on Zintle's well-being and Lizo's Social/Cognitive abilities while only marginal and possibly negative effects were observed in the caregiver-child relationship, and Zintle's satisfaction with the services. Despite the marginal effects, Zintle reported that she and Lizo thoroughly enjoyed their participation in the service-learning programme finding it to be helpful, empowering and acknowledging of her role as a caregiver to a child with disabilities.

## CHAPTER 6

### Research Findings: Unathi and Mandla

This chapter presents the findings on the process and outcomes of the service-learning programme with the third and final caregiver-child dyad, Unathi and Mandla. The chapter includes an introduction to the participants that informs the reader of their demographic details, the presenting problems and reasons for being included in the service-learning programme. This will be followed by the presentation of the data collected during the study. The data will be presented in relation to the specific research questions outlined in chapter 3. Both the quantitative and qualitative data pertaining to each question will be outlined in answer to the question. The chapter ends with a summary of the questions and overall findings that came from them.

#### 6.1 Case Introduction

##### 6.1.1 Demographic Information

Mandla, a black male, was born in March 2013 to an isiXhosa speaking family from Queenstown in the Eastern Cape. He was 3 years and 4 months old at the start of the data collection process. Mandla has multiple disabilities which were present from birth. He has a rare form of mixed cerebral palsy with a GMFCS level of 5. He is also believed to be visually impaired and he also has suspected hearing impairment.

Mandla's mother, Unathi, is a black 27-year-old woman. Unathi is married and together, her and her husband also have a daughter who is younger than Mandla. Unathi is a full time carer for Mandla and during the course of the study she remained unemployed but seeking work.

Their household income totals in the brack of R 1 000,00- R3 000,00 per month and is supplied by a child support grant and a disability grant. Unathi, her husband and their two children rent a small single room that is semi-detached from the main residence. The room is made from brick with a corrugated iron roof and their main source of water comes from a tap in the garden.

### **6.1.2 Background Information**

Information from the Demographic Questionnaire (Appendix 7: Section 1, Table A) is provided herein. Mandla was born by an emergency caesarean section at full term, weighing a healthy 3,5 kg. Soon after his birth Mandla took ill and had to be admitted to a neonatal intensive care ward in where he remained for the first three months of his life.

Mandla has been diagnosed with multiple disabilities that suggest several areas of his brain have been adversely affected by injury or lack of oxygen. He has GMFCS level 5 cerebral palsy that presents in a mixed manner with spasticity in his legs, low muscle tone in his trunk, and fluctuating high and low tone in his arms. Mandla was also diagnosed with cortical blindness caused by damage to the occipital lobe of the brain. Unathi has also questioned Mandla's ability to hear. Due to these disabilities, Mandla is immobile and unable to track, roll, sit, vocalise or reach for objects.

Upon their discharge from the hospital, Unathi and Mandla returned to their hometown where they struggled to find intervention services to meet their needs. They were referred to the clinic, which is located in a town approximately 240 km's away from their hometown. Initially, Unathi and Mandla made a monthly commute to attend the clinics. However, in 2015 a decision was made to relocate the family in order to live closer to the clinic, which they felt would best assist Mandla.

The clinic has aided Unathi in obtaining a Madiba Buggy for Mandla. The Madiba Buggy is an off-road wheelchair and full postural supportive device that helps Mandla sit correctly and makes it easier for Unathi to transport him as he grows.

### **6.1.3 Presenting Problem**

During the research Mandla continued to exhibit extreme delays and disabilities in his functioning due to his various disabilities. His therapeutic goals at the Clinic focussed on trying to teach him how to roll over. Other therapeutic interventions involved play that stimulates him with different textured objects, gentle massaging, sounds, lights, reflective objects and cause and effect toys. Due to his immobility, Mandla often lay on his back, which resulted in him suffering with chest infections and croup. To help this he needs to often change positions. Due to his

spasticity in his legs he also needed to wear a therapeutic doughnut when lying on his side.

## **6.2 Participation in the Research**

Unathi and Mandla were unable to attend the first data collection period in May due to unforeseen circumstances that required them to travel back to their hometown during the data collection period. The researchers opted to keep them in the research study despite this setback, as baseline data was still collected at the second data collection period. Therefore, only two sets of data will be presented for Unathi and Mandla. This somewhat compromises the validity of their findings as there is no longitudinal baseline data to understand the changes that were taking place prior to their engagement in the service-learning programme.

## **6.3 Research Findings**

The research findings will be presented in terms of the specific research questions in order to integrate the quantitative and qualitative accounts of the data in a rich, descriptive manner that hopes to offer insight into the effects of the intervention programme on the caregiver's well-being, the child's functioning, the caregiver-child relationship and the caregiver's experience of care received. This will be done by presenting the quantitative data from tests specific to the question and then discussing the qualitative themes that emerged from the IPA interviews that relate to the specific question. A brief discussion will ensue to comment on the integration of the quantitative and qualitative results. After answering each of the specific questions, a final discussion will summarise the effect of the service-learning programme in addition to the Clinic, on Unathi and Mandla.

The result tables for Unathi and Mandla referenced in this chapter can be found in Appendix 7. The Appendix is divided into three sections, firstly, the quantitative result tables for the CORE-OM, PEDI-CAT, EIS and MPOC-8 SA can be found in Section 1. This is followed by Section 2, which holds the Marschak Interaction Method (MIM) Clinical Reports that relate to the EIS results. Lastly, the attached tables in Section 3 outline all of the themes extracted from the pre and post interpretative phenomenological analysis of the qualitative interview data collected

around Unathi's experience of being a caregiver to Mandla and participating in the intervention services.

### **6.3.1 What is the impact of the intervention of the caregiver's well-being?**

**6.3.1.1 Quantitative: Clinical Outcomes in Routine Evaluation- Outcomes Measure (CORE-OM).** The attached table in Appendix 7: Section 1, Figure B shows the results of the CORE-OM questionnaire for Unathi, which aims to ascertain the caregiver's well-being and level of distress.

**Baseline result.** At the second data collection period, prior to the start of the service-learning programme, Unathi's CORE-OM clinical score was recorded at 11,2 which is clinically significant of mild levels of distress. Unathi presented with a good level of well-being with a low clinical score of only 5. However, she exhibited a moderate score of 15 for psychological problems and a poor score of 14,2 for life functioning. Unathi's results also showed signs of at risk behaviour for self-harm/harm to others with a significant score of 17 in this domain. Therefore, it can be surmised that although Unathi experienced herself as having a relatively good level of subjective well-being, it was apparent that she was exhibiting psychological problems that possibly resulted in her poor level of life functioning and at risk behaviour.

**Post-Intervention results.** Results from Unathi's follow up after the service-learning intervention indicate that she remained significantly distressed with a score of 11,5 which did not vary substantially from the pre data collection, increasing by 0,3 points. However, the post intervention data saw Unathi's well-being domain score double to 10, suggesting a decreased sense of subjective well-being from data collection 2. Unathi continued to exhibit high symptoms with a psychological problem domain score of 14,2 that only decreased marginally from data collected before the intervention. She also experienced a slightly lower level of life functioning with a slightly increased score of 15. However, she no longer showed signs of at risk behaviour for self-harm.

Thus, despite attending the clinic and participating in the service-learning programme, Unathi's well-being remained at a clinically significant level, albeit indicative of mild level of distress. What did change during the course of adding the service-learning programme was that risk behaviour disappeared.

**6.3.1.2 Qualitative IPA Interview.** Presented below are some of the themes that arose in Unathi's baseline and post intervention interviews regarding her emotional experience of raising a child with disabilities and the impact it may have had on her sense of well-being. A summarised tables of themes from the IPA interviews regarding Unathi's well-being can be found in Appendix 7: Section 3, Figure H. These themes can be interpreted alongside the quantitative CORE-OM data in order to gain a deeper understanding of Unathi's well-being.

A full outline of the themes and subordinate themes collected from the interviews with Unathi are outlined in Appendix 7: Section 3, Figure F (Baseline Themes) and Figure G (Post Intervention Themes). A breakdown of the themes pertaining to Unathi's well-being can be found in Appendix 7: Section 3, Figure H.

**Baseline interview.** The themes that emerged during Unathi's baseline interview regarding her experience of being a caregiver to a child with disabilities and the impact it had on her emotional well-being are discussed below. The themes that emerged were, acceptance of the disability, worries about her children falling ill, not having time to herself.

*Acceptance - "I am fine but I was not fine".* Unathi stated that Mandla's disability had once seriously affected her and saddened her as she realised that he would not be able to do what other children his age could. However, she felt that in recent years, she had been better able to accept his disabilities and limitations and this made her feel better.

"I am fine but I was not fine at first because of the way my child is. But as time passes I have accepted it now, so I am fine." (Page 2)

"I am not fine but I have accepted it now, so I am fine but I wasn't fine at first...I wouldn't be fine, especially when I would see children of his age and think to myself, my child would be doing this now and that affected me." (Page 3/4)

*Happy seeing child accepted by others.* Unathi experienced happiness from seeing her child being accepted by others, particularly other children who came to play with Mandla, which brought him much enjoyment.

“No we were just happy because there were other kids visiting Mandla, so we were outside playing together... it makes me happy because I know other kids do want to play with him.” (Page 3)

“The other kids know how to play with him, the ones from next door, they are now used to him and he enjoys playing with them, you will see him kicking his legs and so on.” (Page 6)

*Worry about illness.* Unathi expressed that when her children are sick it affects and saddens her. Due to Mandla’s disabilities, he is often chesty from lying still in one position. Recently, Mandla also developed epileptic seizures. These health worries affect Unathi’s well-being negatively.

“I usually don’t feel alright when my child gets sick.” (Page 3)

“He was sick, so I am usually not fine when if he is not... because he bites himself and hurts himself (from the seizures), so that hurts me.” (Page 3)

*No time to self.* Caring for a child with disabilities, as well as an additional young able-bodied child has left Unathi with little time to herself. She stated that this often left her feeling sad or upset because she could not attend to herself as she is constantly minding the children. Although this is a problem typical of most caregivers, Unathi seemed to express an additional burden in caring for Mandla due to the special care he requires.

“Sometimes I am not fine because I have no time to attend to myself...I feel sad.” (Page 5)

*Post intervention interview.* Unathi continued to express many of the same emotions and feelings around her experience of caring for a child with disabilities and the impact it had on her well-being. She reiterated that she had previously found it difficult to deal with but she had come to accept it and was fine now, even experiencing happiness in caring for Mandla. However, she also reiterated her worries around her children’s health, the immense life changing responsibility that comes with caring for a child with disabilities, and the sadness she sometimes feels.

“*I am fine now*”. Unathi reiterated that although she had previously struggled to come to terms with Mandla’s disabilities, she had in recent years come to accept it. Although she states that she is fine now and no longer feels sad about it, she also alludes to it not being pleasant to have a child with a disability.

“Since I’m okay with it now, but at first I was not alright, whenever I saw children his age I would think to myself, even he would be walking by now, things like that and that would affect me. But I am fine now.” (Page 5)

“It’s not nice but I accepted it man, what he is like and I told myself that I must accept it so I am fine now.” (Page 5)

“I don’t feel anything that, I don’t feel any sadness now I’m fine, I used to be sad when he was still young but now I don’t feel sad anymore.” (Page 8)

*Child makes her happy.* Unathi’s described her emotions as very much attuned to those of Mandla. Although she spoke about experiencing negative emotions, she also reported finding much happiness in spending time with him and stated that when he was happy, so was she.

“Uhm, Mandla is happy. When I am with him then I am happy.” (Page 4)

*Life changing responsibility.* Unathi experienced caring for Mandla as a life changing responsibility. She spoke about how Mandla needs full time care and attention, which has changed her life in many ways as his primary caregiver. She felt that she had to be with him at all times and also feared leaving him with other people. This immense responsibility has prohibited her from being able to go out and obtain employment.

“It’s very different because he needs to constantly be with someone and you can’t even go to work or do uhm, because all the time you have to be looking after him.” (Page 5)

“Uhm, it has changed because (sigh) I am unable to do some for the things I would like to do because he is here and there is no one else I can leave him with who will look after him so that’s my life now.” (Page 6)

“Things like, because he, looking for a job, yes things like that, looking for a job... I am unable to do it now.” (Page 6)

“Yho no, I hardly ever leave him, I don’t leave him... Yes, I don’t think they would manage, especially when it’s feeding time because he eats so slowly, I fear that someone might rush him... they might rush him to finish so I am avoiding things like that.” (Page 7)

*“Sometimes I just feel sad”.* Although Unathi states that she is fine emotionally, she still expressed that she experienced overwhelming feelings of sadness at times. Unathi also struggled to express her emotions and stated that there was nothing that makes her happy which shows the depth of sadness and despair she may be harbouring.

“(Deep sigh), yho how can I say it, (pause) sometimes I feel sad or just not feel alright.” (Page 5)

“Something that made me happy (pause, mumbling) yho (laughs) no there’s nothing.” (Page 8)

*Worries about health.* Unathi expressed that she continued to be affected by her children’s ill health, which repeatedly worried her and upset her.

“Last week (my other child) was not well, she had chest problems, so that is what was bothering me.” (Page 4)

“It is when Mandla is not fine that really affects me.” (Page 4)

**6.3.1.3 Discussion.** Looking at the findings from the IPA, it seems as if Unathi continued to experience similar emotions and problems caring for a child with disabilities at both the baseline phase and after the addition of the service-learning programme with few changes. This is in line with the similar scores recorded for her level of distress on the CORE-OM, which did not fluctuate significantly.

The themes extracted from the baseline and post-intervention interviews give insight into Unathi’s world, which seemingly revolves around her children due to the full time responsibility of caring for a child with disabilities. Although this is typical plight of most caregivers, Unathi expressed the specific difficulties and responsibilities involved in raising a child with disabilities which requires specialised care and attention. Her well-being and affect are also seemingly dependent on how her children are doing, stating that she is happy when they are happy or being accepted by others and feeling sad when they are not well. Children with disabilities tend to have more health challenges which may point to a vulnerability in Unathi’s well-being.

In both the baseline and post intervention interviews, Unathi reiterated that although she had initially struggled to accept Mandla's disabilities, she had in time come to terms with it and was now fine. The consistent use of the word fine is a rather neutral description of her emotional well-being and it seemed as if Unathi struggled to speak openly about her emotions, often giving short answers and never elaborating on the cause of negative feelings. This was apparent when she explained that she sometimes felt sad, or nothing made her happy which were small glimpses into her true affect. It is possible that the narrative of "I'm fine" has become a defence mechanism that attempts to downplay the distress she once felt in an effort to help her cope with the responsibilities and worries she feels.

This is in line with Unathi's CORE-OM scores which show that she has a relatively good level of well-being, particularly during the baseline phase, however, there are symptoms of psychological problems and low functional abilities that indicate that despite the good levels of well-being there are underlying problems. Thus Unathi seems to be resilient which acts as protective measure in shielding an impression of good well-being that allows her to cope, however, the underlying problems remain apparent.

### **6.3.2 What is the impact of the programme on the child's functioning?**

**6.3.2.1 Quantitative: The Paediatric Evaluation of Disability Inventory-computer adaptive test.** The attached table in Appendix 7: Section 1, Figure C shows the scaled scores collected for Mandla from the PEDI-CAT.

**Baseline results.** Mandla's results from the baseline collection showed lower scores in the domains of Daily Activities and Responsibility, which were 37 and 34 respectively. Mandla showed higher scores for the domains of Mobility, 54, and Social Cognitive functioning, 50. Due to the lack of comparative scores at the baseline phase, the possible effect of the Clinic on Mandla's functional abilities cannot be deduced.

**Post results.** After the addition of the service-learning programme, Mandla showed a decrease in all of the domain scores. The domain of Daily Activities saw only a slight decrease of 2 points from 37 to 35. There was a moderate decrease in Mandla's scores for the domains of Responsibility and Social/Cognitive.

Responsibility decreased by 5 points from 34 to 29, while the Social/Cognitive score decreased by 6 points from 50 to 44. The most extreme decrease was seen in Mandla's score of Mobility function, which dropped by 19 points from a score of 54 to 35.

Thus, results from the PEDI-CAT would suggest that the service-learning programme, in addition to the clinic, possibly had a very poor effect on Mandla's level of functioning which could be seen in all the functional domains, particularly the domain of Mobility.

**6.3.2.2 Qualitative IPA Interview.** Below, are some of the themes that arose in Unathi's baseline and post intervention interviews regarding her experience of Mandla's functional abilities and disabilities.

A full outline of the themes and subordinate themes collected from the interviews with Unathi are outlined in Appendix 7: Section 3, Figure F (Baseline Themes) and Figure G (Post Intervention Themes). A breakdown of the themes pertaining to Unathi's experience of Mandla's functional abilities and disability can be found in Appendix 7: Section 3, Figure I.

**Baseline interview.** During the baseline data collection, Unathi experienced Mandla as physically growing fine, however, she pointed out that he had limited abilities that he could perform by himself. Despite these limitations, Unathi also noted functional improvements in his abilities. These themes are further discussed below.

*Growing fine.* Unathi experienced Mandla as growing physically bigger, stating that he is now the same size as other children his age, which gave her a sense of normalcy. This growth also gave him the ability to do things he was not previously able to.

“Mandla is growing up just fine, there are certain things that he could not do... he is growing up fine.” (Page 1)

“I can tell, he is the same size as the other children his age. There is a child who is the same age as him in the (area), they are the same size, so he is growing up just like other kids.” (Page 2)

*Limited abilities.* Unathi described Mandla as being very limited in his functional abilities with him not being able to do basic tasks such as sitting, talking, seeing or eating. Therefore, Unathi experiences Mandla as being completely reliant on her to care for him.

“He cannot walk, he cannot speak, he cannot see, and he cannot sit up.”  
(Page 1)

“Lately he has started having fits but I have been told that’s what happens at some point to kids like him, they eventually develop fits. He doesn’t really eat properly, he always vomits but he can do some things like drink water. The only thing he does not do is eat properly.” (Page 1)

“He depends entirely on me.” (Page 5)

*Functional improvements.* Although Unathi experienced Mandla as having seriously limited abilities, she was also able to see slight functional improvements that he had made over time. She found that Mandla no longer cried as much and he was also able to stretch his arms and hands. Although these were small improvements, they were significant to her and indicated that Mandla was improving.

“He used to cry a lot but now he doesn’t anymore, as time passes, he doesn’t cry as much at night.” (Page 2)

“There are certain things that he could not do like stretching his arm but during physio at the clinic they always stretch his arm.” (Page 1)

*Post-intervention interview.* Despite acknowledging Mandla physically growing and slight functional improvements in Mandla's abilities, Unathi recognized how hard it was knowing he could not really do anything. Despite this, Unathi experienced Mandla as being a happy child.

*Improvements.* Unathi found Mandla to be continually growing like a normal child, comparing him to other children of his age who he is the same size as. She also experienced various improvements in Mandla's abilities, noting that he was getting better at doing tasks such as eating, using his hands to hold objects, sleeping better and crying less.

“Health wise, uhm, he is growing up alright, yes, he is growing up and is the same size as children his age. ...No he is growing, he is growing up just fine let me put it that way...when I look at him he is getting taller.” (Page 2)

“Ok, uhm, at least he, with some things he is becoming, he is getting better at doing other things like eating. He can, he used to be unable to eat, uhm, noodles nut now he can eat them when I prepare them for him he eats them. Uhm, even holding he used to, he was not really able to but now at least he is trying to hold.” (Page 1)

“He is fine man, but he is not always crying.” (Page 1)

“Even sleeping, at night he used to cry and refuse to sleep but now he can even sleep during the day and before he could not sleep during the day.” (Page 3)

*Hard knowing he cannot do anything.* Unathi found it difficult knowing Mandla had limited abilities and he would not be able to do basic things for himself. She described seeing how these limitations affected him and she described noticing

that he wants to engage with others and do things, but he does not have the functional abilities to do so.

“I don’t think it’s nice because he, when other kids are playing he, he tries to get up but he can’t, so yes it’s not nice.” (Page 2)

“What makes it not nice is the fact that he cannot walk, and cannot do anything for himself.” (Page 6)

“*He is happy*”. Despite Mandla’s limited abilities, Unathi experienced him as being a very happy child that was generally cheerful and content.

“Yoh, he is always happy, let me just say he is always fine.” (Page 7)

“Uhm, it’s when he, when we, when I play with him he becomes happy and when I massage him so he can sleep, that makes him happy.” (Page 8)

**6.3.2.3 Discussion.** Unathi expressed similar sentiments in the pre and post intervention interviews saying she experienced Mandla as growing up well but that he was severely limited in his abilities, not being able to do much for himself. However, she noted functional improvements at both data collection points, which suggest that despite his severe disabilities and limitations, Unathi experienced slight yet consistent improvements in Mandla’s abilities. The improvements Unathi felt included Mandla sleeping better, crying less, improved eating, stretching his arms and hands, and trying to hold onto objects.

This is in contrast to the outcomes of the PEDI-CAT scores which found that from baseline 2 to post intervention Mandla’s functional abilities decreased being seen in all the domains, particularly Mobility.

Although Unathi reported improvements in Mandla, these improvements may have only been very slight and may not have corresponded with the PEDI-CAT measure, which does not necessarily ask about specific abilities or react sensitively enough to them to pick up on small improvements.

### **6.3.3 What is the impact of the programme on the caregiver-child relationship?**

**6.3.3.1 Quantitative: Emotional Interaction Style- Assessment of the Marschak Interaction Method.** The scores for the EIS Assessment can be found in Appendix 7: Section 1, Figure D. The corresponding MIM Clinical Reports are in Appendix 7: Section 2.

**Baseline result.** During the baseline data collection, Unathi and Mandla presented as having an inadequate/variable relationship with an overall score of 24 on the EIS. The MIM report summary stated that “Unathi came across as quite a quiet and reserved carer that struggled to openly engage with Mandla”. This resulted in Unathi scoring poorly in the EIS domains of Playfulness (2) and Structure (3). It was apparent that “Unathi seemed to battle with certain tasks, particularly free play tasks”. During these tasks “when Unathi wasn’t able to engage Mandla she became quite frustrated and discouraged to continue with the task, thus she was not encouraging to Mandla and offered very little praise”. She also seemed to “rush through the activities at times when she felt uncomfortable”. However, Unathi seemed to be more comfortable performing daily nurturance activities with Mandla, such as feeding, cradling and cleaning him. Thus, she scored better in the domains of Parental Nurture (3,5) and Emotional Reciprocity (3,5). Mandla also responded extremely well to Unathi’s nurturance scoring 4 in this domain.

**Post intervention result.** Unathi and Mandla scored an overall score of 26 on the EIS for their post intervention data collection. This is only a slight increase of two point from their baseline score of 24. Despite only being a minor increase in score, it does indicate a more variable relationship that is slightly improved from the initial baseline score. Unathi scored well in the domains of Structure (4), Emotional Reciprocity (4), and Nurture (4) providing “a safe, comfortable and soothing environment for Mandla, catering to all of his needs and truly caring for him”. The MIM report stated that Unathi was “very nurturing towards Mandla and provided him

with a good amount of structure in tasks”. However, Unathi continued to score lower in the domain of Playfulness (3) with the report stating she “came across as very soft spoken and quiet which resulted in her struggling to engage Mandla and challenge him in an encouraging and playful manner” which was apparent in his low domain scores of Playfulness (2) and Cooperation (2,5).

The scores for the MIM EIS show that during the course of the service-learning programme Unathi and Mandla saw a slight improvement in their relationship, and certainly there was no deterioration. Although Unathi continued to be quite quiet and reserved in her interactions throughout the research, she seemed to be more comfortable operating in the situation and outside of her comfort zone during the post intervention phase. Thus, she was better able to structure the situation, be emotionally reciprocal, nurturing and a little more playful in her interaction with Mandla.

**6.3.3.2 Qualitative IPA Interview.** A list of extracted subordinate themes from the IPA Interview regarding Unathi’s experience of her relationship with Mandla at the baseline phase and post-intervention can be found in Appendix 7: Section 3, Figure J.

**Baseline results.** During the baseline phase, Unathi described her relationship with Mandla as good. The emerging themes were that they got along well and enjoyed spending time together. Unathi was also proud to be Mandla’s caregiver. These themes are further discussed below:

*“We get along well all the time”.* Unathi felt that she and Mandla got along very well and there were very rarely times that she found him to be difficult. She felt that every day with Mandla was a good day.

We get along all the time...we always get along, there is not time that is better than the previous, we always just get along.

*Enjoyment in spending time together.* Unathi described how both she and Mandla experience great enjoyment and happiness in spending time together. Unathi

described Mandla as enjoying his time with her the most and stated that when he spent time with others he was not the same as he was with her, implying that Mandla was happiest spending time with Unathi. Unathi placed great significance on being recognised as Mandla's mother by him and the love and attachment that comes with this recognition.

“He is always happy when he is with me, I can tell, and I know how to play with him and make him, laugh. But when he is with other kids he is not the way he usually is when we are together.” (Page 4)

*Proud to be his parent.* Unathi expressed that being a parent to Mandla made her very happy. She stated that being his parent was not necessarily special or distinct, but for her it made her happy.

“Yho, no I am happy to be his parent, there is nothing special about it, I am just happy.” (Page 5)

*Post intervention interview.* During the post-intervention interview, Unathi continued to experience a good relationship with Mandla. The themes that arose were around them being happy together and really knowing each other. These are discussed below:

*Happiness together.* Unathi experienced Mandla as being a happy child whenever they were together. She expressed that they always had a good time together and being with him made her incredibly happy.

“We get along, he is always happy when he is with me and whenever we are together we have a good time.” (Page 6)

“Mandla makes me happy, when I am with them I am happy.” (Page 4)

*Knowing each other.* Unathi also felt that her and Mandla really knew each other very closely and shared a special bond. Knowing Mandla's need and wants so well made Unathi really happy. She also expressed that Mandla could tell her apart from other people and often laughed when he was handed to her, which showed her the happiness he felt when spending time with her.

“Another thing is that he is used to me more than anyone, so when he is with other people and he is different compared to when he is with me. ... (laughs) we get along err Mandla and I always get along.” (Page 7)

“I know it what he is like when he is with someone else and when he is with me even when I take him, he usually laughs.” (Page 7)

“What makes me happy is knowing him yes, knowing him such that I know how to handle him when he acts a certain way.” (Page 8)

**6.3.3.3 Discussion.** From the quantitative and qualitative accounts of the caregiver-child relationship between Unathi and Mandla, it seemed as if they had a relatively good relationship and got along well with one another at both the baseline and post intervention. Unathi reported in both the baseline and post intervention interviews that they enjoyed their time together and made each other happy. She also felt that they had a very special, unique bond and got along well at all times.

The observation of the MIM reiterated this good relationship with some inadequate and variable interactions observed. During the initial baseline data collection, Unathi was observed as being reserved which impacted on her expression of playfulness and her ability to take charge and structure unfamiliar tasks. However, she excelled at tasks that involved daily activities and nurturance which Mandla reciprocated well towards. These findings improved only marginally in the post intervention observation with Unathi remaining reserved and quiet which resulted in her struggling to engage Mandla. However, she was better able to structure activities and provided Mandla with a safe, comfortable and nurturing environment.

Thus, it can be surmised that Unathi and Mandla seemed to have a good relationship throughout the research process with only slight improvements being seen in the observation after the addition of the service-learning programme. This may be indicative that their participation in the service-learning programme certainly did not impact negatively on their relationship and may have even had a slightly positive impact on the caregiver-child relationship which Unathi described in the interviews.

### **6.3.4 What is the impact of the programme on the caregiver's experience of care received from service providers?**

**6.3.4.1 Quantitative: The Measure of Process of Care- 8 South Africa.** The attached table Appendix 7: Section 1, Figure E shows the scores for the MPOC-8 SA that aimed to assess Unathi's experience of care received from the Clinic prior to the intervention and then her experience of care received from the service-learning programme in addition to the Clinics after the intervention. The scores obtained from the test are then expressed as percentages in order to understand the score in terms of the percentage of satisfaction with the services.

**Baseline data.** At the second data collection period, Unathi rated her satisfaction with the Clinics at 60,71% satisfied which is a good level of satisfaction with the services. Unathi was particularly satisfied with questions that pertained to how the Clinic provided her with enough time to talk, treating her as an equal and giving her suggestions on how to handle and look after her child. She was not satisfied with the lack of additional information available such as booklets, and she felt that they did not guide her on where to find additional support or advice such as parent support groups.

**Post Data.** After the service-learning programme, Unathi rated her satisfaction with the service-learning programme in addition to the Clinic at 48,21% satisfied, which is a relatively low level of satisfaction. Her answers remained somewhat consistent with the first data collected with Unathi being fairly satisfied with how she was treated and greatly satisfied with the opportunities she was provided to talk and voice her concerns. However, she felt extremely dissatisfied with the lack of information available in various forms such as booklets, or how to get information on

support groups, and she felt that she was not given any suggestions or ideas on how to make it easier to look after her child.

Thus, Unathi was less satisfied with addition of the service-learning programme and seemed to be more satisfied with the services provided by the Clinic alone.

**6.3.4.2 Qualitative IPA Interviews.** Below, are some of the themes that arose in Unathi's baseline and post intervention interviews about the services she received from the Clinics prior to the intervention and again after the intervention with the addition of the service-learning programme. The themes for the baseline and post intervention interview regarding Unathi's experience of care received are outlined in Appendix 7: Section 3, Figure K.

**Baseline interview.** At the baseline interview, Unathi expressed themes of great enjoyment in attending the Clinic, finding it to be extremely helpful and encouraging.

*Enjoyment going to the Clinic.* Unathi described enjoyed attending the Clinic very much. She stated that she loved attending the clinic, she particularly liked seeing, and learning all the therapies they applied to Mandla.

“I love it there, it's nice... the things they do to him, stretching him and massaging him, all that.” (Page 5)

*Clinic as Helpful.* Unathi experienced the Clinic as being extremely helpful to her and Mandla. Since they started attending the clinic a lot has changed and improved due to their help and assistance. In particular, the Clinic assisted Mandla in acquiring a Madiba buggy, a rural off-road postural support wheelchair that assists Unathi in transporting Mandla with ease.

“He gets a lot of help there because he even has a chair now and let me just say, a lot has changed since we started going there... like the fact that he now has the chair, so I no longer struggle carrying him on my back, things like that.” (Page 6)

*Encouraging.* In addition to being helpful, Unathi experienced the Clinic's therapists as being very encouraging of her. She found that they offer her the opportunity to talk and ease her worries about Mandla.

"I also get some encouragement and things like that, when they talk to me and tell me that the child will be fine." (Page 5)

*Post intervention interview.* During the post intervention interviews, Unathi continued to express positive experiences of the Clinic and she found the addition of the service-learning programme to be useful too. Some of the themes she expressed around the addition of the service-learning programme were that it was nice to see people accepting Mandla, it gave her time to rest, and she was empowered through teaching the students how to care for Mandla. However, Unathi attributed improvements in Mandla's functional abilities to the clinic, stating they were extremely helpful, they taught her how to care for Mandla, and she received support from other parents.

*Service-learning programme was nice.* Unathi described the service-learning programme as being nice, she felt really happy to participate in it and enjoyed having the students visit.

"Oh it was nice (pause), yes it was nice, it was fine." (Page 9)

"Mhh, it's nice yes, I feel happy about it, let me put it that way." (Page 9)

*Mandla accepted by other people.* An aspect that Unathi really enjoyed about the service-learning programme was seeing Mandla being accepted and loved by the students despite his disabilities. She felt it was special to have the students come especially to play with Mandla and bring him so much happiness.

“To see that there are people who love him, even though he is like this.”  
(Page 9)

“I feel happy to see other people coming, coming to play with him.” (Page 9)

“Helpful was the fact that I could tell that they loved him, they did everything like playing with him, it was nice and you could see that he was also happy.”  
(Page 9)

*Time to rest.* Unathi also found that having the students visit her gave her time to rest as she is usually solely responsible for Mandla’s full-time care. Having the students gave her time to take a break from these responsibilities, which she thoroughly enjoyed.

“Mhh it was helpful because I would, I mean I would get time to rest and have other people do all of what I had been doing.” (Page 9)

*Empowering caregiver.* Unathi also felt that she was able to teach the students how to care for a child with disabilities and impart the knowledge and experience she had gained over the years from attending the clinic and being Mandla’s carer.

“I think I taught them, those things that I, so on Fridays we would go to the clinic and then they would also join us, so I would tell them what they told us at the clinic and show them as well.” (Page 10)

“What I taught them is how to take care of a child like that, playing with him, what to do with him when he is happy or unhappy. So those are the things.”  
(Page 10)

*Improvements attributed to learning from the Clinic.* Unathi continued to attribute the functional improvements she experienced in Mandla to the clinic but the emphasis had seemingly shifted to the improvements being through what the clinic had taught. This emphasised Unathi's own role in the functional improvements. She felt that what she had learned at the clinic had empowered her to help her son and she was able to give herself credit in relation to the clinics teachings.

“It's all those things they taught us there, those massages, so that he can, just after I've finished bathing him in the evening I have to massage him so that he can sleep. I think that is what has helped him.” (Page 3)

“It's all the things we were told to help him do at the clinic, that's what I think (pause), like stretching his arms, so I think those are some of the things that have helped.” (Page 3)

*Helpful learning support.* Unathi continued to experience the Clinic as helpful. She found it particularly supportive for all the learning experiences she had been granted to better care for Mandla. She felt that without the clinic she may not have been able to care for him or make him happy as she wouldn't have known how to feed him, help him sleep or help better his functioning.

“Something I have learned is how to take care of a disabled child and the importance of loving him and making time for him.” (Page 6)

“I think it was helpful because, maybe if they clinic wasn't there, we wouldn't know some things, what to do with our children... like how to feed them, how to take care of them, and hot to, how to help them become better and happy.” (Page 11/12)

“What we are doing this month, we don’t repeat it the following month, they show me something new to do. So when we were there they were showing me how to take care of him; how to massage his back. There are these bumps like things on his back, so I rub them until they are soft and go away. Even in front, in his tummy, on his ribs so that they can go, so that he can be able to, to be ok at the back yes, so those were the things.” (Page 11)

“It was helpful to me because (sigh) it was helpful because Mandla’s arms were, they couldn’t stretch. So at the clinic they showed me how to stretch them and gave me, the (Madiba) buggy so that even when I travel with him it would be easier for and I don’t have to put him on my back all the time, yes.” (Page 12)

*Support of other parents.* Unathi also found the Clinic to be a place to meet other caregivers of children with disabilities who she experienced as being very supportive and helpful to talk to. She found that talking to them also gave her new ideas and helped her learn other ways to care for Mandla.

“You learn from others, I mean, because there are so many of us bringing kids with different disabilities. So we learn from others by talking to each other and from those conversations you take away something that you can add to what you are doing, maybe in the way that you play with your child.” (Page 11)

**6.3.4.3 Discussion.** The quantitative and qualitative results regarding Unathi’s experience and satisfaction with the services received at the Clinic during the baseline phase show that Unathi was very satisfied with the services she was receiving. She stated that the Clinic was helpful, enjoyable and encouraging. These sentiments regarding the Clinic were reiterated during her post intervention interview with Unathi attributing the improvements in Mandla’s functioning to the Clinic, stating that attending the clinic was a helpful learning experience. She also felt that the

Clinics gave her the opportunity to meet other caregivers of children with disabilities who she could talk to and find additional support in.

The post-intervention interview also found Unathi praising the service-learning programme. However, it was not as highly praised as the Clinic and Unathi did not attribute any improvements in Mandla's abilities to their participation in the programme. However, Unathi still found it useful to participate in the service-learning programme, saying it made her happy to see Mandla being accepted by others. She also felt that the service-learning programme was helpful as it gave her time to rest from the full-time responsibility of caring for Mandla. In addition to this, Unathi was empowered by the students as she was able to teach them how to care for a child with disabilities.

Despite these positive remarks, Unathi's quantitative results of the MPOC-8 SA seemingly showed dissatisfaction with the services after the addition of the service-learning programme.

**6.3.5 Are there trends and patterns of change that can be identified? What sense can be made of the impact of the programme in light of the caregivers' subjective experiences of the programme?**

In summary, this chapter aimed to assess the impact of the service-learning programme in addition to the Clinic on Unathi and Mandla by gaining an in-depth, rich framework of their experiences and the effects of the programme through the use of both quantitative and qualitative data in a mixed method. Unathi and Mandla were assessed at two data collection periods, once prior to the start of the service-learning programme at the baseline phase, and again after the service-learning programme had come to an end. They were assessed with regards to caregiver well-being, child functional abilities, the caregiver-child relationship, and satisfaction with the services.

By looking at both the quantitative and qualitative data collected for the various questions, we can surmise that the service-learning programme itself seemed to have very little impact on the caregiver-child dyad. The results for Unathi and Mandla showed that although they enjoyed participating in the service-learning programme and found it to be restful, empowering and enjoyable, Unathi did not attribute any improvements to their participation in the service-learning programme

and some of the quantitative scores showed negative results which could imply an undesirable impact in certain areas.

From the results, the service-learning programme seemingly had a slightly negative impact on Unathi's level of distress and well-being, Mandla's functional abilities, and Unathi's satisfaction with the services. Unathi's level of distress, measured using the CORE-OM, deteriorated only slightly over the course of the service-learning programme, particularly in the domain of Well-being which amplified in severity. This decline in score was reiterated in the interview, which found that Unathi continued to face some of the same worries as she had experienced at the baseline phase. However, there was also a notable improvement in Unathi's scores at risk behaviour.

Mandla's functional abilities, as measured on the PEDI-CAT, also decreased drastically after the addition of the service-learning programme, particularly in the domain of Mobility. However, this was contrasted by Unathi's experiences as she stated in the interview that she had seen improvements in Mandla's abilities at both the baseline and post-intervention data collection points. However, during the interviews these improvements were attributed to the Clinic and the techniques they had taught Unathi to help Mandla.

Unathi's satisfaction with the services, as measured by the MPOC-8 SA, also decreased drastically after the addition of the service-learning programme. However, this was contrasted in the interviews where Unathi continued to show satisfaction with the Clinic and she shared her enjoyment in participating in the service-learning programme. Unathi did not share any grievances and felt that there was nothing bad about either intervention service. Thus, the quantitative and qualitative data often painted disparate pictures but there was a possibility that there was a slightly negative impact on Unathi and Mandla.

Despite the possibility of a negative impact in these areas, there were also positive aspects that Unathi and Mandla possibly gained from participating in the service-learning programme. This was seen in the area of caregiver-child relationship, the MIM observation of which showed improvements after the addition of the service-learning programme with the EIS score increasing slightly. The MIM Clinical Report described that although Unathi continued to be quite reserved, she came across

as more comfortable during the post-intervention data collection and was better able to structure the tasks, and provide emotional reciprocity, nurturance and playfulness after the intervention.

Therefore, despite the minimal and possibly negative effects of their participation in the service-learning programme in terms of the quantitative outcomes, the qualitative data seemed to point towards satisfaction and enjoyment in participating in the service-learning programme. The enjoyment seemed to come from aspects that were not necessarily measured in the quantitative tests, such as the service-learning programme giving Unathi a break from taking care of Mandla, Unathi being empowered to teach the students how to care for a child with disabilities, and the love and attention the students showed Mandla during their visits which Unathi reported as making him happy.

## CHAPTER 7

### Discussion and Conclusion

This chapter will give a general overview of the research study and discuss the main findings in relation to the perceived efficacy of the programme and caregivers' experiences of the service-learning programme. Due to the small sample and lack of a randomised control group, the findings are not generalizable and inferences regarding the effect of the programme cannot be drawn (Carey & Boden, 2003). However, descriptions of the problems and experiences that caregivers had of the impact and process of their participation in the service-learning programme will be discussed and used to make recommendations for the future application of the service-learning programme. Thereafter, the researcher will evaluate the research, wherein the strengths and limitations of the study will be outlined and recommendations for future studies will be discussed.

#### 7.1 Overview of the Study

This research aimed to evaluate a service-learning programme that formed part of an Honours in Psychology course at a university in the Eastern Cape of South Africa. The service-learning programme is run in collaboration with the local clinic and a local branch of a national non-profit organisation. The Eastern Cape remains one of the poorest provinces in South Africa and access to resources in this area is considered largely inadequate and inequitable (Woolard, 2002). Children with disabilities are often affected by this underprovided system as resources and tools to identify and track disabilities are deficient and general healthcare services for children with disabilities remain fragmented and unequal, generally only being made available monthly (AFCP, 2011; Saloojee, 2008). The service-learning programme aimed to utilise what the students were learning in class and apply these skills to community problems in order to achieve positive outcomes for the community, and a deeper understanding and skills for themselves (Eyler & Giles, 1999; as cited in Mouton & Wildschut, 2005).

It is important to establish an understanding of the processes and effectiveness of the service-learning programme as this has key implications for developing services through research, and for the development of further community based interventions that are relevant and empowering within the local communities and able to meet their needs (Mkhizi, 2004). In order to know whether the intervention service offered is effective, relevant and appropriate, it is central to look at the outcomes of the service-learning programme alongside the views, experiences, and perceptions of those involved (Saloojee, 2011). Therefore, the research aimed to evaluate the programme's impact on the caregivers and their children with disabilities, and the processes involved in their engagement with the programme. Specifically, the research aimed to look at the impact of the service-learning programme on; the caregivers' well-being, the child's functioning, the parent-child relationship, and the caregivers' experience of care received from both the clinic and the service-learning programme. The research also aimed to assess what sense could be made of the impact of the programme in light of the caregivers' subjective experiences of the programme.

Due to the small population of caregiver-child dyads taking part in the service-learning programme, a descriptive case-series design was used to assess the impact of the service-learning programme on a small sub-population of three of the participant dyads receiving the same intervention. This longitudinal study evaluated the caregiver-child dyads at three data collection points over a period of 21 weeks, with two data collection points taking place prior to the service-learning programme in order to obtain a rich understanding of the baseline data, and then again after the service-learning intervention had ended. A mixed methods approach to data collection was used to make use of various forms of subjective and objective, quantitative and qualitative data. Repeated observations, testing and interviews took place in order to obtain the topography of change during the course of the study- before and after the addition of the service-learning programme (Borckardt & Nash, 2002). This allowed for an intensive analysis of the individuals over time and conditions.

## **7.2. Summary of Findings**

The summary of findings of this research aims to give insight into the impact and process of the caregiver-child dyads' participation in the service-learning programme. The themes and experiences found in this research are not generalizable to the entire population of caregiver-child dyads due to the small sample of the study; however, the research results hope to provide a cautious description for an initial report on the intervention strategies utilised.

### **7.2.1 What is the impact of the intervention on the caregiver's well-being?**

The intervention services seemed to have a generally positive influence on the caregivers' well-being, although the extent of this varied between caregivers and a direct correlation cannot be inferred. This positive effect was seen in the decreases in some of the quantitative CORE-OM scores at both the second baseline data collection phase and again after the post-intervention data collection. However, the most prominent decreases in the CORE-OM scores were seen between the two baseline phases prior to the start of the service-learning programme, with a lesser reduction in scores being shown after the addition of the service-learning programme.

The fluctuation in scores between Baseline 1 and Baseline 2 can be considered of particular interest, as some of the caregivers did not receive any intervention services during this period. For caregivers that received intervention services at the clinic during this period, it is worth noting that upon observation of the clinic intervention services, the focus of the healthcare workers was predominantly on the child with little room being made for an interest in the caregiver's well-being. This is in line with Saloojee's (2008) observation whereby she describes caregivers of children with disabilities often being disempowered, passive recipients of therapy programmes. It is also important to consider the possibility of the caregivers' participation in the research being perceived as an intervention in itself. The predominant focus of the research was on the caregivers who were also offered the opportunity to speak openly about the struggles they were facing. This can be quite a relieving process that makes the caregivers feel heard and there is the possibility that this may have inadvertently impacted the scores. Alternatively, the caregivers may have also been excited in anticipation for the start of the service-learning programme

at the second baseline phase, which may too have influenced their sense of well-being.

Overall, the decreased CORE-OM scores indicated that caregiver's seemed to be experiencing fewer symptoms of their poor well-being and improved functional ability at both the second and final data collection phases. Although a lesser decrease in scores was seen after the addition of the service-learning programme, this suggests that the service-learning programme may have played a role in maintaining the caregivers' improved well-being. However, the decreases in the quantitative scores were at times quite unsubstantial and caregivers continued to complain about similar difficulties and worries during the post-intervention qualitative interviews. These qualitative and quantitative accounts may indicate that the intervention services did not necessarily impact the caregivers' psychological well-being or change their problems; however, they may have assisted in the reduction and maintenance of symptoms and at risk behaviour, as well as creating an improvement in functional ability.

### **7.2.2 What is the impact of the programme on the child's functioning?**

The findings from the impact of the service-learning programme on the children's functional abilities showed varied results that were somewhat contrasting in nature. This was apparent in the divergence between the quantitative PEDI-CAT scores and the qualitative interview data.

In the qualitative interviews, all of the caregivers generally cited that their children were growing well and showing improvements in their abilities and health. However, there was also an acknowledgment of how slow and difficult the development in children with disabilities often is. This was also evident in the improvements that caregivers noticed which were in areas such as sleeping better, crying less, improved eating and self-feeding, and an improved ability to stretch or hold onto objects. These improvements, despite being slight, were cited by parents and celebrated as great milestones.

The caregivers' qualitative narratives were contrasted by the quantitative PEDI-CAT scores that showed little improvements in functional ability, with some decreases being observed. Although the caregivers reported improvements in their children's functional abilities it is important to consider these developments may have

only been very slight and may not have corresponded with the PEDI-CAT measure, which does not necessarily ask about specific abilities or react sensitively enough to them to pick up on minor improvements. This is particularly apparent when assessing children with disabilities whose functional abilities tend to oscillate as they grow. Due to this, the mere maintenance of functional ability can in itself be seen as an achievement.

The caregivers initially attributed the perceived improvements in functional abilities to their attendance at the clinic. However, the attendance at the clinic was often described vaguely as a place where the healthcare workers took the child and stretched him. This points to the caregivers being passive, uninvolved recipients of healthcare services at the clinic (Saloojee, 2008). However, during the post-intervention interview, some of the participants were better able to recognise their own involvement in the clinic intervention, citing that they had recognised their own role in the improvement of their child's abilities through their involvement and learning at the clinic.

The caregivers also attributed the functional improvements seen in their children to their participation in the service-learning programme. Some of the caregivers expressed appreciation for the students who helped teach the children new skills, such as throwing a ball. However, they also articulated great pride in themselves for being able to teach the students about their child's disabilities and pass on the knowledge that they had learnt from the clinic. This seemed to empower the caregivers and give them the ability to recognise their own positive role and immense knowledge of their children.

In addition to the clinic and the service-learning programme, the research was also mentioned as contributing to the improvement in some of the children's functional abilities. Therefore, it is important to consider the perception of the research and how this may have impacted the outcomes for this study.

### **7.2.3 What is the impact of the programme on the caregiver-child relationship?**

During the initial data collection phase, the caregivers generally exhibited relatively good relationships with their children as observed during the MIM. However, one of the caregivers seemed to be struggling as she became easily

overwhelmed, impatient and frustrated with her child's difficult behavioural challenges which she expressed as naughtiness.

During the initial MIM observation, the caregivers tended to perform particularly well on the tasks of daily nurturance; however, they seemed to struggle with more creative tasks that required play or imaginative tasks such as story telling. During the play activity some of the caregivers turned to the therapy they had learnt at the clinic such as stretching, positioning the child, or trying to get the child to hold/reach for something. During the interviews the caregivers' spoke of how they really enjoyed their time together with their children and how they made each other happy. One of the caregivers felt that she shared a very unique and special bond with her child with disabilities as compared to her other children.

The data collected after the service-learning programme showed some improvements in some of the caregiver-child relationships, particularly with the dyad that had initially struggled. In the MIM observations, caregivers showed increased understanding and greater abilities to structure tasks and engage their children in a more comfortable manner. However, some instances of frustration were noted too. Interestingly, the caregivers seemed to be able to better express their frustration and difficulties they experienced in the caregiver-child relationship. This was apparent in the qualitative interviews where caregivers were able to express the difficulties in their relationships with their children and admit to needing help from others at times.

A general theme that was apparent amongst the caregivers was that they all placed a great emphasis on trying to understand their children and have their children recognise them as their primary caregiver in order to have an extremely close bond. There was a sense of fear around misunderstanding their child and causing them any further distress. This can be considered a normal experience of most mothers, however, this fear seemed to be exacerbated by their children's disabilities and different communication styles.

#### **7.2.4. What is the impact of the programme on the caregiver's experience of care received from service providers?**

The quantitative results from the MPOC-8 SA showed that the caregivers had a level of good satisfaction with the clinic during the baseline phase. However, the second baseline collection phase garnered the highest scores for level of satisfaction

with the services. The qualitative interviews showed that caregivers experienced the Clinic as a great source of guidance, acknowledgement and motivation. They felt that the Clinic provided them with an opportunity to learn and help their children through improved functional abilities. They also expressed that the Clinic brought together caregivers of children with disabilities and gave them the opportunity to meet one another, which made them feel supported and encouraged, as they were no longer alone in having a child with a disability.

The caregivers also expressed some of the difficulties they faced with the Clinic intervention. These were predominantly structural barriers including, difficulties getting transport to the clinic, the prescribed clinic dates not being suitable, and difficulties in dealing with children with disabilities outside of their normal environment.

The increase in satisfaction with the services at the second baseline data can be seen as interesting as no changes were made to the Clinic intervention, and some caregivers did not attend the intervention services during this period. Again, this points to the possibility of the research being perceived as an intervention in itself. Alternatively, the caregivers may have also been excited about the impending start of the service-learning programme, which may have increased their perceived satisfaction with the services.

During the post-intervention data collection, the caregivers' MPOC-8 SA scores of satisfaction with the services decreased showing a lesser satisfaction with the services received. However, the qualitative interviews with the caregivers showed incongruent results, as they did not allude to this dissatisfaction. The caregivers expressed their enjoyment and satisfaction in taking part in the service-learning programme. They felt it was particularly helpful in that the students gave them a break from caring for their children during their visits. The students were also able to help some of the caregivers with structural barriers they faced, such as offering them lifts to the clinic and acting as intermediaries between the clinic staff and the caregiver. The caregivers expressed that being seen and visited by the University students made them feel very important and garnered them more respect amongst their communities. The service-learning programme was also experienced as empowering for the caregivers who were able to pass on the skills that they had learnt at the clinic and teach the students how to care for a child with disabilities.

The incongruence between the quantitative and qualitative scores and data may point to the fact that the service-learning programme had already ended at the time of the final data collection period and caregivers may have been feeling somewhat deserted and hurt following the abrupt ending of the programme. Therefore, the reduction in services may point to their dissatisfaction.

### **7.2.5 Discussion of the Findings**

Each of the caregiver-child dyads presented a unique and rich personal experience of their participation in the intervention services that generated insights into the impact, processes, trends and patterns of change they experienced during their involvement in the research process.

The caregivers described how living with a child with disabilities within an impoverished setting had substantial implications for them as individuals, for their households, and the community. Caring for a child with disabilities was described as a full time commitment that could be isolating, lonely, financially strenuous and exhausting. These difficulties seemingly had a great effect on caregivers' levels of well-being, which were all quite low at the start of the research study. Caregivers' also described difficulties in the caregiver-child relationship in which they sometimes became easily frustrated and overwhelmed. This is in line with other research findings that found families of children with disabilities often face additional stressors due to the problematic parent-child relationship, the added burden, financial implications, and the demand on family resources (Smith et al., 2001).

Although some drastic fluctuations occurred in caregiver well-being and satisfaction with the services between the two baseline data collections, it is acknowledged that this improvement may be attributable to the research, which caregivers saw as an intervention in itself. It is also acknowledged that caregiver may have been excited for the impending start of the service-learning programme which could have also impacted their well-being and perceptions of the services positively. This suggests the importance of providing the caregivers with a platform to express their experiences and speak openly about their well-being within the intervention service. It also reiterates the importance of maintaining hope in caregivers of children with disabilities and how looking forward to something may impact one's sense of well-being, particularly within an impoverished area where little resources are

available.

The service-learning programme in itself did not provide any substantial changes to the caregiver's well-being. However, some positive increases were noted and most of the improvements from the baseline stages were maintained with caregivers showing less symptomology, improved functional abilities and less at risk behaviour. This suggests that caregivers were better able to cope with the strenuous experiences they faced. It was also noted that after the service-learning programme caregivers seemed better able to express themselves, opening up more about both positive and negative experiences. During the caregiver-child interaction observations, improvements were seen in caregivers that had previously had difficult relationship with their children. The caregivers were better able structure tasks, empathise with the child, and provide nurturance in challenging tasks without becoming overwhelmed. Some caregivers alluded to the service-learning programme being empowering as they were placed in a position of expertise whereby they taught the students to care for their children. As suggested, involving the caregiver in the intervention service, allowing them the space to speak openly about their experiences, and allowing them to draw on their own personal expertise can be seen as one of the most effective outcomes for an intervention programme as it empowers the caregiver and creates room for a more secure attachment style to develop between the caregiver and child (Dunst, et al., 1988; McDowell, et al., 1995).

Despite contrasting scores in the MPOC-8 SA, the caregivers expressed a general satisfaction with both the clinic and the service-learning programme. The drastic increase in level of satisfaction reported at the second data collection period is interpreted with caution as this may too have been influenced by the caregivers' participation in the research, as well as their excitement for the start of the service-learning programme. However, the caregivers generally reported the Clinic as being a supportive and encouraging environment where they were able to get effective treatment for their children, learn therapeutic techniques, and meet other caregivers of children with disabilities. However, some caregivers initially described the experience at the clinic quite vaguely, as a place where the healthcare workers took the child and stretched him. This excludes and disempowers the caregiver and points to the difficulty of caregivers being passive, uninvolved recipients of healthcare services at the clinic (Saloojee, 2008). This seemed to change after their participation

in the service-learning programme which seemed to assist caregivers better recognise their own involvement in the clinic services and how they had played a role in assisting their children through the tasks the clinic had told them to do. Recognising this important role seemed to be somewhat empowering for the women.

The major difficulties that caregivers reported were in structural barriers that prevented them from accessing the clinic. This is in line with the literature that found that access barriers including, vast distances and high travel costs (Harris, et al., 2011), high out of pocket payments for care (Goudge et al., 2009), long queues (Nteta, et al., 2010), and disempowered patients (Schneider, et al., 2010) continue to be the greatest barriers to access to care in South Africa. According to Harris et al. (2011), these barriers are the result of uneven social-power relationships and the inequitable distribution of resources.

The caregivers praised the service-learning programme for its accessibility as the students came to the caregivers' houses. Another aspect of the service-learning programme that the caregivers admired was that the students were able to assist them with the structural barriers they faced by offering the caregiver-child dyads lifts to the clinic/ town and acting as intermediaries between the clinic staff and the caregivers. This relationship points to the persistence of social-power relationships whereby the caregivers reported being seen in a greater social regard within their communities and at the clinic when visited and assisted by the students. The students were also able to assist the caregivers with some daily tasks such as minding the child during their visits, which the caregivers described as being helpful as it gave them a break. Although the practical aspects were not seen to have a role in the service-learning programme, it seemed to be regarded as one of the most important aspects of the service-learning programme for caregivers.

The satisfaction with the services reported by the caregivers after the cessation of the service-learning programme was quantitatively rather low in comparison to the baseline data. It is acknowledged that collecting the final data after the ending of the programme may have had multiple influences on the scores, as caregivers felt deserted, reluctant and saddened by the ending of their involvement in the service-learning programme as well as the research. This highlights the short-term nature of the service-learning intervention and the lack of follow up to the intervention which creates a sense of abandonment in the participants.

### 7.3. Recommendations

From the study's findings, preliminary recommendations and possible amendments for the future application of the intervention services are made. These recommendations aim to further develop the intervention services so that the services offered are more effective, relevant and appropriate for the community, creating empowerment and furthering their own needs (Saloojee, 2008; Mkhizi, 2004). The recommendations are based on the array of rich data collected from the caregiver-child dyads that can be used to adjust the services to be more in line with their own perceptions and views (Saloojee, 2008).

#### 7.3.1 The Clinic Intervention

The following recommendations are made for the consideration of the Clinic healthcare workers, management and the Department of Health to consider as possible areas to address and make adjustments that can be integrated into the Clinic intervention to address the difficulties that arose and assist in making the intervention more relevant for the caregivers:

- It is recommended that the Clinic intervention service attempt to address the caregivers' well-being and mental health. Currently, the team is comprised of multi-disciplinary healthcare workers, however a psychologist is not included. The focus remains on the health of the child whilst the caregiver is often overlooked. Addressing caregiver well-being is an important aspect for intervention as it has been found that a caregiver's poor state of mind is one of the greatest predictors for future maltreatment of the child and the development of an insecure attachment (Howe, 2006). The addition of support services for mothers is believed to mediate maternal stress and reduce the risk of the development of an insecure attachment (Benedict et al., 1992; Mobarak et al., 2000).
- The Clinic intervention is also encouraged to recognise the importance of involving the caregiver in the intervention services. The Clinic services are predominantly aimed at assessing the child, whilst the mother is often a bystander who is asked a few questions and given verbal instructions to follow. This does not address the dyadic caregiver-child relationship and fails to include the caregiver's perspective. Involving caregivers in the

intervention services has been found to have the most effective outcome (Dunst, Leet, & Trivette, 1988; McDowell, et al., 1995). Encouraging and improving the caregiver-child interaction has been found to lead to better care for the child and better cognitive development (Maulik & Darmstadt, 2009).

- The caregivers described many structural barriers to accessing the current healthcare interventions available to them. It is recommended that solutions to their access difficulties be addressed. Accessing health care is considered a multi-level process that needs to be considered from a broad intersectional lens (WHO, 2010). This includes a multiplicity of barriers that affect access, including geography, attitudes, and transport barriers (Harris et al., 2011) as well as those linked to experiences of exclusion.

### **7.3.2 The Service-learning Intervention**

The following recommendations are made for the furtherance of the service-learning programme. The service-learning course co-ordinators, as well as all those implementing similar programmes within the impoverished South African setting should contemplate these recommendations in order to understand and address the difficulties faced in implementing service-learning programmes:

- The eight-week period of the service-learning intervention can be considered relatively short. The caregivers found this time to pass incredibly quickly and were saddened to see the programme end so abruptly. The abrupt cessation seemed to leave caregivers feeling somewhat deserted and abandoned at the end of the programme. It is recommended that the service-learning programme consider the possibility of using a longer cessation period whereby the visits are first halved, and then followed by a longer term follow up with the caregivers after the programme has ended.
- The research findings showed that the caregivers placed great emphasis on the practical usefulness of the students in helping them mind their child, giving them a break, and assisting with transport difficulties. This aspect of the service-learning programme is often overlooked and discouraged due to the unsustainable nature thereof. However, the importance of practical assistance for the caregivers should be acknowledged and encouraged in the future applications of the service-learning programme.

## **7.4 Evaluation of the Study**

It is acknowledged that the research has various limitations. These limitations are believed to exist in the research methodology, measures and the data analysis. A key purpose of case-series studies is to generate hypotheses that can be further tested with greater methodological rigor. Therefore, the study limitations are outlined below in the hope that they will guide future research that is methodologically sounder.

### **7.4.1 Limitations of Methodology**

A case-series design study is considered to be a low level (Level IV) evidence based study compared with other more rigorous methodologies, such as a randomised control trial. The lack of a control group, who do not receive the intervention, implies that causal inferences cannot be made about the relationship between the treatment and outcomes, as it is impossible to determine whether the outcomes are attributable to the treatment effect or characteristics of the participants (Kooistra, Dijkmam, Einhorn & Bhandari, 2009). Therefore, all inferences made in this study should be considered tentatively as hypotheses about the apparent relationships between the caregiver-child dyads and the intervention services. Case-series design studies are also considered to be prone to bias, particularly selection and measurement bias, as well as poor validity.

The small nature of the service-learning programme allowed for only a minor number of three caregiver-child dyads to participate in the research process. Therefore, we cannot view the experiences as representative of all caregivers of children with disabilities; instead, each case should be seen individually.

The case series design used was a longitudinal study that required data collection at three separate points over a twenty-one-week period. It is noted that a limitation of this method of research is that it is considerably time consuming and costly compared to other methods of data collection. It also requires a long-term commitment from the participants, which increases the possibility of attrition. This was experienced during the second baseline data collection phases where one of the caregiver-child dyads that had originally committed to partake in the research and service-learning programme had to drop out due to personal circumstances.

#### **7.4.2. Limitations of the Measures**

Some of the quantitative measures used for the study were found to be possibly insufficient, which resulted in contradictory outcomes between the quantitative and qualitative findings. Some of the measures used in the study were self-report measures. It is important to consider that these measures are systemically biased towards the respondent's perception of what is correct and socially acceptable (Maecoby & Maecoby, 1954). Therefore, all of the self-report measures used can be considered have a degree of social desirability bias that may have distorted the data.

In particular, the results from the PEDI-CAT seemed be insensitive to some of the minor changes explained by the caregivers in their interviews. This may have also been due to the measure not picking up on selective incidences of change. The researcher noted that the measures were also culturally inappropriate towards the impoverished setting at times as the children did not have access to things such as television remotes, gaming consoles, or juice boxes which the PEDI-CAT used to evaluate them on. Measures, like the MPOC-8 SA were also seemingly influenced by external factors such as the caregivers' excitement for the research and their disappointment with the service-learning programme ending which may have influenced the scores.

#### **7.4.3. Adequacy of the Data Collection and Analysis**

The data collection process made use of a trained research assistant in order to collect the data in the participants' home language of isiXhosa. The research assistant conducted the interviews and also acted as an interpreter to assist the researcher and the occupational therapist in administering some of the data collection tools. Due to the assortment of data collection tools that were time consuming, the decision was made for the research assistant to conduct the interviews directly with the caregivers so as not to further delay the process through supplementary interpretation. Additionally, the researcher was aware of her differing demographic characteristics of age, race, language and education, which may have impacted on the caregiver's responses. These demographic differences often perpetuate structurally ingrained power inequalities, some of which were alluded to by the caregivers in the interviews. Therefore, the researcher chose rather to act as an observer of the research process and allow the research assistant, whose demographic characteristics were more

related, to lead this process. The researcher was able to observe all of these interactions through a one-way mirror.

Due to the longitudinal nature of the study and the multiplicity of tests used, the data-collection process was quite long and demanding. The researchers decided to split the process into two days per a data collection period so that the IPA interview, CORE-OM, and the MPOC-8 SA were collected on one day and the MIM observation and the PEDI-CAT were collected on the second day. This allowed for caregivers to leave their child at home for the first data collection day as only the caregiver needed to be present for the interview. However, many of the caregivers did not have access to baby-sitters and the children were generally present throughout the interview processes. At times this was disrupting, as the children demanded their caregivers attention away from the interviews. It is acknowledged that the research process was particularly burdensome for caregivers and the researchers attempted to accommodate them by providing transport, offering snacks and drinks, allowing them ample breaks between tests, and allowing a day off between the two data collection days.

A professional translator was used to translate the interview transcripts collected by the research assistant from isiXhosa to English. It is acknowledged that when translated there is always the possibility that the participants' intended meaning may in some way be altered. Therefore, the conclusions drawn from the study are based on the translated dialogue, which may at times differ significantly from the original meaning intended by the participants.

#### **7.4.4. Recommendations for Future Research**

The limitations of the study show the difficulties experienced in planning and carrying out research of this nature. Despite the small sample, it is important to consider the longitudinal design of the study was burdensome, time consuming and costly. The case-series design is also limiting and only hypotheses can be drawn due to the lack of a randomised control group. Additionally, the use of measures, specifically quantitative measures, can be inappropriate, insensitive and influenced by self-report bias. Therefore, future researchers should consider these difficulties in attempting to carry out studies of a similar nature. Researchers may attempt to conduct research on a larger population of caregiver-child dyads and include a control

population in order to garner more rigorous results. Where possible, the use of other, more relevant tests should be explored.

Lastly, it is hoped that the research offers insight into the current clinic intervention and the service-learning programme so that further research may be carried out to benefit and grow these intervention services that are much needed in the South African community.

### **7.5 Conclusion**

Overall, the mixed methodology often generated incongruent findings between the quantitative and qualitative results, however, this method painted a rich picture of the caregivers' experiences of being the caregiver of children with disabilities, and being recipients of the clinic intervention and the service-learning programme. The following tentative conclusions are offered from the research findings.

The caregivers perceive the clinic as an important intervention service that is highly respected and recognised for assisting them in providing therapeutic interventions to address their child's functional abilities. The clinic also assists in as teaching the caregivers how to cope with their child's disability and how best to assist their child at home, as well as providing them a space to meet other caregivers of children with disabilities. However, caregivers explained how they were often external to the process that took place at the clinic intervention and not completely involved in the intervention process. The caregivers also experienced structural barriers that impeded their attendance.

The service-learning programme in itself did not provide any substantial changes in outcome measures, however, improvements noted during the baseline phase prior to the start of to the service-learning programme seemed to be maintained and some improved. This was seen in the children's functional abilities, the caregiver-child relationship and caregiver well-being. In particular, the caregiver's well-being and most of the improvements from the baseline stages were maintained with caregivers showing less symptomatology, improved functional abilities and less at risk behaviour. This suggests that caregivers were better able to cope with the strenuous experiences they faced. It was also noted that after the service-learning

programme caregivers seemed better able to express themselves, opening up more about both positive and negative experiences.

It is also noted that the research may itself be seen as an intervention with caregivers citing some of the positive effects and changes in their well-being and their child's functional abilities to their participation in the research study. Caregivers were also seemingly affected by other confounding variables such as the excitement they faced prior to the start of the service-learning programme, as well as the negative feeling of abandonment after its abrupt cessation which may have impacted their scores.

Recommendations have been made for the clinic to address caregiver well-being, better include the caregivers in the programme and address structural barriers to the access of services. The service-learning programme is encouraged to reconsider the short period of the intervention and the abrupt cessation that left caregivers feeling abandoned, as well as consider the practical advantages of the service-learning programme that caregivers most appreciated.

Overall, the caregivers cited both positive and negative attributes to both of the intervention services. However, it may be concluded that although few substantial effects were seen in the outcome measures, the caregivers seemed to be very grateful for and enjoyed their participation in both of the intervention services which they believed they benefited from. This points to the importance of continuing with existing intervention services and the development of new intervention services in impoverished areas of South Africa where social support may be low and intervention services few for caregivers of children with disabilities.

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**APPENDIX 1**  
**The Service-Learning Programme**

Appendix 1, Figure A  
*Honours Childhood Disability and Mental Health Course Outline*

Date	Seminar Topic	Details
19 July	Childhood Disability in South Africa: Introduction	This seminar introduces students to the international context of disability studies in order to locate this particular course. The service-learning component of the course will be introduced and the role of the students will be clarified. In this seminar students will be taught about the definition and classification of Cerebral Palsy as all the children they will be learning from have CP. Guest lecturer: Fiona Semple (Physiotherapist, APD)
20 July	Childhood disability in South Africa: The importance of the environment	This seminar introduces students to the social model of disability, a model that emphasises the environment as more or less disabling for children with impairments. The seminar will explore the environmental challenges faced by children with disabilities and their caregivers living in rural and semi-urban disadvantaged communities in South Africa. Guest lecturers from the Department of Health and the Association for Persons with Physical Disabilities (APD) will provide students with information regarding the services currently available in Grahamstown. Students will be supported in reflecting on their expectations for their first home visit.
<b>Week 18<sup>th</sup> July HOME VISIT 1</b>		
26 July	Childhood disability and child mental health	This seminar continues with the emphasis on disability as an interaction between the person and the environment, with a specific focus on thinking about the quality of life and participation in the community of children with disabilities. The impact of these factors on the children with disabilities mental health will be discussed. Students will reflect on what they have already learnt from the children they are visiting in relation to disability and mental health.
27 July	Childhood disability and maternal mental health	This seminar engages with the literature on the experience of caring for a child with developmental disabilities. Students will reflect on what they have learnt regarding the challenges faced by the caregivers they visit as well as the resilience and resourcefulness they demonstrate.

<b>Week 25<sup>th</sup> July HOME VISIT 2</b>		
2 August	Disability and relationships: Implications of disability for the caregiver- child relationship	This seminar introduces attachment theory as a useful theoretical framework for thinking about the caregiver- child relationship in the context of neurodevelopmental disabilities. The effects of CP on early attachment are explored with discussion focusing on the supporters and hindrances of the attachment relationship in South African contexts. Students will be encouraged to reflect on what they have learnt about these issues from the caregiver and child they are visiting.
4 August	Disability and relationships: Supporting wondering and play	In this seminar we will discuss the importance of play for all children and the practical ways in which play can be encouraged for children with neurodevelopmental disabilities in disadvantaged South African contexts. The theoretical framework of attachment theory and the concept of metallization will be drawn upon to think about playing in relationships. Students will discuss ways of supporting play and wondering with the caregiver and child they are learning from.
<b>Week 2<sup>nd</sup> August HOME VISIT 3</b>		
8 August	Relationships in context: Exploring psycho- emotional understandings of disablism	In this seminar we explore disablist oppression and in particular, Watermeyer and Swartz description of the psycho-emotional aspects of disability and impairment to further understand the impact of this oppression. Students will draw on their own experiences of discrimination and social injustices to reflect on the disablist context in which the caregiver and child they are visiting are living.
10 August	Relationships in context: Challenging disablism	This seminar reflects on the practices of exclusion and inclusion that impact on children with disabilities in South Africa. Students will reflect on the practices of the household and communities in which the caregiver and child they are visiting currently lives. Students will also reflect on their own practices in relation to the caregiver and child and critically engage with the extent to which they contribute to social injustices. The contribution of psychology to challenging discriminatory practices will be discussed as well as the ways in which students can challenge disablism during their home visits.
<b>Week 8<sup>th</sup> August HOME VISIT 4</b>		
<b>Week 15<sup>th</sup> August HOME VISIT 5</b>		

<b>Week 22<sup>nd</sup> August HOME VISIT 6</b>		
23 August	Reflective supervision	Students will continue to reflect upon their experiences of supporting play and wondering with the caregiver and child they are learning from, while also reflecting on contextual aspects that impact on their experiences.
<b>SEPTEMBER VACATION</b>		
6 September	Reflective Supervision	Students will continue to reflect upon their experiences of supporting play and wondering with the caregiver and child they are learning from, while also reflecting on contextual aspects that impact on their experiences.
<b>Week 5<sup>th</sup> September HOME VISIT 7</b>		
13 September	Reflective Supervision	Students will continue to reflect upon their experiences of supporting play and wondering with the caregiver and child they are learning from, while also reflecting on contextual aspects that impact on their experiences. Students will begin to reflect on preparing for the ending of home visits.
<b>Week 12 September HOME VISIT 8</b>		
20 September	Reflective Supervision	During this final reflective supervision session, students will reflect on their initial expectations and assumptions that they brought to the course and whether/how/why these have shifted and changed. Students will reflect on what they have learnt from the caregiver and child they visited as well as what the service that they have provided in return.
<b>Week 19 September HOME VISIT 9</b>		

Appendix 1, Figure B  
*Service-Learning Programme Information Leaflet*  
*English*

**Information about Masibambane**

Greetings to all caregivers of children with disabilities. This is a letter to you to tell you about Masibambane. Masibambane is a home visiting programme run jointly by the Department of Health (Settler's Hospital/Developmental Clinics), Association for Persons with Physical Disabilities (APD) and Rhodes University. It involves students from Rhodes University visiting caregivers and their child with disabilities in their homes for a number of weeks. Some of you might already know about Masibambane from other caregivers. Some of you might have already had students visit you and your child as Masibambane has been running for a number of years.

Every year we invite some caregivers to take part in Masibambane. We try our best to give everyone a turn to take part. We can only invite a few caregivers because we are limited in the number of students we have. If you are not invited to be part of Masibambane this year and would like to take part, please contact Zuki or Francine at APD on 046 622 5359 or 078 537 4111. They will make a note of your name and contact number and we will try our best to invite you to take part in 2019 or 2020.

If you have any questions about Masibambane please also ask someone at APD or a therapist at the Developmental Clinic.

*Service-Learning Programme Information Leaflet  
isiXhosa Translation*

**Ulwazi ngeMasibambane**

Siyanibulisa nonke bazali/banakekeli babantwana abakhubazekileyo. Lencwadi yeyok wazisa ngeMasibambane. IMasibambane yinkqubo yokundwendwela ekhayeni lakho.

Yenziwa ngabaseDepartment of Health (Settlers Hospital/Developmental Clinic), neAssociation for Persons with Disability, kunye neRhodes University. Lenkqubo idibanisa abafundi base Rhodes University, nawe, kunye nomntwana wakho. Ababafundi bayakuchita iiveki izeliqela benindwendwela emzini wakho. Abanye bazi ngokuva ngabanye abazali ebele bethat he inxaxheba kulenkqubo. Abanye benu sebenalo ulwazi lweMasibambane ngokudi bana nabafundi kuleminyaka iMasibambane sele ikhona.

Rhoqo ngonyaka, siye simeme abazali bathathe inxaxheba. Siyazama ngokungako uk unika wonke umntu ithuba lokuthatha inxaxheba kulenkqubo. Ngenxa yobuncinci lwe nani labafundi, sikwazi ukwamela iqela labazali kunye nabantwana babo. Ukuba uno mdla wokungenela kulenkqubo, kodwa awusifumani isimemo kulonyaka, nceda uxho mane noZuki okanye Francine base APD ku046 622 5359 okanye 078 527 4111. Bazakuthatha zonke iincukacha zakho. Zizakuthi sizame ukuba ufumane ithuba kunyaka ka 2019 okanye 2020.

Ukuba uthe wanayo imibuzo malunga neMasibambane, nceda ubuze umntu wase AP D okanye enye yetherapists eDevelopmental Clinic.

Appendix 1, Figure C  
*Consent to Partake in the Service-Learning Programme*  
*English*

**Invitation to take part in Masibambane**

Dear \_\_\_\_\_

We would like to invite you to take part in Masibambane, a home visiting programme run jointly by the Department of Health (Settler's Hospital/Developmental Clinics), Association for Persons with Physical Disabilities and Rhodes University.

This letter has been written to tell you about the programme. Please feel free to ask any questions you might have about Masibambane before you sign this letter.

In 2016 the programme will involve two students from Rhodes visiting you and your child in your homes every week for 8 weeks between April and May. The students will spend time getting to know you and your child and would like to learn from you. They would especially like to learn about what it is like looking after a child with disabilities. The students would like to support you in following the home programme that the therapists at the Developmental Clinic have asked you to do. They would also like to support you by listening to stories that might sit heavily on your heart. The stories you share with them will only be shared with their supervisors who will respect them as private. The students will also spend time playing with you and your child. They are interested in you and your child's thoughts and feelings. At the end of May the students will say goodbye. Of course, even though the students' visits will end your contact with APD and the therapists of the Department of Health will continue at the Developmental Clinic.

If you agree to participate in the programme you will also have an opportunity to participate in research that is interested in the impact of the programme. However, your participation in the research will be entirely voluntary

By signing this letter you are saying that you are happy to take part in Masibambane.

If you decide not to sign this letter, you do not have to feel bad or worried as taking part is not compulsory. You can continue to attend the Developmental Clinic even if you do not take part. By signing this letter you are also saying that you understand what Masibambane involves and also that you have had a chance to ask any questions you might have.

If at any point in the programme you have worries you are invited to contact Zuki Gubevu or Francine Mwepu at APD on 046 622 5359 or 078 537 4111 to share these.

\_\_\_\_\_ Signature Date

*Consent to Partake in the Service-Learning Programme  
isiXhosa Translation*

**Isimemo sokuthatha inxaxheba kwiMasibambane**

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Siyakumema uthathe inxaxheba kwiMasibambane, inkqubo yeDepartment of Health (Settlers Hospital/Developmental Clinics), Association for Persons with Physical Disabilities ne Rhodes University.

Lencwadi ibhalelwe wena. Khululeka, ubuze imibuzo ongabe unayo malunga neMasibambane phambi kokuba uvume, kwaye usigne.

Kulonyaka ka2016 lenkqubo izakudibanisa abafundi base Rhodes University ababini, kunye nawe nomntwana wakho. Lenkqubo izakuthatha iiveki ezisibhozo (8), apho ababafundi babini bazakundwendwela wena nomntwana wakho emzini wakho, apho bezawchitha ixesha besazana nomntwana wakho. Ababafundi bafuna ukufunda lukhulu kuwe malunga nokunakekela umntwana okhubazekileyo. Phezu koko, ababafundi bafuna ukuxhasa ngeengecebiso othi uzifumane kwiiTherapists eklinik, kwaye nangezinto apho ekumele uzenze nomntwana wakho. Okunye, abafundi bafuna ukuthi bakuxhase ngokumamela izinto ezithi zikusinde emphefumleni ezidibanisana nokukhulisa umntwana okhubaziekileyo. Abafundi bazakuchitha ixesha bedlala nomntwana wakho. Banomdla kuwe nomntwana wakho. Ekupheleni kwenyanga kaMay, bazakuvalelisa, banishiye. Nangona abafundi bezanishiya, inkqubo yenu neAPD kwaye neTherapist zeDepartment of Health eDevelopmental Clinic izakuqhubeka.

Ngokusigna lencwadi, uthi uyavuma ukuthatha inxaheba kulenkqubo yeMasibambane. Ukuba uzive ungafuni ukusign lencwadi, khululeka, ungakhathazeki, ngokuba auisosinyazelo ukuthatha inxaxheba kulenkqubo. Ungaqhubeka usiya kwiDevelopmental Clinic.

Ukuba uyavuma ukuthatha inxaxheba kule nkqubo uzakubanalo nethuba lokuthatha

inxaxheba kuphando olujolise kwimpembelelo yenkqubo. Nangona kunjalo, uyakuyithatha inxaxheba ukuba uyafuna.

Ngokusign lencwadi, uyavuma ukuba unalo ulwazi ngeMasibambane, kwaye ulifumene ithuba lokubuza imibuzo.

Ukuba uthethe ekuhambeni kwethuba wanayo imibuzo, okanye kukho into ofuna ukuyiqonda, ungaxhomelana noZuki Gubevu okanye Francine Mwepu beAPD ku046 622 5359 okanye 078 537 4111.

\_\_\_\_\_  
Signature Umhla

**APPENDIX 2**  
**Research Recruitment**

Appendix 2, Figure A  
*Summary of Gross Motor Functioning Classification System (GMFCS)- Expanded and Revised*  
*(Palisano, Rosenbaum, Bartlett & Livingston, 2007)*

Level	Function Before 2 <sup>nd</sup> Birthday	Function Between 2 <sup>nd</sup> and 4 <sup>th</sup> Birthday	Function Between 4 <sup>th</sup> and 6 <sup>th</sup> Birthday
<b>I</b>	Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.	Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.	Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.
<b>II</b>	Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.	Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.	Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.
<b>III</b>	Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.	Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.	Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain
<b>IV</b>	Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.	Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.	Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.
<b>V</b>	Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.	Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. Children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.	Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations

Appendix 2, Figure B  
*Research Information Leaflet-  
 English*

2016  
Masibambane  
Research

**CALL TO TAKE PART IN RESEARCH ON  
THE MASIBAMBANE PROGRAMME.**

Dear Caregivers,

This year, researchers from Rhodes University Psychology Department will be doing research on the Masibambane programme under the supervision of Lisa Saville Young. The reason for this research is to find out whether the programme is helping everyone involved in it in a meaningful way, and to find out how we can make the programme even better.

A very important part of the research is about getting feedback from the caregivers and children that are receiving the programme to see if it is working for them and to understand what they think of the programme and what they do and do not like about it.

The researchers are looking for four caregivers and their children to participate in the research. To participate you must be the primary caregiver of a disabled child between the ages of 0 and 5 years old that has never participated in the Masibambane programme before 2016. Priority will be given to caregivers who seem to be struggling with low mood or those who are having difficulty building a relationship with their child and implementing the home programme.

Participation will consist of:

1. The researchers meeting with the caregiver and child at the caregiver's home and asking the caregiver questions about their well-being, caring for their child, and their experience of the students visits.
2. The researchers meeting with the caregiver and child at their home to video record them completing a set of tasks together.
3. The caregiver taking the child to the developmental clinic to the Developmental Clinic for the Occupational Therapists to assess the child's abilities. (if necessary transport can be arranged).

You will have to participate in these interviews and observations at four different times during the year, in May, July, September, and possibly December.

Participation in the research is voluntary and you do not have to participate if you do not want to. If you can't or don't want to take part in the research it will not affect the services you and your child receive from the therapists or the students.

If you do want to take part in the research you will be given a R100 Checkers voucher at each data collection point to say thank you for your time and input to the project. You will also be given copies of the videos taken and a feedback session will be given to your family to see the outcomes of the research and to help you plan a more specific intervention for you and your child.

If you would like more information on the research project or would like to volunteer, please contact the researcher, Nicole, on 082 805 9145, or email [nicolcooke91@gmail.com](mailto:nicolcooke91@gmail.com). Alternatively, you can let APD know that you are interested and ask them to have the researchers contact you. The researchers, Nicole and Sizayo, will also contact you during the course of the week to answer any questions you may have.

We look forward to hearing from you.

Best wishes,  
 Nicole Cooke  
 Student- Masters in Psychology  
 Rhodes University

Contact Nicole before the  
22<sup>nd</sup> April to participate:  
082 805 9145  
[nicolcooke91@gmail.com](mailto:nicolcooke91@gmail.com)

Research Information Leaflet-  
isiXhosa Translation

2016  
Uphando  
LweMasibamban

**IKHWELO LOKUTHATHA INXAXHEBA  
KWINKQUBO IMASIBAMBANE**

Kuni bakhathaleli babantwana abakhubazekileyo,

Kulo nyaka, abaphandi besebe leNzululwazi ngeNgqondo kwiDyunivesithi iRhodes bazakwenza uphando ngenkqubo iMasibambane bonganyelwe nguLisa Saville Young. Isizathu solu phando kukuzama ukuqonda ukuba ingaba le nkqubo iyabanceda bonke abantu abanxulumene nayo ngendlela eyiyo, nokuqonda ukuba singayiphucula njani le nkqubo.

Inxenye ebaluleke kakhulu yolu phando kukufumana izimvo zabakhathaleli nabantwana abaxhamla kule nkqubo ukuze sizobona ukuba iyabasebenzela na, nokuqonda ukuba bona bacinga ntoni ngale nkqubo, iyintoni abayithandayo nabangayithandiyo ngayo.

Abaphandi bafuna abakhathaleli zbane nabantwana babo bathathe inxaxheba kolu phando. Ukuze uthathe inxaxheba kufuneka ubengumkhathaleli womntwana okhubazekileyo ophakathi kweminyaka eyi 0 - 5 ubudala ongazange athathe inxaxheba kwinkqubo kaMasibambane phambi ko2016. Kuzakugxilwa kubakhathaleli abangathi baziva bephantsi emoyeni okanye abo banobunzima ekwakheni ubudlelwane nabantwana babo nasekuzalisekiseni inkqubo kaMasibambane emakhayeni abo.

Ukuthatha inxaxheba kuzakuqoka oku:

1. Ukudibana komphandi nomkhathaleli, nomntwana ekhayeni labo nokubuza umkhathaleli imibuzo ngokuphila kwakhe, ukukhathalela umntwana wakhe, namava akhe ngokuhanjelwa ngabafundi.
2. Ukudibana komphandi kunye nomkhathaleli nomntwana ekhayeni labo kuthathwe ividiyo yabo besenza imisebenzi abayinikiweyo bobabini.
3. Ukuziswa komntwana kwikliniki yophuhliso ayobona ugqirha osebenza ngabantu abakhubazekileyo ukuze ahlole ukukhubazeka komntwana. (Ukuba kuyadingeka isithuthi esiya apho sakukhutshwa).

Kuzakufuneka uthathe inxaxheba kudliwano-ndlebe nokujongwa kumatyeli amane ohlukeneyo enyakeni; ngoMeyi, Julayi, Septemba mhlabi nangoDisemba.

Inxaxheba kolu phando uyithatha ukuba uyafuna, akunyanzelekanga ukuba uthathe inxaxheba ukuba akufuni. Ukungakwazi kwakho okanye ukungafuni kwakho uthatha inxaxheba kolu phando akusoze kubenachaphaza kwinkonzo ozifumanayo wena nomntwana wakho kwilingcali zokunyanga nabafundi.

Ukuba uyafuna ukuthatha inxaxheba kolu phando igalelo nexesha lakho olichithe kule projekthi liyakubulelwa ngevawtsha yeR100 yakwa-Checkers ngamatyeli onke okuqokelelwa kweenkcukacha zophando. Uyakunikwa neekopi zevidiyo ezithathiweyo, kwenziwe iseshoni yengxelo apho usapho lwakho luyakwaziswa khona ngeziphumo zophando ukuze ukwazi ukucebela wena nomntwana wakho indlela yokulamla ethe ngqo.

Ukuba nifuna ulwazi oluthe vetshe ngale projekthi yophando okanye ungathanda ukuvolontiya, nceda uqhagamshelane nomphandi uNicole ku082 805 9145 okanye uthumele imeyile [ku-nicolecooke91@gmail.com](mailto:ku-nicolecooke91@gmail.com). Abaphandi, uNicole noSinazo, nabo bazakuqhagamshelana nawe evekini ukuze baphendule nayiphina imibuzo ongathi ubenayo.

Singakuvuyela ukuva kuwe.

Ozithobileyo,  
Nicole Cooke  
Mfundi – Masters kwiNzululwazi ngeNgqondo  
Dyunivesithi iRhodes

Ukuba ufuna uthatha  
inxaxheba qhagamshelana  
noNicole phambi kwe22  
kaAprili ku 082 805 9145  
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Appendix 2, Figure C  
*Important Dates of Research-  
 English*

<b>Data Collection Phase</b>	<b>Data Collection Dates</b>
<b>Baseline 1- before Masibambane</b>	28 April- 06 May
<b>Baseline 2- before Masibambane</b>	11 July- 15 July
<b>Masibambane weekly visits</b>	19 July- 20 September
<b>Post- after Masibambane</b>	26 September- 30 September

*isiXhosa Translation*

<b>Intsuku zika-Masibambane nophando zonyaka ka 2016</b>	<b>Intsuku zoku qokelela ulwazi</b>
<b>Udliwano-ndlebe lokuqala phambi koba kuqale inkqubo ka Masibambane</b>	Ukususela ngomhla we 28 April uyawkutsho ngomhla we 06 Meyi
<b>Udliwano-ndlebe lwesbini phambi koba kuqale inkqubo ka Masibambane</b>	Ukususela ngomhla we 11 Julayi uyawkutsho ngomhla we 15 Julayi
<b>Ukuqala kwe nkqubo ka Masibambane (ukuvakashelwa emizini rhoqo nge veki)</b>	Ukususela ngomhla we 19 Julayi uyawkustho ngomhla we 30 Semptemba
<b>Emva kwe nkqubo ka Masibambane</b>	Ukususela ngomhla we 26 ka Semptemba uyawtsho ngomhla we 30 ka Septemba

**APPENDIX 3**  
**Data Collection**

Appendix 3, Figure A  
*Data Collection Timeline*

	Demographic	CORE-OM	PEDI-CAT	MPOC-8 SA	Video	IPA
Measure of	Socio-demographic Characteristics	Caregiver Well-being	Child Functioning	Satisfaction with services	Affect Attunement	Caregivers experiences
April/May 2016: Intake Baseline	X	X	X	X	X	
July 2016: Baseline 2		X	X	X	X	X
September 2016: End of intervention		X	X	X	X	X

Appendix 3, Figure B  
*Demographic Questionnaire-  
 English  
 (Adapted from Saloojee, 2008)*

Demographic Questionnaire		
Interview Details		
101	Interview number	
102	Date of interview (dd/mm/yy)	
103	Place of interview	1= Home where child resides 2=Other home 3=Clinic/hospital 4=Other
104	Person interviewed	1= mother 2=caregiver
105	If caregiver (other than mother), what is relationship to child?	1=Father 2=Grandmother 3=Grandfather 4=Sibling 5=Relative 6=Neighbour 7=Friend 8=Other _____
106	Responsible for how much of child's care?	1=All the time (day and night) 2=Day only 3=Night only 4= After school care 5=other _____
Caregiver's Characteristics and Relationship with Child		
201	Date of birth (dd/mm/yy)	
202	Age (years)	
203	Sex	1=Male 2=Female
204	Race	1= Black 2=White 3=Indian 4=Coloured 5=Chinese 6=Other
205	Home language	1=English 2=Xhosa 3= Zulu

		4=Afrikaans 5=Other _____
206	Current marital status	1= Married 2= Living together 3=Divorced 4= Separated 5=Widowed 6= Never married
207	What is the highest grade of schooling that you have completed?	1=None 2=Primary School 3=High school 4=High school (matric) 5=Diploma 6=University degree
208	Do you work?	1=yes, full time 2= yes, part time 3= no, seeking work 4=no, not seeking work
209	Where does your main source of income come from?	1=Regular income from working 2= Occasional income from working 3=Pension 4=Child support grant 5=Disability grant (for self) 6= Disability grant (for child) 7= Foster care grant 8= Maintenance grant 9=Income fro husband 10= Income from other family members 11= Other _____ 12. No income
210	Approximate monthly income?	
211	How many hours a day do you spend with the child?	1=During the week? 2=During the weekend? 3=none
212	How much of the time are you responsible for the child?	1= all of the time 2= During the day only 3= During the night only 4= Only some days
213	During a typical day, how much do you play with your child?	1=During the week? ____ 2= During the weekend? ____ 3=None
214	Compared to other children is this a difficult child?	1=Yes 2=No

215	Is there someone you can trust to leave your child with when you are busy?	1=Yes 2=No
216	Who is this person?	1=My mother 2=my in-laws 3= my neighbour 4=my relatives 5=my friend 6=other
Child's Characteristics and Disability Treatment		
301	Child's date of birth (dd/mm/yy)	
302	Child's age	_____years _____months
303	Child's sex	1=Male 2=Female
304	Type of Birth	1=Singleton 2=Twin 3=Triplet or more
305	Place of birth	1= Hospital 2= Clinic 3= Home 4= Other
306	Method of delivery	1=Natural 2= Caesarian section 3=Breech
307	Child's impairment (more than one can be circled)	1=Moving and walking 2=Talking 3= Hearing 4= Seeing 5=Learning 6=Behaviour 7=Other _____
308	Gross Motor Function Classification System	1= Level 1 2=Level 2 3=Level 3 4=Level 4 5=Level 5
309	Was your child born with the disability or did he/she acquire the disability later on?	1=congenital (at birth) 2= acquired If acquired: Date: _____ Reason: _____
310	How does your child mostly communicate?	1= Speaking 2= Using gestures/ signs 3= Facial expressions

		4=Crying 5= Making sounds or noises 6= Does not communicate 7= Unknown
311	Do other people understand what your child is telling you?	1=all the time 2=some of the time 3=hardly at all 4=never
312	Does your child receive a care dependency grant?	1=Yes 2=No 3=Applied, still waiting 4=Child not eligible 5=Unknown 6=No, but does receive child support grant
313	Does your child currently attend therapy?	1=Yes 2=No
314	Where does your child receive therapy? (can circle more than one)	1=Hospital 2=Clinic 3=Home 4=Other _____
315	How often during the past 6 months has the child attended therapy?	1= More than 6 times 2= 6 times 3= 4-5 times 4= 2-3 times 5=1-2 times 6= Not at all
316	How long have you been attending therapy?	1= 6 months or less 2= 7-12 months 3= 13- 24 months 5= 2- 4 years 6= more than 5 years
317	How long does it take you to get to the clinic/ hospital from where you stay?	1= 30mins or less 2= 31-60mins 3= 1 hour- 2 hours 4= more than 2 hours
318	How do you usually get to the clinic or hospital for therapy?	1= taxi 2=bus 3= by foot 4= by private car (It is your own car? Y / N) 5=other
319	Does your child attend school/ day care?	1=Yes 2=No
Household Characteristics		

401	Number of occupants in the house?	Children: ____ Adults: ____
402	Total income of household per average month?	1= Less than R100 2= R100- R500 3=R500- R1000 4= R1000-R3000 5=R3000-R5000 6= More than R5000 7=Unknown
403	From where does the household earn income? (more than one option may be circled)	1= Regular income from working 2= Seasonal income from working 3= Occasional income from working 4= Pension 5= Child support grant 6= Disability grant (adult) 7= Care dependency grant (child) 8= Foster care grant 9= Maintenance grant 10= Other _____ 11= No income at all 12=Unknown
404	Construction material of main house walls?	1= brick, cement blocks 2= wood 3= informal/shack 4= mud 5= other _____
405	Construction materials of main houses roof?	1= Tiles, cement, bricks 2= Corrugated iron, wood, asbestos 3=Thatch 4=Informal/shack
406	Main water supply?	1= Tap in house 2= Tap in yard 3= Tap in street 4= Water truck 5= cement well 6= Traditional well 7= Open, unprotected (pond, river, dam) 8= Rainwater tank
407	In the household do you have a functioning: Stove If yes (gas, coal, electricity)	1=yes                      2=no

	Primus or paraffin stove	1=yes	2=no
	Hot plate	1=yes	2=no
	Fridge	1=yes	2=no
	Microwave	1=yes	2=no
	TV	1=yes	2=no
	Hifi/stereo/tape/CD player	1=yes	2=no
	Video	1=yes	2=no
	Radio	1=yes	2=no
	Phone (fixed)	1=yes	2=no
	Cellphone	1=yes	2=no
	Car/truck	1=yes	2=no
	Bicycle	1=yes	2=no
	Kariki cart/sled	1=yes	2=no
<b>Judgment form Interviewer</b>			
501	In your opinion is the information accurate?	1=Good	2=Fair 3=Poor
502	Any other information on the child or family that you would like to add?		

*Demographic Questionnaire-  
isiXhosa Translation*

<b>Iphepha-mibuzo ngobume babantu</b>		
<b>Iinkcukacha zodliwano-ndlebe</b>		
101	Inombolo yodliwano-ndlebe	
102	Umhla wodliwano-ndlebe (dd/mm/yy)	
103	Indawo yodliwano-ndlebe	1= Ikhaya apho ahlala khona umntwana 2=Elinye ikhaya 3=Ikliniki/ isibhedlele 4=Okunye
104	Umntu ekwenziwe naye udliwano-ndlebe	1= umama 2=umkhathaleli
105	Ukuba umkhathaleli (ingenguye umama), buthini ubudlelane nomntwana?	1=Utata 2=Umakhulu 3=Utat'omkhulu 4=Umntakokwabo 5=Isihlobo 6=Ummelwane 7=Umhlobo 8=Okunye _____
106	Unoxanduva olungakanani ekukhathaleleni umntwana?	1=Lonke ixesha (imini nobusuku) 2=Emini kuphela 3=Ebusuku kuphela 4= Xakuphuma isikolo 5=Okunye _____
<b>Iimpawu zomkhathaleli kunye nobudlelwane kunye nomntwana</b>		
201	Umhla wokuzalwa (dd/mm/yy)	_____/_____/_____
202	Ubudala (iminyaka)	
203	Isini	1=Indoda 2=Umfazi
204	Uhlanga	1= Mnyama 2=Mhlophe 3=Indiya 4=Ikhaladi 5=Itshayina 6=Olunye
205	Ulwimi lwasekhaya	1=IsiNgesi 2=IsiXhosa 3= IsiZulu 4=IsiBhulu

		5=Okunye _____
206	Ubume bomtshato ngoku	1= Nditshatile 2= Ndiyahlalisana 3=Ndidivosile 4= Ndohlukene 5=Ndingumhlokokazi 6= Zange ndatshata
207	Leliphi ibanga lesikolo eliphezulu oliphumeleleyo?	1=Alikho 2=Amabanga aphantsi 3=Amabanga aphezulu (Ibanga 8) 4=Amabanga aphezulu (imatriki) 5=Idiploma 6=Isidanga saseDyunivesithi
208	Uyasebenza?	1=ewe, ngokupheleleyo 2= ewe, amaxesha athile 3= hayi, ndikhangela umsebenzi 4=hayi, andikhangeli msebenzi
209	Ingaba ngowuphi owona mthombo wakho ungenisa imali?	1=Umvuzo oqhelekileyo wasemsebenzini 2= Umvuzo wethutyana wasemsebenzini 3=Umhlalaphantsi 4=Isibonelelo sabantwana 5=Isibonelelo sokukhubazeka (sam) 6= Isibonelelo sokukhubazeka (somntwana) 7= Imali yesondlo yembedlenge 8= Imali yesondlo 9=Ingeniso esuka kumyeni 10=Ingeniso esuka kwamanye amalungu osapho 11= Okunye _____ 12. Akukho mvuzo
210	Imali oyamkelayo ngenyanga?	
211	Zingaphi iyure ozichithayo ngosuku kunye nomntwana wakho?	1=Phakathi evekini? _____ 2=Ngempela-veki? _____ 3=akukho nanye
212	Lingakanani ixesha onoxanduva ngalo emntwaneni?	1= Lonke ixesha 2= Emini kuphela 3= Ebusuku kuphela 4= Ngeemini ezithile kuphela
213	Ngosuku, udlala kangakanani nomntwana wakho?	1=Phakathi evekini? _____ 2= Ngempela-veki? _____ 3=Andidlali

214	Xa uthelekisa nabanye abantwana, ingaba lo ngumntwana osokolisayo?	1=Ewe 2=Hayi
215	Ingaba ukhona umntu omthembayo onokushiya umntwana wakho naye xa uxakekile?	1=Ewe 2=Hayi
216	Ngubani lo mntu?	1=Ngumama wam 2=abasemzini wam 3= ummelwane wam 4=izihlobo zam 5=umhlobo wam 6=okunye _____
<b>Iimpawu zomntwana nonyango lokukhubazeka</b>		
301	Umhla wokuzalwa womntwana (dd/mm/yy)	
302	Iminyaka yomntwana	_____ iminyaka ____ iinyanga
303	Isini somntwana	1=Indoda 2=Umfazi
304	Uhlobo lokuzalwa	1=Uzelwe yedwa 2=Liwela 3=Ngamawele                      amathathu nangaphezulu
305	Indawo yokuzalwa	1= Esibhedlele 2= Ekloniki 3= Ekhaya 4= Okunye
306	Indlela yokubeleka	1=Ukuzibelekela ngendalo 2= Ukubeleka ngosikwa 3=Ukubeleka ngebritshi
307	Ukhubazeko lomntwana (ungakhetha ngaphezu kwempendulo enye)	1=Ukushukuma nokuhamba 2=Ukuthetha 3= Ukuva 4= Ukubona 5=Ukufunda 6=Ukuziphatha 7=Okunye _____
308	Iqondo lokukhubazeka komntwana ( <i>Gross Motor Function Classification System</i> )	1= Inqanaba lokuqala 2=Inqanaba lesibini 3=Inqanaba lesithathu 4=Inqanaba lesine 5=Inqanaba lesihlanu
309	Ingaba umntwana wakho uzelwe enokukhubazeka okanye ukufumene ekukhuleni?	1=Uzelwe                      ekhubazekile (ekuzalweni) 2= Wakufumana Ukuba wakufumana:

		Umhla: _____
		Isizathu:
310	Ingaba umntwana wakho unxibelelana njani amaxesha amanintsi?	1= Ngokuthetha 2= Ngokusebenzisa izangotsha/ isayini 3= Usebenzisa ubuso 4=Ngokulila 5= Ukwenza isandi okanye ingxolo 6= Akanxibelelani 7= Ayaziwa
311	Ingaba abanye abantu bayakuqonda osube ukuxelelwa ngumntwana wakho?	1=Ngalo lonke ixesha 2=Ngamanye amaxesha 3=Nzima kakhulu 4=nakanye
312	Ingaba umntwana wakho uyasifumana isibonelelo sokukhathalelwa?	1=Ewe 2=Hayi 3= Ndifake isicelo, ndisalindile 4=Umntwana akakufanelanga 5=Andiyazi 6= Hayi, kodwa uyasifumana isibonelelo sabantwana
313	Ingaba umntwana wakho uyalufumana ululeko ngoku?	1=Ewe 2=Hayi
314	Ingaba umntwana wakho ulufumana phi uloluleko? (ungakhetha ngaphezu kwenye)	1=Esibhedlele 2=Ekliniki 3=Ekhaya 4=Enye _____
315	Kwezi nyanga zisithandathu zidlulileyo, ingaba umntwana wakho uluhambe kangakanani na uloluleko?	1= Ngaphezu kwamaxesha asi-6 2= amaxesha asi-6 3= Amaxesha ama 4-5 4= Amaxesha ama 2-3 5=Ixesha eli1-2 6= Khange aye
316	Sele ilithuba elingakanani usiya kuloluleko?	1= Iinyanga ezisi-6 okanye ngaphantsi 2= Iinyanga ezisi 7-12 3= Iinyanga ezili 13- 24 5= Iinyanga ezi 2- 4 6= Ngaphezu kweminyaka emi-5
317	Ingaba kukuthatha ixesha elingakanani na ukuya ekliniki/ esibhedlele ukusuka apho uhlala khona?	1= imizuzu engama-30 nangaphantsi 2= imizuzu engama 31-60 3= iyure enye ukuya kwezimbini 4= ngaphezu kweeyure ezimbini
318	Ingaba uyangantoni ekliniki nasesibhedlele	1= ngeteksi

	kuloluleko?	2=ngebhasi 3= ngeenyawo 4= ngesithuthi sabucala (Ingaba yimoto yakho? (Y / N) 5=okunye
319	Ingaba umntwana wakho uyasihamba isikolo/ ikhreshi?	1=Ewe 2=Hayi
<b>Iimpawu zekhaya</b>		
401	Inani labantu abahlala endlini?	Abantwana: _____ Abadala: _____
402	Umvuzo opheleleyo wekhaya ngenyanga nganye?	1= Ngaphantsi kwe R100 2= R100- R500 3=R500- R1000 4= R1000-R3000 5=R3000-R5000 6= Ngaphezu kwama R5000 7=Awaziwa
403	Ingaba uvela phi umvuzo kweli khaya? (ungakhetha ngaphezu kwempendulo enye )	1= Umvuzo wesiqhelo wasemsebenzini 2= Umvuzo wexesha elithile wasemsebenzini 3= Umvuzo wethutyana wasemsebenzini 4= Umhlalaphantsi 5= Isibonelelo sabantwana 6= Isibonelelo sokukhubazeka (umntu omdala) 7= Isibonelelo sokukhathalelwa (umntwana) 8= Imali yesondlo sembedlenge 9= Imali yesondlo 10= Enye _____ 11= Akukho mvuzo kwaphela 12=Ayaziwa
404	Izixhobo zokwakha zodonga lwendlu enkulu?	1= isitena, izitena zesamente 2= amaplanga 3= engamiselwanga/ityotyombe 4= udaka 5= enye _____
405	Izixhobo zokwakha zophahla lwendlu enkulu?	1= iithayilizi, isamente, izitena 2= amazinki, amaplanga, i-asibhestozi 3=Ifulelwe 4=engamiselwangwa/ityotyombe
406	Oyena ndoqo wokubonelela ngamanzi?	1= Impompo endlini 2= Impompo eyadini 3= Impompo esitratweni 4= Itraka yamanzi

		<p>5= Iqula lesamente          6= Iqula eliqhelekileyo          7= kwindawo evulekileyo,          engakhuselwanga (ichibi,          umlambo, idama)          8= Itanki lamanzi emvula</p>
407	<p>Ingaba endlini niyazisebenzisa ezi zinto zilandelayo:          Isitovu              Ukuba ewe (igesi, amalahle, umbane)          Iprayima okanye isitovu separafini          Isitovu sombane esinamacala amabini          Ifriji/ isikhenkcezisi          Isifudumezi-kutya/ makhrowevu          Umabonakude          Hi fi/isitiriyo/isishicileli/isishicileli samacwecwe          Ividiyo          Unomathotholo          Imfono-mfono yasendlini          Unomyayi          Imoto/itraka          Ibhayisekile          Inqwelo yokuhambisa/isileyi</p>	<p>1=ewe            2=hayi           1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi          1=ewe            2=hayi</p>
<b>Ukuphawula komthathi-nxaxheba</b>		
501	<p>Ngokoluvo lwakho, ingaba ezi nkcukacha zichanekile?</p>	<p>1=Zilungile          2=zifanelekile          3=azifanelekanga</p>
502	<p>Ingaba zikhona ezinye iinkcukacha ongathanda ukuzongeza ngomntwana okanye ngosapho?</p>	

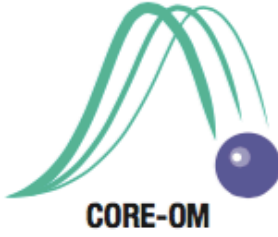


Over the last week		Frequency					Dimension
		Not at all	Only Occasionally	Sometimes	Often	Most or all the time	
15	I have felt panic or terror	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	P
16	I made plans to end my life	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	R
17	I have felt overwhelmed by my problems	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	W
18	I have had difficulty getting to sleep or staying asleep	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	P
19	I have felt warmth or affection for someone	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	F
20	My problems have been impossible to put to one side	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	P
21	I have been able to do most things I needed to	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	F
22	I have threatened or intimidated another person	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	R
23	I have felt despairing or hopeless	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	P
24	I have thought it would be better if I were dead	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	R
25	I have felt criticised by other people	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	F
26	I have thought I have no friends	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	F
27	I have felt unhappy	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	P
28	Unwanted images or memories have been distressing me	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	P
29	I have been irritable when with other people	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	F
30	I have thought I am to blame for my problems and difficulties	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	P
31	I have felt optimistic about my future	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	W
32	I have achieved the things I wanted to	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	F
33	I have felt humiliated or shamed by other people	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	F
34	I have hurt myself physically or taken dangerous risks with my health	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	R

**THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE**

<b>Total Scores</b>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	→	<input type="text"/>	→	<input type="text"/>
<b>Mean Scores</b> <small>(Total score for each dimension divided by number of items completed in that dimension)</small>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>		<input type="text"/>		<input type="text"/>
	(W)	(P)	(F)	(R)		All Items		All minus R

*The Clinical Outcomes in Routine Evaluation -Outcome Measures (CORE-OM)-  
isiXhosa Translation*



Yazisa indawo yakho (indawo ohiyala kuyo)

**Umazisi wakho (client/isiguli/patient)**

iID yeTherapist

Usuku okwagqitywa ngalo le fomu

UnyakaInyangaUmhla

Ubudala  Umfazi

Indoda

bhala ixesha ogqibe ngalo

1 Ekuqaleni

2 Ekuyibhekiseni komnye umntu  Inqanaba

3 Xilonga

4 Indibano yokuqala yetherapy

5 Itherapy yangaphambili ziyelwanga

6 Kwinkqubo yetherapy

7 Kwinkqubo yetherapy yokugqibela  I-episodi

8 Elandelayo yokuqala

9 Elandelayo yesibini

**KUBALULEKILE- NCEDA FUNDA APHA KUQALA**

Le fomu inenkcazelo ezingama-34 zokuba ubuziva njani na KULE VEKI IPHELILEYO. Nceda funda inkcazelo nganye uze ucinge ukuba uzive njalo kangakanani na kwiveki ephelileyo. Phawula ibhokisi ekufutshane nendlela ozive ngayo nge-

		Khangela konke konke	Kancinci	Ngamaxesha athile	Kakhulu	Phantse ngamaxesha onke/Rhooqo						
1 Ndizive ndindedwa ndililolo	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	F
2 Bendibambe umzimba, ndinexhala okanye ndiphaku-phaku	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	P
3 Ndizive ndinaye umntu onokundixhasa xa ndidinga inkxaso	<input type="checkbox"/>	4	<input type="checkbox"/>	3	<input type="checkbox"/>	2	<input type="checkbox"/>	1	<input type="checkbox"/>	0	<input type="checkbox"/>	F
4 Ndizive kakuhle ngesiqu sam	<input type="checkbox"/>	4	<input type="checkbox"/>	3	<input type="checkbox"/>	2	<input type="checkbox"/>	1	<input type="checkbox"/>	0	<input type="checkbox"/>	W
5 Ndizive ndityhafile ndingenamandla akwenza nto	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	P
6 Bendindlongo-ndlongo kwabanye abantu	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	R
7 Ndizive ndikwazi ukumelana nezinto xa zingahambi kakuhle	<input type="checkbox"/>	4	<input type="checkbox"/>	3	<input type="checkbox"/>	2	<input type="checkbox"/>	1	<input type="checkbox"/>	0	<input type="checkbox"/>	F
8 Bendikhathazwa ziintlungu, iingqaqambo okanye ezinye iingxaki zomzimba	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	P
9 Bendinengcinga yokuzenzakalisa	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	R
10 Bendizitsala ukuthetha nabantu	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	F
11 Ukubamba umzimba nonxunguphalo kundithintele ukwenza izinto ezibalulekileyo	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	P
12 Zindonwabisile izinto endizenzileyo	<input type="checkbox"/>	4	<input type="checkbox"/>	3	<input type="checkbox"/>	2	<input type="checkbox"/>	1	<input type="checkbox"/>	0	<input type="checkbox"/>	F
13 Bendiphazanyiswe zilingcinga neemvakalelo ezingafunekiyo	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	P
14 Ndizive ndifuna ukukhala	<input type="checkbox"/>	0	<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3	<input type="checkbox"/>	4	<input type="checkbox"/>	W

**Nceda uguqule iphepha**

**Kule veki iphelileyo**

	Khangxe konke konke	Kancinci	Ngamaxesha athile	Kakhulu	Phantsisa ngamaxesha onke/Robo	
15 Bendinonxunguphalo noloyiko	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
16 Ndiye ndenza amalungiselelo okuzibulala	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> R
17 Ndive iingxaki zam zindongamele	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> W
18 Andilali kakuhle okanye ndiyaphuthelwa	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
19 Ndive ubushushu okanye uthando komnye umntu	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> F
20 Bekungakwazeki ukubeka iingxaki zam ecaleni	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
21 Ndikwazile ukuzenza izinto ezininzi ebendinga ukuzenza	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> F
22 Ndigrorise okanye ndoyikisa omnye umntu	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> R
23 Ndizive ndinikezele okanye ndiphelelwe lithemba	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
24 Ndingce ukuba bekunokuba ngcono ukuba bendifile	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> R
25 Ndive ngathi abanye abantu bayandigxeka	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> F
26 Ndingce ukuba andinabahlobo	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> F
27 Ndizive ndingonwabanga	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
28 Imifanekiso engafunekiyo yezinto ezenzekayo, okanye iinkumbulo ezingafunekiyo bezindihlupha	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
29 Bendikruquka xa ndinabanye abantu	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> F
30 Ndingce ukuba ndizenzile ngeemeko neengxaki zenzima zam	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> P
31 Ndizive ndinethemba ngengomso lam	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> W
32 Imizamo yam iphumelele	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	<input type="checkbox"/> F
33 Ndizive ndiyintlekisa ndiphoxekile kwabanye abantu	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> F
34 Ndizenzakalisile okanye ndenze izinto ukubeka impilo yam emngciphekweni	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> R

**SIYABULELA NGOKUGCWALISA ELI PHETSHANA LEMIBUZO**

**Amanqaku ewonke**  
**i'mean score**  
(Amanqaku ewonke kuluhlu ngalunye athula-hulwe ngenani lamanqaku apheleleyo kwelo luhlu)

(M)

(F)

(F)

(F)



Amanqaku sicike

Amanqaku ewonke endibise ngqR

Appendix 3, Figure D  
*Examples of items from the four domains of the Pediatric Evaluation of Disability Inventory - (PEDI-CAT)*  
 (Haley, Coster, Dumas, Fragala-Pinkham & Moed, 2012)




**Table 4-2. Daily Activities (DA) Items**

The Daily Activities domain includes items in four content areas: Getting Dressed, Keeping Clean, Home Tasks, and Eating & Mealtime. Sixty-eight items address basic self care and instrumental activities of daily living such as eating, grooming, dressing, and household maintenance.

Item Number	Content Area	Item	Illustration
DA002	Eating & Mealtime	Swallows pureed/ blended/ strained foods	
DA003	Eating & Mealtime	Finger feeds small or bite-size pieces of food	

**Table 4-3. Mobility (MB) Items**

The PEDI-CAT Mobility domain addresses five content areas: Basic Movement and Transfers, Standing and Walking, Steps & Inclines, Running and Playing, and Wheelchair. Seventy-five items address early mobility and physical functioning activities such as head control, transfers, walking, climbing stairs, and playground skills, while an additional 12 items are specifically for children who use walking aids (canes, crutches, walkers). A separate domain addresses functional mobility using a wheelchair.

Item Number	Content Area	Item	Illustration
MB002	Basic Movement & Transfers	When lying on belly, turns head to both sides	
MB003	Basic Movement & Transfers	When lying on back, turns head to both sides	
MB006	Basic Movement & Transfers	When lying on back, reaches for toy	

**Table 4-4. Social/Cognitive Items**

The PEDI CAT Social/Cognitive domain includes 60 items that address communication, interaction, safety, behavior, play with toys and games, attention, and problem-solving in the four content areas of Interaction, Communication, Everyday Cognition, and Self Management.

Item Number	Content Area	Item
SC001	Communication	Uses words, gestures or signs to ask for something
SC002	Communication	Uses several words or signs together such as "go home now" and "daddy go"
SC004	Communication	Uses words or signs to ask questions such as "Where's Mommy?" or "What's that?"
SC005	Interaction	Carries on a conversation with a familiar person by listening and responding appropriately
SC008	Communication	Teaches another person a new game or activity by giving examples and explanations
SC010	Interaction	Greets new people appropriately when introduced
SC011	Everyday Cognition	Follows directions given by adult leader of a small group (4-5 children or teenagers)
SC012	Interaction	Asks permission before using someone else's property
SC013	Everyday Cognition	Attends to and follows direction given by a coach or teacher while in a large group (20-30 children or teenagers)
SC014	Interaction	Uses language appropriate to the situation such as formal language at a job interview or informal language when hanging out with friends

**Table 4-5. Responsibility (RS) Items**

The PEDI-CAT Responsibility Domain includes 51 items that assess the extent to which a young person is managing life tasks that enable independent living with items that address daily schedules and planning, health and hygiene, and cooking and nutrition. The items are organized into the following four content domains: Organization & Planning, Taking Care of Daily Needs, Health Management, and Staying Safe. The items in the Responsibility Domain require children to use several functional skills in combination to carry out life tasks. For this reason, this is a more difficult domain and is estimated to assess children and youth beginning at the age of 3 years and extending up to the age of 21 years.

Item Number	Content Area	Item	Includes
RS001	Organization & Planning	Getting ready in the morning on time	Getting up; Getting dressed; Grooming and hygiene activities; Eating breakfast; Completing on time
RS002	Organization & Planning	Keeping track of time throughout the day	Arriving on time to scheduled activities or appointments; Coming back home at planned time; Ending an activity on time to stay on schedule
RS004	Organization & Planning	Planning and following a weekly schedule so all activities get done when needed	Identifying what needs to be done during a week; Determining how much time each activity will need and when it should be done; Carrying out plan; Making necessary adjustments due to unexpected delays or events

Appendix 3, Figure E  
*Measure of Process of Care (MPOC-8 SA)-*  
*English*  
*(Saloojee, 2008)*

**MODIFIED MEASURE OF PROCESSES OF CARE QUESTIONNAIRE - SOUTH AFRICAN  
 VERSION- MPOC-8(SA)**

We want to understand and measure the feelings and experiences of parents who have a child with a disability, such as cerebral palsy. We are especially interested in knowing about your perceptions and your view of the care and service you have received during the past year from the hospital or clinic where you go for therapy.

There are a number of questions we would like to ask you. These questions are based on what parents, like you have told us about the way that the care and service is sometimes given. We are interested in your own personal thoughts and would be thankful if you would answer these questions. There is no right or wrong answer. It is important that you feel free to answer the questions as honestly as possible.

For each question, you need to tell us to what extent you have experienced the events or the situations described. A score of 7 means that you have experienced this aspect to a very great extent, or most of the time. A score of 1 means that you have not experienced this aspect at all. In other words, the higher the score, the more you have experienced this situation or this aspect of the service. A score of 0 means that the question does not apply to you.

In the questions, the word **people** means those persons who work directly with you or with your child when you come for therapy. It may include the physiotherapists, the occupational therapists, speech therapists, social workers, doctors, nurses, etc.

The following is an example of the kinds of questions you will be asked. This example also shows you what your answer could mean.

To what extent do the person who gave you this questionnaire explain to you why they want you to take part in this study?

To a very great extent	To a great extent	To a fairly great extent	To a moderate extent	To a small extent	To a very small extent	Not at all	Not applicable
7	6	5	4	3	2	1	0

A score of 7 means that the person who gave you this questionnaire explained everything.

A score of 4 means that person who gave you this questionnaire explained some things clearly but there are some things you are not clear about.

A score of 1 means that the person did not explain anything to you at all and you know nothing at all about this study.

A score of 0 means that you never received any questionnaire and so you cannot answer the question. The question does not apply to you.

In the past year to what extent do the people who work with you child...	Indicate how much this aspect or situation happens to you.							
	7	6	5	4	3	2	1	0
9. provide enough time to talk so that you don't feel rushed?	7	6	5	4	3	2	1	0
10. treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
12. treat you as an individual rather than as a "typical" parent of a child with disability?	7	6	5	4	3	2	1	0
17. have information available about your child's disability (e.g. the causes, how it progresses, the future)?	7	6	5	4	3	2	1	0
19. have information available to you in various forms, such as booklets, video, pamphlets, etc.?	7	6	5	4	3	2	1	0
20. provide advice on how to get information or to contact other arents (e.g., parent groups such as DICAG, or other disabled peoples organisation)?	7	6	5	4	3	2	1	0
21. ensure that you have had the chance to explain the concerns and the things which worry you most about your child?	7	6	5	4	3	2	1	0
23. give you suggestions and ideas of things to do which make i easier to handle and look after your child?	7	6	5	4	3	2	1	0

*Measure of Process of Care (MPOC-8 SA)-  
isiXhosa Translation*

**IPHEPHA-MIBUZO ELILUNGISIWEYO LOMLINGANISELO WENKQUBO  
YONONOPHELO- INGUQULELO YASEMAZANTSI AFRIKA- 22 (SA)**

Sifuna ukuqonda nokulinganisela iimvakalelo kunye namava abazali abanomntwana okhubazekileyo, okufana nophazamiseko lwasengqondweni (*cerebral palsy*). Sinomdla kakhulu ekwazini iingcinga kunye nombono wakho ngononophelo kunye neenkonziso othe wazifumana kulo nyaka udlulileyo kwisibhedlele okanye iikliniki apho ufumana khona uloluleko.

Kukho inani lemibuzo esingathanda ukukubuza yona. Le mibuzo ibhekiselele kwindlela abazali, abafana nawe, abasixelele ngayo ngendlela oluthi unonophelo kunye neenkonziso lwenzeke ngayo ngamanye amaxesha. Sinomdla ncakasana kwiingcinga zakho kwaye singabulela kakhulu ukuba unokuphendula le mibuzo. Akukho mpendulo ingalunganga nelungileyo. Kubalulekile ukuba uyiphendule le mibuzo ngokunyanisekileyo.

Ngombuzo ngamnye, kudingeka ukuba usixelele ukuba unamava angakanani ngezi ziganeko okanye iimeko ezichaziweyo. Isikora esingu-7 sithetha ukuthi uchatshazelwe kakhulu ngulo mba okanye amaxesha amanintsi. Isikora esingu-1 sithetha ukuba akukhange uchatshazelwe ngulo mba kwaphela. Ngamanye amazwi, xa isikora siphezulu sithetha ukuthi uchatshazelwe kakhulu ngulo mba wenkonzo. Isikora sika-0 sithetha ukuthi lo mbuzo lowo awukuchaphazeli wena.

Kule mibuzo, igama elithi **abantu** lithetha aba bantu basebenzisana ngqo nawe okanye nomntwana wakho xa nisiya kuloluleko. Ingaquka iphysiotherapists, occupational therapists, speech therapists, oonontlalontle, oogqirha, abongikazi, njalo njalo.

Esi sivakalisi silandelayo ngumzekelo wentlobo zemibuzo ozakuyibuzwa. Lo mzekelo ukwabonisa oko kuthet

hwa yimpendulo yakho.

*Kungomyinge ongakanani umntu okunike eli phepha-mibuzo...*

...ukuchazele ukuba kutheni befuna uthathe inxaxheba kolu phando

Undichaze le kakhulu kakhulu	Undichaze le kakhulu	Undichazele ngokufanelekile yo	Undichaze le nje	Undichaze le kancinci	Undichaze le kancinci kakhulu	Akandichazela nga kwaphela	ayinge ni
7	6	5	4	3	2	1	0

Isikora esingu-7 sithetha ukuba lo mntu ukunike eli phepha-mibuzo ukuchazele yonke into

ngokucacileyo nakakuhle kwaye ukuqonda kakuhle ukuba kutheni uthatha inxaxheba kolu phando

Isikora esingu-4 sithetha ukuba lo mntu ukunike eli phepha mibuzo uzicacisile ezinye zezinto kodwa zikhona ezinye izinto ongacacelwanga zizo.

Isikora sika-1 sithetha ukuba lo mntu akakucaciselanga kwanto kwaye awazi kwanto ngolu phando.

Isikora sika-0 sithetha ukuba zange ufumane kwaphhepha-mibuzo ngoko ke awukwazi kuphendula umbuzo. Umbuzo awukuchaphazeli.

Kulo nyaka ugqithileyo, basebenze kangakanani nomntwana wakho...	Bonisa ukuba wenzeka kangakanani lo mba okanye imeko kuwe							
	7	6	5	4	3	2	1	0
9. ukunike ixesha eloneleyo lokuthetha ukuze ungaziva uxheshiwe?	7	6	5	4	3	2	1	0
10. ukuthathe njengomntu olinganayo naye kunokuba akuthathe njengomzali nje wesigulane (umzekelo angakubizi ngo “mama” okanye “tata”)?	7	6	5	4	3	2	1	0
12 bakuthathe njengomntu kunokuba bakujonge njengomzali womntwana okhubazekileyo?	7	6	5	4	3	2	1	0
17. ukuba neenkukacha ngokukhubazeka komntwana wakho (umzk., unobangela, ukukhula kwayo, nengomso)?	7	6	5	4	3	2	1	0
19. ukuba neenkukacha ezikhoyo ngeendlela ezohlukileyo ezifana neencwadana, ividiyo, etc.)	7	6	5	4	3	2	1	0
20. akunike icebiso ngokufumana iinkukacha okanye ukuqhagamshelana nabanye abazali (umzk., iqela labazali elifana neDICAG, okanye umbutho wabantu abakhubazekileyo)	7	6	5	4	3	2	1	0
21. aquinisekise ukuba unalo ithuba lokuchaza ngezinto ezinothi kanti ziyaku khathaza okanye zikwenzela iwari malunga nomntwana wakho	7	6	5	4	3	2	1	0
23 akunike iingcebiso neembono ngezinto onokuzenza ezenza kubelula ukwazi ukukhathalela nokujonga umntwana wakho?	7	6	5	4	3	2	1	0

Appendix 3, Figure F  
*Marschak Interaction Method Instructions (MIM)*

**Instruction:**

I am going to give you and your child seven fun activities to do together. Please interact with your child so that you both feel comfortable and enjoy the tasks together. Try to do this in a way you would if no one was here, as if you are at home alone with your child. There is no right or wrong way to go about the tasks. We would just like to see how you interact together.

This interaction will be video-recorded but please try and ignore the camera and interact with your child in as normal a way as possible.

We will be observing your interaction from behind the mirror. After you have completed each task we will give you verbal instructions for the next task. Do not feel rushed to get through the tasks-take as much time as you would normally take at home and enjoy this time together.

**Tasks:**

1. Settle your child in by playing with your child in a familiar way that you would normally play with him at home.
2. Use some of the toys provide to make up a game to play with your child that he might enjoy.
3. Tell your child any story about when he was younger.
4. Feed your child something he might like from the selection.
5. Wipe your child's mouth and hands with a wet wipe/serviette and then take your time to massage some cream onto his face and hands.
6. Leave your child alone in the room for 1 minute. I will instruct you when to return.
7. Cradle your child in your arms and sing him a song.

Appendix 3, Figure G  
*Interpretative Phenomenological Analysis (IPA) Semi-Structured Interview*  
*Schedule*

**Prelude**

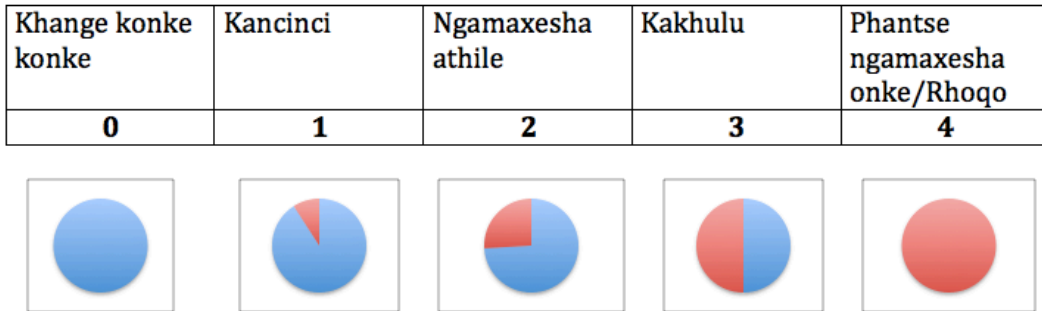
This interview aims to look at your **experiences of being a caregiver to [child’s name]** and how you have experienced the Developmental Clinic and the students’ visits. Specifically, I would like to know how you have felt, mentally and emotionally, how you have experienced changes in your child, and what the relationship is like between you and your child. I am really interested in your experiences, good and bad, to a full extent, drawing on your personal emotions and reflecting on specific incidents that you can remember.

	<b>Pre-intervention</b>	<b>Post-intervention</b>
<b>Child’s functioning and level of impairment?</b>	<ul style="list-style-type: none"> <li>• Can you describe [child’s name] to me.</li> <li>• Tell me about [child’s name]’s disability.</li> <li>• Tell me about how your child is developing/growing?</li> <li>• What has helped your child develop/grow? How has this helped?</li> </ul>	<ul style="list-style-type: none"> <li>• [Can you tell me how [child’s name] is doing?</li> <li>• Tell me about how (child’s name) disability is still affecting him/her?</li> <li>• Tell me how your child is developing/growing?</li> <li>• What has helped you child develop/grow? How has this helped?</li> </ul>
<b>Caregiver-well-being</b>	<ul style="list-style-type: none"> <li>• Tell me how you are feeling today.</li> <li>• Describe a time to me in the last week where you felt really good.</li> <li>• Describe a time to me in the last week where you felt really bad.</li> <li>• How is [child’s name] disability affecting you?</li> </ul>	<ul style="list-style-type: none"> <li>• Tell me how you are feeling today.</li> <li>• Describe a time to me in the last week where you felt really good.</li> <li>• Describe a time to me in the last week where you felt really bad.</li> <li>• How is [child’s name] disability affecting you?</li> </ul>
<b>Parent child relationship/ affect attunement?</b>	<ul style="list-style-type: none"> <li>• Tell me about your relationship with [child’s name], (Prompt:how you get along).</li> <li>• Can you describe a time to me in the last week where you and [child’s name] really got along?</li> <li>• Can you describe a time to me in the last week where you and [child’s name] did not get along?</li> <li>• What gives you the most joy in being a parent to [child’s name]?</li> <li>• What gives you the most pain and difficulty in being a parent to [child’s</li> </ul>	<ul style="list-style-type: none"> <li>• Tell me about your relationship with [child’s name], (Prompt:how you get along).</li> <li>• Can you describe a time to me in the last week where you and [child’s name] really got along?</li> <li>• Can you describe a time to me in the last week where you and [child’s name] did not get along?</li> <li>• What gives you the most joy in being a parent to [child’s name]?</li> <li>• What gives you the most pain and difficulty in being a parent to [child’s</li> </ul>

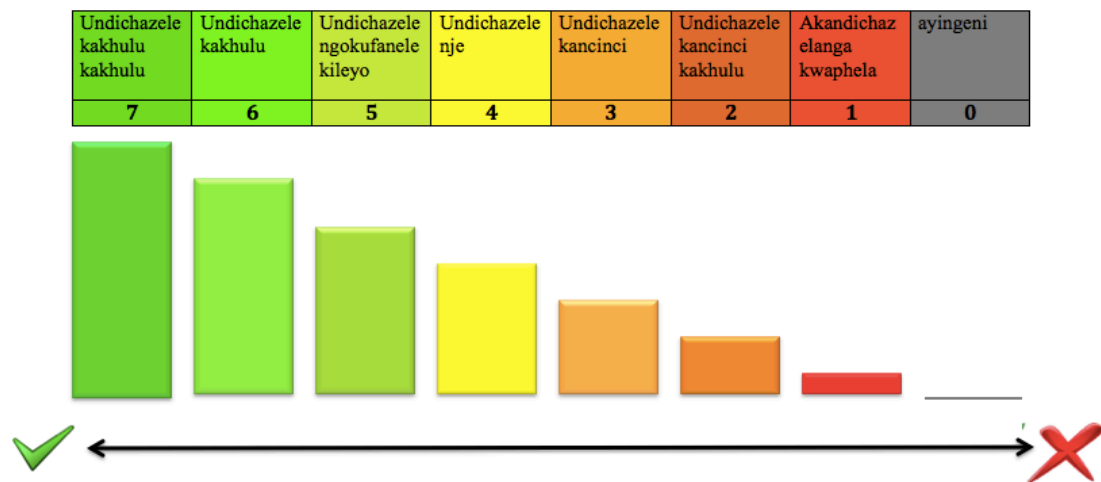
	name]?	name]?
<p><b>How do the caregiver's experience the Developmental Clinic (and the service-learning programme)?</b></p>	<ul style="list-style-type: none"> <li>• Describe what it is like for you to visit the Developmental Clinic?</li> <li>• Prompts: How do you feel about going to the clinic?</li> <li>• What is helpful about attending the clinic?</li> <li>• What is not helpful about attending the clinic?</li> </ul>	<ul style="list-style-type: none"> <li>• Describe what it is like for you to have the students visiting you and [child's name]?</li> <li>• How do you feel about the students' visits?</li> <li>• What is helpful about the students visits?</li> <li>• What is not helpful about the students' visits?</li> </ul>

Appendix 3, Figure H  
*Visual Representation of Questionnaire Scales-  
 CORE-OM, MPOC-8 SA, and PEDI-CAT*

**CORE-OM Scale**



**MPOC-8 SA Scale**



**Responsibility Response Scale:**

Umstu omdala okanye umkhathaleli womntwana uthatha uxanduva yedwa; umntwana yena akaluthathi	Umstu omdala okanye umkhathaleli womntwana ngoyena othatha uxanduva; umntwana yena uthatha uxanduva kancinci	Umstu omdala okanye umkhathaleli kunye nomntwana bathatha uxanduva bobabini ngokulinganayo	Umntwana ngoyena onoxanduva ancediswe kancinci ngumntu omdala okanye ngumkhathaleli wakhe	Umntwana uthatha uxanduva yedwa engakhangane ancediswe ngumntu omdala okanye ngumkhathaleli wakhe
--	--	--	---	---



Appendix 3, Figure I  
*Playroom Setup*



Appendix 3, Figure J  
*Marschak Interaction Method Key of Observations*

< looks in the direction of  
>  
.> looks intently at  
<.  
<< moves in the direction of  
>>

Bci Body contact initiated  
Bcr Body contact received  
BcR Body contact rejected  
U smiles  
C Frowns/sad  
L laughs  
X kiss

## APPENDIX 4

### Ethics

Appendix 4, Figure A  
*Ethical Approval- Rhodes University Research Proposal and Ethics Review  
Committee (RPERC)*



**RHODES UNIVERSITY**  
*Where leaders learn*

Psychology Department  
1 University Road, Grahamstown, 6139, South Africa  
PO Box 94, Grahamstown, 6140, South Africa  
T: +27 (0) 46 603 8500  
T: +27 (0) 46 603 7614  
E: psychology@ ru.ac.za

#### RESEARCH PROJECTS AND ETHICS REVIEW COMMITTEE

9 September 2015

Nicole Cooke  
Department of Psychology  
RHODES UNIVERSITY  
6140

Dear Nicole

#### ETHICAL CLEARANCE OF PROJECT PSY2015/32

This letter confirms your research proposal with tracking number PSY2015/32 and title, 'A case-series evaluation of the impact and processes of a service-learning programme on and for caregivers and their children with disabilities', served at the Research Projects and Ethics Review Committee (RPERC) of the Psychology Department of Rhodes University on 26 August 2015. The project has been given ethics clearance.

Please 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

Dr Jacqui Marx  
CHAIRPERSON OF THE RPERC

Appendix 4, Figure B  
*Ethical Approval- Rhodes University Ethical Standards Committee (RUESC)*



Rhodes University Ethical Standards Committee, Rhodes University, P O Box 94, Grahamstown, 6140  
Tel: +27 46 603 7366 • Fax: +27 46 603 8934 • Email: [ethics-committee@ru.ac.za](mailto:ethics-committee@ru.ac.za)

29-Jan-2016

Dear Nicole Cooke

**Ethics Clearance:** A case-series evaluation of the impact and processes of a service-learning programme on and for caregivers and their children with disabilities.

**Principal Investigator:** Nicole Cooke

This letter confirms that a research proposal with tracking number: RU-HSD-15-11-0005 and title: **A case-series evaluation of the impact and processes of a service-learning programme on and for caregivers and their children with disabilities.** was given ethics clearance by the Rhodes University Ethical Standards Committee.

Documents should be edited so that there is consistency in the way that service learning is written. In some places "service learning" and in others "service-learning".

Please ensure that the ethical standards committee is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators. Please also ensure that a brief report is submitted to the ethics committee on completion of the research. The purpose of this report is to indicate whether or not the research was conducted successfully, if any aspects could not be completed, or if any problems arose that the ethical standards committee should be aware of. If a thesis or dissertation arising from this research is submitted to the library's electronic theses and dissertations (ETD) repository, please notify the committee of the date of submission and/or any reference or cataloguing number allocated.

Yours Sincerely,

Professor M. Goebel: Chairperson RUESC.

**Note:**

1. This clearance is valid from the date on this letter to the time of completion of data collection.
2. The ethics committee cannot grant retrospective ethics clearance.
3. Progress reports should be submitted annually unless otherwise specified.

Appendix 4, Figure C  
*Permission to Conduct Research at Settler's Day Hospital*

From:REGISTRY SETTLERS

To:0466037614

01/04/2016 08:15

#028 P.001/001



Settlers Hospital, Milner Street, Grahamstown, Eastern Cape  
Private Bag X1007, Grahamstown, 6140, REPUBLIC OF SOUTH AFRICA  
Tel: +27(0) 46 602 5000 Fax: +27(0) 46 622 5366

---

**24 March 2016**

TO: Dr Lisa Young  
Psychology Department  
Rhodes University

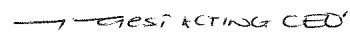
CC: Ms Nicole Cooke  
Rhodes University

**RE: PERMISSION TO CONDUCT RESEARCH STUDY**

This communiqué seeks to acknowledge permission granted to you by the Eastern Cape Department of Health with reference number ( EC\_2016RP36\_9). Settlers Management has no objection in conducting the proposed research.

Thank you

Yours in service

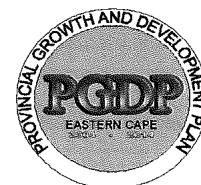
  
Ms N.Y. Ngesi  
Acting Chief Executive Officer

United in achieving quality health care for all

24 hour call centre: 0800 0323 64

Website: [www.ecdoh.gov.za](http://www.ecdoh.gov.za)

Ikamva eliqaqambileyo!



Appendix 4, Figure D  
*Ethical Approval- Department of Health*



Eastern Cape Department of Health

Enquiries: Zonwabele Merile

Tel No: 040 608 0830

Date: 23 February 2016  
e-mail address: zonwabele.merile@echealth.gov.za

Fax No: 043 642 1409

---

Dear Ms. N. Cooke

**Re: A case-series evaluation of the impact and processes of a service learning programme on and for caregivers and their children with disabilities (EC\_2016RP36\_9)**

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 anywhere 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



*Ikamva elizaqambileyo!*

Appendix 4, Figure E  
*Agreement to Act as an External Investigator- Jolene Tarr*



---

Settlers Hospital, Milner Street, Grahamstown, Eastern Cape  
Private Bag X1007, Grahamstown, 6140, REPUBLIC OF SOUTH AFRICA  
Tel: +27(0)46 622 2215 Fax: +27(0)46 622 5366 Website: [www.ecdoh.gov.za](http://www.ecdoh.gov.za)

REF: Ms N Cooke Masters Research  
Date: 16 November 2015

Dear Rhodes University Ethics Committee

**RE: A case series evaluation of the impact and process of a service learning programme on children with disabilities and their caregivers**

I am writing to confirm that I have agreed to act as an external investigator on the above mentioned project, pending ethics approval and approval from the Department of Health. Specifically, I have agreed to assist in part of the data collection process.

Yours sincerely

Jolene Tarr  
Occupational therapist  
Settlers Hospital

Appendix 4, Figure F  
*Informed Consent –  
 English*



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**CONFIDENTIALITY AGREEMENT:  
 Agreement Between Student Researcher and Research Participant**

I \_\_\_\_\_ (participant's name) agree to participate in the research project of Nicole Cooke/researcher's name on the exploration of the process and impact of a service-learning programme on caregivers and their children with disabilities.

I understand and agree on the following:

1. The researcher, Nicole Cooke, is a Rhodes University student who is conducting the research as part of the requirements for a Master's degree in Psychology by Thesis.
2. The researcher may be contacted on 082 805 9145 (cell phone) or nicolecooke91@gmail.com (email). The research project has received ethical approval and 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 is interested in what impact, if any, the research has had on you and your child, and in what it has been like for you to receive visits from the students. My participation in the research will involve:
  - a) Meeting with researchers together with my child in my home to filling out three questionnaires about my demographics, my well-being, and my satisfaction with the services I receive from the therapists and students.
  - b) Meeting with the researchers and answering questions in an interview related to caring for my son/daughter and my experience of the students' visits. These interviews will be audio recorded.
  - c) Meeting with the researchers at my home to answer three questionnaires about my demographics, my well-being and my satisfaction with the services I receive from the therapists and students.
  - d) Meeting with researchers together with my child in my home and playing with my child while being video recorded
  - e) Taking my son/daughter to the Developmental clinic to be assessed by the Occupational Therapist (if necessary, transport to the clinic for these visits can be arranged).
4. My participation in the research will involve participating in these interviews and observations together with my child at four separate points in time in February, April, June and August. Convenient times will be arranged in consultation with you.
5. The researchers will visit me and my child at our place of residence to conduct some of the research measures. I grant them permission to conduct this research at my place of residence.

6. I may be asked to answer questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.
7. My and my child's participation in this research is voluntary. However, we will be granted a R100 Checkers Supermarket gift voucher at each of the data collection points to thank us for the time and effort we are dedicating to the project.
8. I am invited to voice to the researcher any concerns I have about my participation in the study, or consequences I may experience as a result of my participation, and to have these addressed to my satisfaction. If I feel I need additional support due to the effects of the research, I can contact the Rhodes University Psychology Clinic on 046 603 8502 to make an appointment with Lisa Saville Young, a clinical psychologist.
9. I am free to withdraw from the study at any time – however I commit myself to full participation unless some unusual circumstances occur, or I have concerns about my participation which I did not originally anticipate.
10. The report on the project may contain information about my personal experiences, attitudes and behaviours, but the report will be designed in such a way that it will not be possible to be identified by the general reader.
11. Feedback will be provided to me based on the interviews and observations in November.

Signed on (Date): \_\_\_\_\_

Participant: \_\_\_\_\_

Researcher: \_\_\_\_\_

*Informed Consent –  
isiXhosa Translation*



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**ISIVUMELWANO SENTEMBEKO:**

**Isivumelwano phakathi komfundi ongumphandi kunye nothatha inxaxheba kuphando**

Mna \_\_\_\_\_ (igama lomthathi-nxaxheba) ndiyavuma ukuthatha inxaxheba kwiprojekthi yophando kaNicole Cooke (igama lomphandi) yokupicotha ucwangciso nempembelelo yenkqubo engokufunda ngokuncedisa kubakhathaleli nabantwana babo abakhubazekileyo.

Ndiyaqonda kwaye ndiyavumelana noku kulandelayo:

1. Umphandi, uNicole Cooke, ngumfundi weDyunivesithi iRhodes owenza uphando oluyinxalenye yeemfuno zethisisi yesidanga seeMasters kwizifundo zakhe zeNzululwazi ngengqondo.
2. Kungaqhagamshelwana nomphandi ku 082 805 9145 (inombolo yemfono-mfono) okanye ku [nicolecooke91@gmail.com](mailto:nicolecooke91@gmail.com) (i-imeyile). Le projekthi yophando iphunyezwe ngokusesikweni kwaye yonganyelwe nguLisa Saville Young, noyiNjingalwazi kwisebe leNzululwazi ngengqondo kwiDyunivesithi iRhodes. ULisa Saville Young kunganxityelelwana naye kule nombolo 046 603 8047 (eye-ofisi) okanye ku [l.young@ru.ac.za](mailto:l.young@ru.ac.za) (i-imeyile).
3. Umphandi unomdla kwimpembelelo, ukuba ikhona, eyenziwe luphando kuwe nomntwana wakho, nokuthi kubanjani kuwe ukumane undwendwelwa ngabafundi. Ukuthatha kwam inxaxheba kolu phando kuza kuquka:
  - a) Ukuhlangana nabaphandi kunye nomntwana wam kwikhaya lam, ukugcwalisa amaphepha-mibuzo amathathu malunga nobume ngabantu, ubume bam bezempilo kunye nolwaneliseko lwam ngeenkono endizifumana kubeluleki nakubafundi.
  - b) Ukuhlangana nabaphandi nokuphendula imibuzo kudliwano-ndlebe olumayelana nokunakekela unyana/intombi yam kunye namava ngokundwendwelwa ngabafundi. Lonke udliwano-ndlebe oluzakwenzeka luzakuthi lushicilelwe ngesishicileli-lizwi.

- c) Ukuhlangana nabaphandi ekhayeni lam, ukuphendula amaphepha-mibuzo ngobume babantu bam, ubume bam bezempilo kunye nolwaneliseko lwam ngeenkonzelo endizifumana kubeluleki nakubafundi.
  - d) Ukuhlangana nabaphandi kunye nomntwana wam kwikhaya lam kunye nokudlala nomntwana wam lo gama kushicilelwa ividiyo.
  - e) Ukuthabatha unyana/ intombi yam ndiyise kwikliniki esebenza ngokukhula komntwana ukuze ahlolwe ngumoluleki oqeqeshiweyo (izithuthi zokuya kwenza oku ekliniki zingalungiselelwa, xa kukho imfuneko)
4. Ukuthatha kwam nomntwana wam inxaxheba kolu phando kuza kuquka ukuthatha inxaxheba kudliwano-ndlebe kunye nokujongwa okuzakwenzeka amatyeli amane ohlukeneyo kwinyanga kuMeyi, ngoJulayi, ngoSeptemba, mhlambi nango Disemba. Amaxesha afanelekileyo azakulungiselelwa ngokucebisana kunye nawe.
  5. Abaphandi bazakundwendwela mna nomntwana wam apho sihlala khona ukuza kuqhuba ezinye izinto eziphathelele nophando lwabo. Ndiyabanika imvume yokuba balwenze olu phando apho ndihlala khona.
  6. Ndinokubuzwa imibuzo engobomi bam, kodwa ndinako ukukhetha ukungayiphenduli nayiphi na imibuzo engemiba yobomi bam endingafuni kuyidandalazisa.
  7. Ukuthatha inxaxheba kwam kunye nokomntwana wam kolu phando kungokuzithandela. Nangona kunjalo, sizakunikwa ivawutsha yakwaCheckers Supermarket kuzo zonke iindawo ekuqokelelwa kuzo iingcombolo ukusibulela ngexesha lethu nemizamo esiyenzileyo kule projekthi.
  8. Ndiyamenywa ukuba ndimxelele umphandi ukuba kukho izinto ezindixhalabisayo malunga nokuthatha kwam inxaxheba kolu phando okanye ndivakalise iziphumo ezingentle endinokuthi ndihlangabezane nazo ngenxa yokuthatha kwam inxaxheba kolu phando, kwaye ezo zinto zilungiswe ndide ndikholiseke. Ukuba ndibona ingathi umntwana udinga inkxaso engaphezulu ngenxa yeziphumo zolu phando, ndinako ukuqhagamshelana nekliniki yeNzululwazi Ngezengqondo kwiDyunivesithi iRhodes (Rhodes Psychology Clinic) ku 046 603 8502 ndenze i-appointment no Lisa Saville-Young, oligcisa lengqondo.
  9. Ndivumelekile ukurhoxa kolu phando nanini na ndifuna- nangona kunjalo, ndiyazibophelela ekuthatheni inxaxheba ngokupheleleyo ngaphandle kokuba kuvele iimeko ezingaqhelekanga, okanye kukho into endikhathazayo ngokuthatha kwam inxaxheba ndiyiqaphele ekuqaleni.
  10. Ingxelo ngeprojekthi ingaqulatha iinkcukacha ezimalunga namava wam, imilo, nokuziphatha, kodwa ingxelo ngendlela yokuba umntu oyifundayo angakwazi ukukrobela ukuba kuthethwa ngam.
  11. Iziphumo zodliwano-ndlebe nokujongwa kwabathathi-nxaxheba zizakukhutshwa ngoNovember.

Ityikitywe nge (umhla): \_\_\_\_\_

Umthathi-nxaxheba: \_\_\_\_\_

Umphandi: \_\_\_\_\_

Appendix 4, Figure G  
*Parental/Guardian Consent –  
 English*



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**Parental/ Guardian Consent to Participate in Research**

The purpose of this form is to provide you (as the parent of a prospective research study participant) information that may affect your decision as to whether or not to let your child participate in this research study. The person performing the research will describe the study to you and answer all of your questions. Read the information below and ask any questions you might have before deciding whether or not to give your permission for your child to take part. If you decide to let your child be involved in this study, this form will be used to record your permission.

I, \_\_\_\_\_ (parent/guardian name), am the parent or legal guardian of the child named below, and I have the authority to fill out this Consent Form on behalf of the child. In this capacity I agree to let \_\_\_\_\_ (child's name) participate in the research project of Nicole Cooke on the exploration of the process and impact of a service-learning programme on caregivers and their children with disabilities.

I understand and agree on the following:

1. The researcher, Nicole Cooke, is a Rhodes University student who is conducting the research as part of the requirements for a Master's degree in Psychology by Thesis.
2. The researcher may be contacted on 082 805 9145 (cell phone) or nicolecooke91@gmail.com (email). The research project has received ethical approval and 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 is interested in what impact, if any, the programme has had on you or your child. My child's participation will involve:
  - a) Meeting the researchers together with my child in my home and playing a set of tasks with my child while being video-recorded.
  - b) Taking my child to the Developmental Clinic to be assessed by the Occupational Therapist (If necessary, transport to the Developmental Clinic will be provided).
4. My child's participation in the research will involve participating in these interviews and observations together with me at four different points in time, in February, April, June, and August. Convenient times will be arranged to meet with me and my child.
5. The researchers will visit me and my child at our place of residence to conduct some of the research measures. I grant them permission to conduct this research at my place of residence.

6. In addition to my permission, my child must agree to participate in the study. If my child does not want to participate they will not be included in the study and there will be no penalty. If my child initially agrees to be in the study they can change their mind later without any penalty.
7. My and my child's participation in this research is voluntary. However, we will be granted a R100 Checkers Supermarket gift voucher at each of the data collection points to thank us for the time and effort we are dedicating to the project.
8. I am free to withdraw my child from the study at any time- however I commit myself and my child to full participation unless some unusual circumstances occurred, or I have concerns about my participation which I did not originally anticipate.
9. I am invited to voice to the researcher any concerns I have about my child's participation in the study, or consequences he/ she may experience as a result of his/her participation, and to have these addressed to my satisfaction. If I feel he/she needs additional support due to the effects of the research, I can contact the Rhodes University Psychology Clinic on 046 603 8502 to make an appointment with Lisa Saville Young, a clinical psychologist.
10. The report on the project may contain information about my child, but the report will be designed in such a way that it will not be possible to identify my child by the general reader.
11. Feedback will be provided to me and my child based on the interviews and observations

Signed on (Date): \_\_\_\_\_

Participant: \_\_\_\_\_

Researcher: \_\_\_\_\_

*Parental/Guardian Consent –  
isiXhosa Translation*



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**Imvume yomzali/umgcini yokuthatha inxaxheba kuphando**

Injongo yale fomu kukukunika (wena njengomzali womthathi-nxaxheba ongahle abeyinxalenye yophando) iinkcukacha olunganegalelo kwisigqibo osithathayo sokuba umvumele okanye ungamvumeli umntwana wakho ekuthatheni inxaxheba kolu phando. Umntu owenza uphando uzakucacisela malunga nofundo olwenziwayo aphendule nemibuzo yakho yonke. Funda ezi nkcukacha zingezantsi ubuze nayiphina imibuzo onayo phambi kokuba uthathe isigqibo sokuba uyamnika okanye akumniki umntwanawakho imvume yokuba athathe inxaxheba. Ukuba uyamnika umntwana wakho imvume ukuba abeyinxalenye yolufundo, le fomu iyakuthathwa njengemvume yakho.

Mna,.....(igama lomzali/umgcini), ndingumzali okanye umgcini osemthethweni walo mntwana ukhankanywe ngezantsi, kwaye ndinegunya lokugcwalisa le fomu yemvume endaweni yalo mntwana. Kwesi sikhundla ndiyavuma ukuba u.....(igama lomntwana) athathe inxaxheba kwiprojekthi yophando kaNicole Cooke engokuhlola ucwangciso nempembelelo yenkqubo engokufunda ngokuncedisa kubakhathaleli nabantwana babo abakhubazekileyo.

Ndiyakuqonda kwaye ndiyavumelana noku kulandelayo:

1. Umphandi, uNicole Cooke, ngumfundi weDyunivesithi iRhodes owenza uphando oluyinxalenye yeemfuno zethisisi yesidanga seeMasters kwizifundo zakhe zeNzululwazi ngengqondo.
2. Kungaqhagamshelwana nomphandi ku 082 805 9145 (inombolo yemfono-mfono) okanye ku [nicolecooke91@gmail.com](mailto:nicolecooke91@gmail.com) (i-imeyile). Le projekthi yophando iphunyezwe ngokusesikweni kwaye yonganyelwe nguLisa Saville Young, noyiNjingalwazi kwisebe leNzululwazi ngengqondo kwiDyunivesithi iRhodes. ULisa Saville Young kunganxityelelwana naye kule nombolo 046 603 8047 (eye-ofisi) okanye ku [l.young@ru.ac.za](mailto:l.young@ru.ac.za) (i-imeyile).
3. Umphandi unomdla kwimpembelelo, ukuba ikhona, ethe yenziwa yinkqubo kuwe okanye umntwana wakho. Inxaxheba yomntwana wam izakuquka:
  - a) Ukudibana nomphandi kunye nomntwana wam ekhayeni lam nokudlala nomntwana wam sithathwa ividiyo.
  - b) Ukuzisa umntwana wam eDevelopmental Clinic ayokuhlolwa ngugqirha ohlola abantu abakhubazekileyo (Ukuba kuyadingeka isithuthi esiya eDevelopmental clinic siyakukhutshwa).

4. Ukuthatha komntwana wam inxaxheba kolu phando kuza kuquka ukuthatha inxaxheba kudliwano-ndlebe nokulolongwa ekunye nam ngamatyeli amane ohlukeneyo, kwinyanga kaMeyi, ngoJulayi, ngoSeptemba mhlambi nango Disemba. Amaxesha afanelekileyo azakulungiselelwa ngokucebisana nam kunye nomntwana wam.
5. Abaphandi bazakuhambela mna nomntwana apho sihlala khona ukuza kuqhuba ezinye izinto eziphathelene nophando lwabo. Ndiyabanika imvume yokuba balwenze olu phando apho ndihlala khona.
6. Ngaphezulu kwemvume yam, umntwana wam kufuneka avume ukuba yinxalenye yophando. Ukuba umntwana wam akavumi ukuthatha inxaxheba akazofakwa kwaye akuyi kubakho sohlwayo ngenxa yaloo nto. Ukuba umntwana wam uvumile ekuqaleni ukubayinxalenye yophando unako ukutshintsha ingqondo yakhe phakathi kungabikho sohlwayo ngenxa yalo nto.
7. Mna nomntwana wam siyazikhethela ukuthatha inxaxheba kolu phando. Kodwa, sizakunikwa ivoucher yakwa-Checkers ye-R100 njengesipho ngamatyeli onke okuqokelelwa kweenkukacha zophando ukusibulela ngexesha nemigudu yethu kule projekthi.
8. Ndivumelekile ukuba ndimrhoxise umntwana wam nangaliphi na ixesha koluphando, nangona kunjalo, ndiyazibophelela mna nomntwana wam ekuthatheni inxaxheba ngokupheleleyo ngaphandle kokuba kuvele iimeko ezingaqhelekanga, okanye kukho into endikhathazayo ngenxaxheba yam endingakhange ndiyiqaphele ekuqaleni.
9. Ndiyamenywa ukuba ndimxelele umphandi ukuba kukho izinto ezindixhalabisayo malunga nokuthatha inxaxheba komntwana wam kolu phando, okanye iziphumo ezingentle anothi ahlangabezane nazo umntwana ngenxa yothatha kwakhe inxaxheba kolu phando, kwaye ezo zinto zilungiswe ndide ndikholiseke. Ukuba ndibona ingathi umntwana udinga inkxaso engaphezulu ngenxa yeziphumo zolu phando, ndinako ukuqhagamshelana nekliniki yeNzululwazi Ngezengqondo kwiDyunivesithi iRhodes (Rhodes Psychology Clinic) ku 046 603 8502 ndenze i-appointment no Lisa Saville-Young, oligcisa lengqondo.
10. Ingxelo yeprojekthi kungenzeka ibeneenkukacha ngomntwana wam, kodwa izakwenziwa ngendlela yokuba umntu oyifundayo angakwazi ukukrobela ukuba kuthethwa ngomntwana wam.
11. Mna nomntwana wam siyakuzinikwa iziphumo eziphathelene nodliwano-ndlebe nololongo.

Ityikitywe nge (umhla): \_\_\_\_\_

Umthathi-nxaxheba: \_\_\_\_\_

Umphandi: \_\_\_\_\_

Appendix 4, Figure H  
*Video-recording and Audio-Recording Permission and Release Form-  
 English*

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	Nicole Cooke
Level of research	Masters by Thesis
Brief title of project	A case-series evaluation of the impact and processes of a service-learning programme on and for caregivers and their children with disabilities.
Name of supervisor	Lisa Saville Young

**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 once the study is complete and the report has been written. OR I give permission for the tape recordings to be retained after the study and for them to utilised for the following purposes and under the following conditions			

Signature of participant: \_\_\_\_\_ Date: \_\_\_\_\_

Witnessed by researcher: \_\_\_\_\_ Date: \_\_\_\_\_

*Video-recording and Audi-Recording Permission and Release Form-  
isiXhosa Translation*

**Rhodes University  
Department of Psychology**

**IFOMU YEMVUME NOKUKHULULWA KWEZISHICILELI LIZWI NGEENJONGO  
ZOPHANDO**

Igama lomthathi nxaxheba	
Iinkcukacha zomthathi-nxaxheba	Idilesi ye-imeyile: Inombolo yomnxeba:
Igama lomphandi	Nicole Cooke
Inqanaba lophando	IMastazi ngethisisi
Isihloko esishwankathelweyo seprojekthi	A case-series evaluation of the impact and processes of a service-learning programme on and for caregivers and their children with disabilities.
Igama lomongameli weprojekthi	Lisa Saville Young

**ISAZISO/ISIBOPHELELO (Nceda uphawule ibhokisi ecaleni kwentetho efanelekileyo)**

1.	Ubume bophando kunye nobume bokuthatha kwam inxaxheba ndizicaciselwe.	Ngomlomo	
		Ngokubhalwe phantsi	
2.	Ndiyavuma ukuba kwenziwe udliwano-ndlebe kunye nam kwaye ndiyavuma ukuba lushicilelwe.	Ngesishicileli lizwi	
		Ushicilelo lwevidiyo	
3.	Ndiyavuma uku _____ kwaye ndiyavuma ukuba kwenziwe ushicilelo.	Isishicilelo-lizwi	
		Ushicilelo-lwevidiyo	
4.	Okurekhodiweyo kungakhutshelwa kubhalwe igama ngegama	Ngaphandle kwemiqathango	
		Ngumphandi kuphela	
		Ngumntu omnye okanye nangaphezulu kwabo batyunjiweyo	
5. Ndazisiwe ngumphandi ukuba okushicilelweyo kuzakucinywa xa uphando sele luphelile sele kubhalwe nengxelo. OKANYE I Ndiyayinika imvume ukuba okushicilelweyo kugcinwe emva kophando kwaye zisetyenziswe ngezi njongo zilandelayo, ngaphantsi kwale miqathango			

Utyikityo lomthathi-nxaxheba: \_\_\_\_\_ Umhla: \_\_\_\_\_

Ingqinise we ngumphandi: \_\_\_\_\_ Umhla: \_\_\_\_\_

**APPENDIX 5**  
**Bongani and Andiswa**

*Section 1: Quantitative Data Scores*

Appendix 5, Figure A  
*Demographic Questionnaire*

<b>Demographic Questionnaire</b>		
<b>Interview Details</b>		
101	Interview number	<b>SSM</b>
102	Date of interview (dd/mm/yy)	<b>10/05/2016</b>
103	Place of interview	1= Home where child resides 2=Other home 3=Clinic/hospital <b>4=Other (Psychology Department)</b>
104	Person interviewed	1= mother <b>2=caregiver</b>
105	If caregiver (other than mother), what is relationship to child?	1=Father <b>2=Grandmother</b> 3=Grandfather 4=Sibling 5=Relative 6=Neighbour 7=Friend 8=Other _____
106	Responsible for how much of child’s care?	<b>1=All the time (day and night)</b> 2=Day only 3=Night only 4= After school care 5=other _____
<b>Caregiver’s Characteristics and Relationship with Child</b>		
201	Date of birth (dd/mm/yy)	<b>12 January 1958</b>
202	Age (years)	<b>58 years old</b>
203	Sex	1=Male <b>2=Female</b>
204	Race	<b>1= Black</b> 2=White 3=Indian 4=Coloured 5=Chinese

		6=Other
205	Home language	1=English 2= <i>Xhosa</i> 3= Zulu 4=Afrikaans 5=Other _____
206	Current marital status	1= Married 2= Living together 3=Divorced 4= Separated 5= <i>Widowed</i> 6= Never married
207	What is the highest grade of schooling that you have completed?	1=None 2=Primary School 3= <i>High school (grade 10)</i> 4=High school (matric) 5=Diploma 6=University degree
208	Do you work?	1=yes, full time 2= yes, part time 3= <i>no, seeking work</i> 4=no, not seeking work
209	Where does your main source of income come from?	1=Regular income from working 2= Occasional income from working 3=Pension 4= <i>Child support grant</i> 5= <i>Disability grant (for self)</i> 6= <i>Disability grant (for child)</i> 7= Foster care grant 8= Maintenance grant 9=Income fro husband 10= Income from other family members 11= Other _____ 12. No income
210	Approximate monthly income?	<i>R3 300,00</i>
211	How many hours a day do you spend with the child?	1= <i>During the week? 24 hours/ 7 days</i> 2= <i>During the weekend? 24 hours</i> 3=none
212	How much of the time are you responsible for the child?	1= <i>all of the time</i> 2= During the day only 3= During the night only 4= Only some days

213	During a typical day, how much do you play with your child?	1=During the week? ____ 2= During the weekend? ____ 3=None <i>Anytime</i>
214	Compared to other children is this a difficult child?	<i>1=Yes</i> 2=No
215	Is there someone you can trust to leave your child with when you are busy?	<i>1=Yes</i> 2=No
216	Who is this person?	1=My mother 2=my in-laws 3= my neighbour 4=my relatives 5=my friend <i>6=other (her daughter)</i>
<b>Child's Characteristics and Disability Treatment</b>		
301	Child's date of birth (dd/mm/yy)	<i>11 June 2011</i>
302	Child's age	___4___ years ___11___ months
303	Child's sex	<i>1=Male</i> 2=Female
304	Type of Birth	<i>1=Singleton</i> 2=Twin 3=Triplet or more
305	Place of birth	<i>1= Hospital</i> 2= Clinic 3= Home 4= Other
306	Method of delivery	<i>1=Natural</i> 2= Caesarian section 3=Breech
307	Child's impairment (more than one can be circled)	1=Moving and walking 2=Talking 3= Hearing 4= Seeing <i>5=Learning</i> <i>6=Behaviour</i> <i>7=Other</i> _____ <i>left hand</i> _____
308	Gross Motor Function Classification System	1= Level 1 <i>2=Level 2</i> 3=Level 3 4=Level 4 5=Level 5
309	Was your child born with the disability or did	1=congenital (at birth)

	he/she acquire the disability later on?	<i>2= acquired (Unkown- thinks acquired but unsure)</i> If acquired: Date: _____ Reason: _____
310	How does your child mostly communicate?	<i>1= Speaking</i> 2= Using gestures/ signs 3= Facial expressions 4=Crying 5= Making sounds or noises 6= Does not communicate 7= Unknown
311	Do other people understand what your child is telling you?	<i>1=all the time</i> 2=some of the time 3=hardly at all 4=never
312	Does your child receive a care dependency grant?	1=Yes <i>2=No</i> 3=Applied, still waiting 4=Child not eligible 5=Unknown 6=No, but does receive child support grant
313	Does your child currently attend therapy?	<i>1=Yes</i> 2=No
314	Where does your child receive therapy? (can circle more than one)	<i>1=Hospital</i> <i>2=Clinic</i> 3=Home 4=Other _____
315	How often during the past 6 months has the child attended therapy?	1= More than 6 times <i>2= 6 times</i> 3= 4-5 times 4= 2-3 times 5=1-2 times 6= Not at all
316	How long have you been attending therapy?	1= 6 months or less 2= 7-12 months 3= 13- 24 months <i>5= 2- 4 years</i> 6= more than 5 years
317	How long does it take you to get to the clinic/ hospital from where you stay?	<i>1= 30mins or less</i> 2= 31-60mins 3= 1 hour- 2 hours 4= more than 2 hours
318	How do you usually get to the clinic or hospital for therapy?	<i>1= taxi</i> 2=bus 3= by foot

		4= by private car (It is your own car? Y / N) 5=other
319	Does your child attend school/ day care?	1=Yes <i>2=No</i>
<b>Household Characteristics</b>		
401	Number of occupants in the house?	Children: <u>  4  </u> Adults: <u>  3  </u>
402	Total income of household per average month?	1= Less than R100 2= R100- R500 3=R500- R1000 4= R1000-R3000 <i>5=R3000-R5000</i> 6= More than R5000 7=Unknown
403	From where does the household earn income? (more than one option may be circled)	1= Regular income from working 2= Seasonal income from working 3= Occasional income from working 4= Pension <i>5= Child support grant</i> <i>6= Disability grant (adult)</i> 7= Care dependency grant (child) 8= Foster care grant <i>9= Maintenance grant</i> 10= Other _____ 11= No income at all 12=Unknown
404	Construction material of main house walls?	<i>1= brick, cement blocks</i> 2= wood 3= informal/shack 4= mud 5= other _____
405	Construction materials of main houses roof?	1= Tiles, cement, bricks <i>2= Corrugated iron, wood, asbestos</i> 3=Thatch 4=Informal/shack
406	Main water supply?	1= Tap in house <i>2= Tap in yard</i> 3= Tap in street 4= Water truck 5= cement well 6= Traditional well

		7= Open, unprotected (pond, river, dam) 8= Rainwater tank
407	In the household do you have a functioning: Stove If yes (gas, coal, electricity) Primus or paraffin stove Hot plate Fridge Microwave TV Hifi/stereo/tape/CD player Video Radio Phone (fixed) Cellphone Car/truck Bicycle Kariki cart/sled	<i>1=yes</i> 2=no <i>1=yes</i> 2=no 1=yes            2=no 1=yes            2=no <i>1=yes</i> 2=no <i>1=yes</i> 2=no <i>1=yes</i> 2=no 1=yes <i>2=no</i> 1=yes <i>2=no</i> 1=yes <i>2=no</i> 1=yes <i>2=no</i> <i>1=yes</i> 2=no 1=yes <i>2=no</i> 1=yes <i>2=no</i>
<b>Judgment form Interviewer</b>		
501	In your opinion is the information accurate?	<i>1=Good</i> 2=Fair 3=Poor
502	Any other information on the child or family that you would like to add?	

Appendix 5, Figure B  
*Clinical Outcomes in Routine Evaluation- Outcome Measure (CORE-OM)*

CORE-OM							
Andiswa							
		Well-being	Problems	Functioning	Risk	All Items	All Items Minus Risk
Data Collection 1	Total Score	5	24	11	0	<b>40</b>	40
	Mean Score	1.25	2	0,92	0	<b>1.18</b>	1.43
	Clinical Score	12,5	20	9,2	0	<b>11,8</b>	14,3
Data Collection 2	Total Score	6	14	5	2	<b>27</b>	25
	Mean Score	1.5	1.16	0.42	0.33	<b>0.79</b>	0.89
	Clinical Score	15	11,6	4,2	3,3	<b>7,9</b>	8,9
Data Collection 3	Total Score	7	8	9	0	<b>24</b>	24
	Mean Score	1.75	0.67	0.75	0	<b>0.71</b>	0.86
	Clinical Score	17,5	6,7	7,5	0	<b>7,1</b>	8,6

Appendix 5, Figure C

*Pediatric Evaluation of Disability Inventory- Computer Adaptive Test (PEDI-CAT)*

PEDI-CAT Scores			
Bongani			
	Baseline Collection 1 Scores	Baseline Collection 2 Scores	Post Collection 3 Scores
Daily Activities	50	48	46
Mobility	59	62	62
Social/Cognitive	56	55	54
Responsibility	39	35	37

Appendix 5, Figure D

*Emotional Interaction Style (EIS)*

EIS- Assessment of MIM				
Andiswa and Bongani				
		Baseline Collection 1 Score	Baseline Collection 2 Score	Post Collection 3 Score
Strucutre and Challenge	1. Parents comprehensive ability to structure the situation relative to the child's developmental level	2,5	3	4
	2. Child's general cooperation and ability to focus on the situation	2	3	3,5
Emotional Recopricity and Initiative	3. Parent's emotional reciprocity and initiative	3	2,5	3
	4. Child's emotional reciprocity and initiative	2	3	3
Nurutre	5. Parental Nurture	2	2	2,5
	6. Child's response to nurture	1,5	1,5	2
Playfulness	7. Parent's playfulness	2,5	2	3,5
	8. Child's playfulness	3	2	3,5
Representation	9. Representation of the child	4	4	4
Overall Score		22,5	23	29

Appendix 5, Figure E  
*Measure of Process of Care- 8 South Africa (MPOC-8 SA)*

MPOC-8 SA			
Andiswa			
	Baseline Data Collection 1	Baseline Data Collection 2	Post Data Collection 3
Score	26	41	27
Percentage	46,42%	73,21%	48,21%

## *Section 2: Marschak Interaction Method Clinical Reports*

### **Marschak Interaction Method Clinical Reports Andiswa and Bongani**

**Child:** Bongani

**Date of Birth:** 11/06/2011

**Age:** 4 years 11 months

**Caregiver:** Andiswa (Grandmother)

#### **Assessment Instrument**

**MIM Tasks:** The following is a list of seven tasks that Andiswa and Bongani were asked to engage in together: The task instructions were delivered by the research assistant through a microphone in their first language, isiXhosa.

1. Play a familiar game that you would normally play at home.
2. Use the toys on the table and make a game with them.
3. Tell your child a story about when he was younger.
4. Feed your child something that you think he would like on the table.
5. Wipe his mouth and hands and then put cream on him.
6. Leave your child alone in the room for 1 minute.
7. Sing your child a lullaby/song.

#### **Data Collection 1:**

#### **Observations**

##### **Task Observations:**

*Familiar game:* Andiswa initiated the game by asking Bongani to run and count with her. She took his hand and did this with him. They then stood on one spot and jumped and counted. Andiswa would do it first followed by Bongani. Andiswa seemed to do it with a lot of energy and encouraged Bongani to “do it as you usually do” and “do it again”. At this point Bongani seemed to be quite intrigued with his reflection in the one-way mirror and quickly became distracted and went up to the mirror. Andiswa seems to go towards him and Bongani seems to run away from her back into the view of the camera but when he gets a chance he goes back to the mirror. Andiswa says, “let’s start this again” and asks Bongani to come and sit with her, however, Bongani is distracted and doesn’t listen. G asks again raising her voice and reaching out for Bongani but he does not respond to her. She eventually runs after him and grabs his arm and pulls him onto the matt with Bongani falling down. Andiswa then begins to tickle Bongani while he is lying on the floor. Bongani laughs but kicks out at her and pushes himself away in an attempt to get away from Andiswa. Andiswa, standing over him, grabs his legs and drags him back to her saying “Don’t run, gran is tickling baby, don’t run, come”. When Andiswa pulls Bongani back towards her she changes up the game and now asks him for the sounds that certain animals make. When Bongani looks at her smiling but doesn’t respond Andiswa then tries to tickle him again, repeatedly asking the question, while Bongani tries to kick and escape. When Andiswa stops tickling Bongani seems to calm down and respond but he is very easily distracted again. Andiswa has to reprimand Bongani saying, “no don’t touch that” and grabbing his arm and taking away a spoon from him. Andiswa again changes up the

game holding Bongani's hands and tries to go back to jumping but Bongani doesn't seem interested and falls to the matt. She pulls him up and again suggests another activity of signing saying, "*Come over here and sin. I'll give you sweets*". She sings and Bongani seems to enjoy it- watching himself dance and jump in the mirror. However, this does not last long as Bongani falls to the floor and looks up at Andiswa saying, "I want to sleep". Andiswa responds by "*You want to sleep, sleep then*" and she sinks to the matt. Bongani kicks out towards Andiswa with his leg and Andiswa reprimands him saying "*don't kick me*" and pushes his legs down saying "*sit up*".

*New game:* Andiswa decides to take two balls to throw to each other for this game. She tells Bongani "*Come let's throw the ball at each other, sit there.*" However, Bongani who is lying on the mat doesn't want to listen. She repeats herself and physically pulls him up and pushes him to go and sit further away from her. Bongani's leg kicks out toward Andiswa and she raises her voice and says, "*Don't kick me, you'll hurt me!*" while putting down the balls and grabbing Bongani with both hands to physically push him to where she wants him to be saying, "*Sit here! Why are you being silly?*" to which Bongani resists by pushing back and falling over. Andiswa moves away and begins the game telling Bongani to sit up. Bongani seems to finally take interest as Andiswa throws the ball up into the air and catches it. She instructs Bongani by saying "*lets do it like this- one, two, three*" while she throws the ball in the air and catches it. Bongani takes the ball and copies Andiswa but he does not throw the ball up, rather, he holds it and lifts his hands up and down while counting (probably because he does not have the skill to catch the ball yet). Andiswa then changes up the game by instructing Bongani to throw the ball, after which she brings in a second ball so that they can each have a ball and throw to each other. When she throws the ball Bongani does not catch it and Andiswa remarks this in a playful/teasing tone saying, "*You can't catch*". Bongani then gets distracted by the mirror again and throws the ball towards the mirror. Andiswa reprimands him for this and goes back to throwing and counting. Bongani does this once and then gets up and goes to fetch the ball he threw away. When he comes back and sits on the mat Andiswa then decides the game should change again and they should stand and kick the ball. Bongani does not seem to want to stand up but Andiswa picks him up saying, "*No man why are you lazy?*" while Bongani protests. When Bongani finally kicks the balls Andiswa responds by saying "Good kick." And she continues to try and get them to kick the ball to one another which they seem to have fun doing for a short while. Then Andiswa grabs Bongani's arm to try and take him to a ball to which he responds by lying down and Andiswa once again tells him "*Get up you're being lazy?*" Bongani tells Andiswa that he would like to wee but Andiswa says "No you'll pee now" and continues with game ignoring his needs and further requests. \* The researchers stopped the recording to allow Bongani to go to the bathroom\*

*Story:* Bongani seemed to want to do his own thing and kept running away from Andiswa. Andiswa tried to entice him to come and sit next to her by calling him to come and hear what other people had to say and offering him the promise of sweets. When Andiswa initiated contact or tried to hold Bongani he would squirm out of her touch and reject her. He was happy to sit next to her and receive help from her to put his shoe on while she was telling a story but when she tried to cradle him or get him to sit on her lap he ran away. Andiswa seemed to become very frustrated by this and started complaining of her own ills saying, "*My arm is so sore*" and "*I am so tired*". Andiswa kept trying to get Bongani to come and sit with her through bribery like

“Come stand here. Look at the yoghurt. I’ll give it to you” and “Get up. I’ll give you something”. Andiswa seems to forget to tell him a story and seems to focus more on trying to get Bongani to sit on her lap which he strongly refuses. She ends up tickling him and Bongani kicks out at her for which she shouts at him but continues to tickle him. \*The researchers eventually remind Andiswa about the story\*. To this Andiswa says, “He is uncontrollable” but manages force Bongani to sit on her lap and starts to tell the story. Bongani tries to squirm free and rejects this close contact and then says “I need to wee, I need to \*kaka (poo)” repeatedly. Andiswa reprimands him for the use of language and ignores his repeated requests saying “no man wait” and continuing with the story.

*Feed:* Andiswa asks Bongani if he would like some yoghurt and questions if he is really going to eat it and finish it because she can’t “open a yoghurt and then suddenly you don’t eat it”. Andiswa feeds the yoghurt to Bongani who sits next to her and she talks to him about going to school. Andiswa then invites Bongani to feed himself when he starts to make a lot of noise. Andiswa holds the yogurt for him and directs him how to hold the spoon. She praises him when he does it saying, “Good. Eat again. Good. Wow. This boy can feed himself now.” She then proceeds to offer a physical reward too saying, “Wow gran will give you something nice” and “Eat. We will go to town and buy some sweets.” Andiswa gets a little frustrated at the pace and manner in which Bongani is attempting to feed himself and takes the spoon from him once again to feed him herself. Bongani then decides to get up and move away from her.

*Lotion:* Andiswa grabs Bongani and gets him to sit down so that she can wipe his face and place lotion on him. Andiswa keeps one hand on him at all times to keep Bongani from getting up and moving away. Andiswa wipes Bongani’s face and applies cream quite swiftly. During this period Bongani seems to tell Andiswa about someone who went on a bus and Andiswa engages in the conversation by trying to ask who. Bongani tries to lick the cream and Andiswa reprimands him by telling him he is so naughty. Bongani seems very preoccupied with watching himself in the mirror and as soon as he Andiswa lets go of him he gets up and moves away from her.

*Leave the room:* Andiswa doesn’t prepare Bongani for her leaving the room but merely gets up and walks out while Bongani is playing with a toy. Bongani calls out for her once she has left the room and tries to follow her by opening the door. When he can’t open the door he calls out to her again and then sits down and plays with his toy- after a couple of seconds he pauses and calls for her again and then continues to play with his toy. When Andiswa re-enters the room Bongani gets up quickly and runs to the other side of the room. When he sees it is her he jumps up and down but seems to move away from her as she approaches him. Andiswa asks him where she was and he responds that she was outside. She invites him to come and sit next to her which he does but at a distance.

*Sing:* Andiswa tries to take the rattle away from Bongani and get him to come and sit with her and sing, however, Bongani does not want Andiswa to take it away from him so he keeps running away from her. Eventually, Andiswa gives up and begins to sing the happy birthday song herself. She then gets up while singing and goes to get Bongani who continues to run away. She manages to corner him and grabs his arm and Bongani sits. Andiswa takes away the rattle and holds Bongani close to her while

singing. Bongani pushes away from her while dancing and watching himself in the mirror. When Andiswa lets go of Bongani and only holds his hand gently he seems to relax and joins in saying “hip hip hooray” and singing along and dancing. When he tries to move away at the end of the song Andiswa grabs him and tries to make him sing it again.

**Domain Observations:**

*Structure:* Andiswa exhibited a poor structuring technique that was task oriented and driven by her own wants and needs rather than considering what Bongani might want or need. Andiswa was often inflexible in what she wanted Bongani to do, such as sitting on her lap, and she would forget what the task called for by continually pressing for the same thing. At times she would also change up the task often demanding more of Bongani which was beyond his developmental abilities. She often did not give clear instructions to Bongani as to what she wanted him to do but rather she was quite authoritative and demanding of him and did not often offer praise. Along with this Andiswa often turned to bribery to try and coerce Bongani into doing tasks and threatening him and calling him lazy when he did not cooperate. Bongani was in turn very rebellious towards Andiswa’s commands and was often unwilling to cooperate, resistant and evasive. This resulted in a very disorganised and chaotic interaction between Bongani and Andiswa.

*Engagement:* Andiswa tended to try and forcefully engage with Bongani to which Bongani reacted by evading her, strongly resisting contact and withdrawing on a recurring basis. Andiswa seemed to be very much emotionally unavailable and in conflict with Bongani’s wants and needs. At times the pair seemed to engage in positive playful activities but Andiswa’s positivity towards Bongani often lacked authenticity as she used a lot of bribery, criticism and teasing. Andiswa did not seem to show empathic awareness towards Bongani and thus their interaction was very much out of tune with one another and Andiswa became frustrated, angry and exhausted which she projected onto Bongani.

*Nurture:* Andiswa did not seem to be very emotionally open and accessible for warmth and nurturing. Their interaction often seemed to be forced, rough and unaffectionate with Bongani avoiding all physical touch and rejecting Andiswa. Andiswa’s forceful responses towards Bongani often created more distress in him as he tried to get away from her- at times kicking and hitting her. Andiswa also ignored Bongani’s needs such as wanting to use the bathroom and being tired. Bongani did approach and accept help from Andiswa when he saw fit such as putting a shoe on or when being fed but even during these times he seemed to be quite uncomfortable with physical touch and nurturing. During the absence task Andiswa left the room without telling Bongani what she was doing. Bongani seemed to show concern for this by calling for Andiswa but when Andiswa returned to the room he got up and ran away from her.

*Challenge:* Andiswa often challenged Bongani to improve beyond his developmental level. She encouraged him to count, throw and catch a ball, and feed himself. However, Andiswa was not very patient in these tasks and would often revert to taking them over again. She also gave very little acknowledgement, praise and encouragement to Bongani when he attempted a task.

### Summary

Overall, the interaction between Andiswa and Bongani was quite chaotic and characterised by an authoritarian style with Andiswa demanding a lot of Bongani and Bongani rebelling against her. Bongani seemed at times to be quite distressed by their interaction and would try and get away from Andiswa's physical touch or presence by running away or even out kicking at her. Andiswa came across as being very emotionally unavailable to truly connect with Bongani and thus she was unable to be empathically aware and attuned to Bongani's needs. She often ignored his requests and was not very encouraging and praising.

### Data Collection 2:

#### Observations

##### Task Observations:

*New Game:* At the start of the interaction Andiswa sits far away from Bongani while Bongani quietly plays with a rattle on his own. After the instruction is given Andiswa crawls over to Bongani and takes the rattle away from him without explaining why and then leans over him awkwardly to get a ball off of the table. Whilst telling Bongani that she wants to play catch ball and manoeuvring herself into place Bongani goes straight back to retrieve the rattles he was playing with and again G forcefully takes them away from Bongani and hides them behind her. Andiswa instructs Bongani on what to do during the game of catch saying, "*Catch, catch the ball... Move backwards... throw the ball to gran.*" Bongani follows Andiswa's instructions but at times Andiswa has to ask a couple of times before Bongani abides and at times she seems to get quite frustrated saying, "*Throw. No man, do it like this. Throw.*" When Bongani caught the ball Andiswa was able to offer some praise saying, "*Wow, you throw well*" but this was only occasionally. At times Bongani would stop on his hands and knees and violently smack his hands up and down on the mat. Bongani asked to go to the bathroom during this activity and Andiswa said, "*Not now man. Catch. No man wait. Where are you going to pee?*". Bongani started pulling down his pants and the researchers had to stop the activity and ask Andiswa to take Bongani to the bathroom.

Upon their return they were instructed to continue with the activity. Andiswa was able to get Bongani to start throwing the ball between each other but became critical that he wasn't using his weaker hand. Andiswa changed up the activity by trying to get Bongani to squeeze the ball with his hand to make it squeak but Bongani did not seem interested in this and went to the table to find something he was interested in (a biscuit). Andiswa takes the biscuit away from Bongani and hands him a ball but he does not want the ball and takes the biscuit again. Andiswa moves away from him and tries to engage him from a distance by asking him to put the biscuit down so that they can throw the ball but Bongani really does not want to and ignores Andiswa. Andiswa then goes and takes Bongani's biscuit away from him which causes Bongani to moan and get upset. She distracts him by throwing balls and asking him to fetch them to which Bongani obliges but still wants his biscuit back. He refuses to cooperate with Andiswa further.

*New game:* Bongani remains fixated on the food going into this activity and keeps taking yoghurt to Andiswa and asking her for it. After she refuses him a few times

Bongani throws a small tantrum which Andiswa ignores and she tries to shift his attention away from the food and onto a toy car by pulling him down onto the mat. Bongani does not seem interested at all and continues to ask for the yoghurt. Bongani eventually plays a little but then decides to kick the car with his foot and then tries to throw the car with his hands. He does not seem to want to play with the car as Andiswa is instructing him to by pushing it around. He then says that he wants to “kaka” (poo) to which Andiswa ignores him and reprimands him by saying, “No don’t lie. No we won’t open. Stop being silly Bongani. Get up come.” Bongani seems to be visibly irritated and grimaces with her face when she looks away from Bongani as if in pain.

*Story:* Andiswa tries to get Bongani to come and sit on the mat by calling him but Bongani does not respond. She then says, “I’m in pain, my arm is sore. Come. Oh this child doesn’t want to sit here. I’m not okay at all- I’m so tired. Come sit here.” Bongani comes and sits on the mat facing Andiswa and almost hiding his biscuit behind his back as he approaches Andiswa. Once he sits on the mat Andiswa continues to complain about her ailments and inability to remember the story she told the first time they did the MIM and she suggests they skip the story telling activity. The instruction is read out to Andiswa again and she is reminded that it does not have to be the same story as she told the last time. Andiswa continues to fixate on the last story and says, “I don’t know where I started the other time. I just suddenly feel sad.” There are long pauses of silence as Bongani waits for an interaction but Andiswa only stares at him in silence and complains about her inability to recall. The instruction is read out for a third time and Andiswa responds by saying, “I don’t have the mind for anything”. Bongani responds to Andiswa by innocently saying, “You don’t have brains. I am smarter” which makes Andiswa smile and laugh. Andiswa responds by saying, “You are smarter than me”. Andiswa is unwilling to take part in a story telling activity and her and Bongani just sit and chat with one another.

*Feed:* Andiswa selects yoghurt asking Bongani, “Do you want some yoghurt?” and saying, “Let me feed you”. Andiswa and Bongani chat while he eats the yoghurt with Andiswa asking questions about whether Bongani is going to save her some yoghurt and share with her to which he agrees. During this interaction Bongani smacks his hands on his legs at intervals. During one of these he accidentally connects with the yoghurt and spills it. Andiswa responds by disapprovingly saying, “Haai Yoh! Why are you hitting it? Don’t hit it again. Look at my hands now!” and when the yoghurt is finished she says “You’ve messed me up with the yoghurt” and begins cleaning up.

*Lotion:* Andiswa begins by rubbing cream onto Bongani’s face telling him to close his eyes and mouth which he repeats and Andiswa laughs. Bongani tries to look away while the cream is being applied to his face. Andiswa then tries to apply cream to Bongani’s hands but he is still hitting them up and down on the mat. Andiswa moves back to Bongani’s face and pushes him to lie down on her legs and holds him there while she rubs cream onto his face. Bongani responds by sitting up and trying to duck under Andiswa’s arm. Andiswa places cream on her own hands before head locking Bongani down on her lap and putting more cream onto his face while remarking that he has so many scratches.

*Leave the room:* Andiswa wonders what Bongani will do when she leaves and prepares him and tells him, “Wait, I’m coming” before leaving the room. Bongani

bangs on the door and says open the door repeatedly while Andiswa is out of the room. When Andiswa enters the room again Bongani runs away and jumps up and down while answering Bongani's question of where she was. When g moves towards Bongani he goes in the opposite direction. Bongani asks Andiswa to come and sit on the mat with her but he goes to the mirror and bangs on it. Andiswa goes to take Bongani from the mirror saying "*No you're gonna break it*". She takes Bongani by the hand and leads him back to the mats. Bongani gets a piece of food from the table and Andiswa says "*Please give me some, give gran a piece.*" but Bongani sits facing away from her and watching himself in the mirror.

*Sing:* Andiswa tries to grab Bongani and pull him onto her lap but she is too far away. When she asks Bongani to come and sit on her lap he gets up and does so willingly. They seem to struggle to get into a comfortable position at first. Andiswa begins to sing and heavily rock Bongani. She pauses and readjusts his arms and legs throwing them into position. She then puts her head against his whilst singing, rocking him and patting his back. Bongani tries to sing and wants to sit up but Andiswa holds him close to her unwilling to let go and saying "*No you have to sleep*". Bongani pulls away from her and makes eye contact singing but Andiswa again tries to pull him in closer to her and put her head against his removing the eye contact. They continue to struggle like this and Bongani announces that he needs to the toilet again to which Andiswa says "*No you are lying*" and continues to sing ignoring his request. Bongani seems to stop resisting and goes with it but does not seem to enjoy the activity.

#### **Domain Observations:**

*Structure:* Andiswa is very rigid and often unmoving in her structuring technique as she has very set expectations of Bongani and gets frustrated when he does not live up to those expectations or follow what she wants him to do. Andiswa tends to only provide Bongani with basic commands, which often come across as demanding. She also often changes up the activity slightly with little warning, which creates a disorganized interaction as Bongani struggles to transition. Bongani tends to be quite defiant towards Andiswa at times and insists on doing his own thing. He also seems distrusting of Andiswa as she often takes things away from him like the toy rattles or biscuits. However, when Andiswa becomes visibly upset Bongani seems to become more compliant and wait for instructions.

*Engagement:* Andiswa tends to engage with Bongani in quite a negative, critical and demanding manner, very rarely acknowledging the positives or openly enjoying her time with Bongani. Andiswa often establishes contact with C in quite a rough manner, forcing herself into Bongani's space and she tends to grab things out of his hands. This results in Bongani trying to get away from Andiswa when she approaches him or tries to make physical contact. Andiswa is also emotionally unavailable and possibly depressed which results in a notable lack of empathic awareness, affect attunement and synchrony between the pair. At times Andiswa was also quite indirectly hostile towards Bongani by showing notable frustration with him, refusing to engage with him and ignoring his requests to use the bathroom by telling him he was lying.

*Nurture:* Andiswa was not very empathically attuned to Bongani's needs and would often overlook his emotional state and personal wants/needs to fulfil what she wanted, withholding gratifying responses from him. She also asked Bongani to look after her needs at times- particularly around the food tasks where she asked Bongani to save

food for her or to give her some. During the separation task Andiswa did not prepare Bongani for her departure but just told him to wait. Bongani became quite distressed by this but when Andiswa returned he walked away from her. Bongani tended not to accept nurturance and physical touch by resisting the interaction. When he resisted interactions Andiswa would not acknowledge Bongani's discomfort and would continue to force the interaction, which escalated Bongani's discomfort. Overall their interaction looked at times quite distant, and uncoordinated.

*Challenge:* Andiswa very rarely challenged Bongani in a nurturing manner but rather she was quite demanding of him- telling him what to do rather than encouraging him to strive. Andiswa only acknowledged Bongani's efforts on the rare occasion showing only a slight pleasure.

### **Summary**

Overall, Bongani and Andiswa seemed to have quite a distant relationship. Andiswa came across as quite depressed having episodes where she became frustrated, overtly sad and complained of pain which at times closed her off to any possible interaction with Bongani. Andiswa seemed to be very demanding of Bongani and she did not often offer praise or positivity. Andiswa was also quite physically forceful and impatient with Bongani- taking away toys or forcing him to interact with her. Thus, Bongani seemed to avoid physical contact with Andiswa and was quite happy to do his own thing. Bongani often expressed himself by physically hitting things such as the mat, his lap or the mirror. They both seemed to appreciate having each other but they seemed quite unsure of how to act in a harmonious, loving and empathically attuned manner together.

### **Data Collection 3:**

#### **Observations**

##### **Task Observations:**

*Familiar game:* Andiswa initiated the game by choosing a toy off of the table. She looked at Bongani and placed the toy down in front from her seated position behind him, telling him to "Come. Come sit here. Do like this" while demonstrating pushing buttons on the toy. Andiswa then briefly explains that it is 'money machine" and asking Bongani "do you know what that is?" to which he replies "yes". They individually push the numbers and then Andiswa tries to pull Bongani closer and use the game as learning task to teach number association. She points and pushes to "1, 2" to show Bongani the numbers, asking him to do the same. Bongani repeats after her "3" but continues pushing random numbers. Andiswa takes Bongani's hand and shows him which numbers to press but Bongani pulls away and continues pushing what he wants. When Andiswa initiates again he then turns to look directly at her and counts back at her somewhat frustrated "1,2, 3 ,3, 4" again without pressing to which she tells him to "click on". Bongani then loses interest in the game and says he wants a yoghurt to which Andiswa replies, "No wait, you will get it" and continues to try and engage him in the same manner saying in a frustrated manner, "click 1". Bongani then repetitively says that he needs the toilet, to which Andiswa tells him "No wait, you will go. Click 1. Click 1, 2 ,3." Trying briefly to forcefully push his hand down to click which he resists. When she stops pushing he engages briefly with her again but soon says "Granny I need to pee". The interviewers stopped the interaction at this point to allow the child to go to the bathroom.

*New game:* Andiswa instructs Bongani to go and get a ball off the table by nudging him, pointing and encouraging “Take the ball, let’s throw at each other.” Bongani obeys the instruction and goes to get the ball, looking back at Andiswa to see that he has chosen the correct one. He tries to bite the ball to which Andiswa tells him not to and encourages him to throw the ball to her which he does. She indicates and explains for him to catch using both his hands, he copies her and manages to catch the ball in his arms. Andiswa offers praise for this saying “well done!”. Thereafter, he drops the ball and she encourages him to go fetch it which Bongani does and throws it back to her. She then instructs him to move over and he obeys but loses concentration as this is close to the food which he helps himself to. Andiswa tells him not to eat and gets up to take the food away from him, saying “No man, leave the food alone, you will get the food.” She throws the food down and grabs him by his arm pulling him away from the food- he relinquishes without a fight. They then continue their game of throwing the ball standing closer together. Bongani is surprisingly able to use his weaker arm to catch the ball to which Andiswa praises him highly, smiling and saying “Wow this boy wow well done, wow catch, yes, catch wow this hand really works”. Bongani seems to get excited by this and jumps up and down. They seemed to be enjoying this game together. When Andiswa drops the ball and looks away from Bongani he goes back to the food, saying “I want bread” repeatedly. Andiswa attempts to engage him again by taking his hand and leading him away from the food area.

*Story:* Andiswa gets a biscuit and tells Bongani to come and sit down. He comes to her and she takes his arm pulling him gently to sit next to her and then handing him the biscuit. He takes the biscuit and faces away from her. Andiswa attempts to engage Bongani in the story by looking at him intently to establish eye contact and asking him if he knows what he would do as a baby. When he does not look at her she reaches out to touch his leg while still looking intently at his face while he distractedly moves around. She tells him that he would cry as a baby and Bongani responds by looking at her and saying “No, I don’t cry”. Andiswa tells him how she would put a nappy on him and asks him if he knows what that is, to which Bongani responds “yes” and Bongani looks at her. She continues to tell the story and ask Bongani questions to keep him engaged. She shows him with her hands how small he was and asks him what he liked, saying porridge. Bongani agrees and shows her the biscuit he is eating. Bongani then talks back to Andiswa asking about other family members. Andiswa tell him how the family member used to hold Bongani and she tries to demonstrate by telling him to come closer. Andiswa tries to touch Bongani on the back but Bongani moves away focusing on his biscuit, almost fearful Andiswa would take it away. Andiswa then touches him again and tries to pull him closer but Bongani leans away from her and moves his arm and biscuit away. Andiswa leaves him to face away and tells him about a song she used to sing and Bongani joyously breaks into song, watching himself in the one way mirror. Andiswa praises his singing saying “wow” and continues telling him how he would quieten down after she sang but Bongani keeps singing and Andiswa places her hand in her head as if laughing. She tries to pull him closer and he reluctantly goes closer to her but with his back towards her. Bongani keeps singing the song and Andiswa says “Who taught you this song, granny. Oh wow you are singing.”

*Feed:* Andiswa asks Bongani “Do you want some yoghurt?” She leans over to get the yoghurt holding Bongani’s hand so he cannot get up. As she lets go, he gets up and moves away. She then asks him “Come let me feed you yoghurt, put the biscuit away and granny will give you yoghurt. Come let me feed you- do you want some? Should granny open it? Come sit here, sit here.” Bongani slowly comes over to see and then sits. Andiswa says “Come let me feed you or would you like to feed yourself” and then hands Bongani the spoon and removes the biscuit. She holds the yoghurt for him and lets him feed himself cautiously and somewhat regulatory by saying “Don’t spill on yourself. Come eat. Try feeding yourself. Try some more. Don’t sing. Eat and we will leave soon.” She also pulls his hand to the yoghurt cup quite forcefully to make him eat. When he does eat she smiles and praises him saying “Good”, “You are eating really well”, “You are very clever, you can eat by yourself.” and asks “is it nice?”. Andiswa then jokingly asks “will you give me some?” and reiterates “It is granny who gave you the yoghurt. Will you save some for me?” When Bongani touches his mouth with his sleeve Andiswa gets quite angry and shouts “Don’t wipe with you clothes!” pulling it away from him and cleaning his sleeve saying “There you go. Don’t wipe yourself again with this shirt”. She then readjusts the spoon in his hand for him and encourages him to finish eating saying “wow you are finishing eat more!” She then offers to help him with the last bit and takes the spoon from him to scoop it up and feed him. Andiswa remains quite concerned with mess saying “don’t spill it on granny, do you hear me” and holding his hand that has yoghurt on it so that he cannot touch anything with it.

*Lotion:* Andiswa holds Bongani’s hand so that he cannot move away while she cleans his hands with a wipe telling him “Don’t dirty your shirt, you hear?”. When she lets go and starts to wipe his face quite vigorously, he stiffens and pulls away from her moving to the other side of the room and she tells him to wait. Andiswa tells Bongani to come back to her while she cleans up telling him “Come let me wipe you, come boy, let me moisturize you with something that smells nice.” Bongani goes back to her and she wipes his face again, he stiffens and tries to pull back and avoid it but Andiswa holds him in place with her hand at the back of his neck. While wiping him she compliments him and engages him by saying “you are so beautiful, who do you look like?” Bongani answers her saying “I look like mom”. When Andiswa lets go again, Bongani moves to the other side of the room. She takes moisturizer and rubs it on her hands and tell him “come let me moisturize you, we will go home now. Come, don’t you want to leave? Come see, come see” while she picks up a toy to try and get him to come to her. Bongani comes for the toy but as Andiswa drops the toy and tries to reach out for him he runs away from her. She then gets up complaining how stubborn Bongani is and goes to him to rub cream on his face vigorously. Bongani stiffens, pulling faces and again trying to evade the cream and her touch- he doesn’t mind his hands being rubbed but when she rubs his face he doesn’t enjoy it. Andiswa jokingly tells him “You so ugly, are you ugly” and then tells him “No don’t be silly now why are you being stiff”. She lets go and he remains stiff with his arms up in a brace position then immediately moves away from her.

*Leave the room:* Andiswa walks to the door and Bongani makes a noise, she says “I’ll be back now now, I’m coming back alright” and then leaves the room. Bongani (out of camera view) seems to be playing in the one way mirror and making babbling sounds/ pulling faces. He then shouts “open” at the door. He moves away from the

door playing with his toy and then accidentally knocks the camera over. The researcher then went into the room to adjust the camera before sending Andiswa back in. Andiswa enters the room and immediately says “No. Wait, wait, your pants are getting loose.” and goes to adjust them. She then leads Bongani back into camera view and says “jump around this side” throwing his toy onto the matt.

*Sing:* Bongani tries to run away from Andiswa as she sits down and she grabs his arm to stop him. Bongani lies down and Andiswa takes the toy rattle he has away from him as she begins to sing saying “come let me put you to sleep, come come!”. Bongani sits up to see where his rattle is and Andiswa pulls him into her arms and onto her lap which he tries to avoid and squirm out of. He then flops down and tries to reach for the rattle but Andiswa grabs it and throws it under the table. Bongani then gets up and runs around saying he needs the loo. She says “no, no you not gonna go to the loo.” Bongani then goes to get the rattle but can’t reach, Andiswa then gets up to help move the table and get it for him. Bongani gets the rattle and runs away. The researchers remind her of the task. Andiswa then sits down and says “come sit in front of me”. Bongani obeys and goes and sits by her and point to a ball on the floor. She passes him the ball and he tries to eat it to which she tells him “No don’t put the ball in your mouth, don’t bite it” and takes it away from him and then give it to him again. The researchers remind her of the task again and she takes the ball and throws it away. She says “let’s sing our song together”. She starts singing and Bongani joins in. She takes the rattle away and moves him to sit in her lap holding him around the waist. They sit and sway singing the song and Bongani claps his hands in enjoyment. This continues for a couple of minutes without Bongani trying to run away.

#### **Domain Observations:**

*Structure:* Andiswa provided Bongani with a fair amount of structure by engaging him and telling him what to do throughout the tasks. At times, her instructions were quite vague and it took her a bit of time to acquire Bongani’s attention which was also quite easily lost. This made Andiswa frustrated and led her to be a quite physically restraining and strict on Bongani in her attempt to rigidly structure tasks and get him to do them. Bongani tended to listen to Andiswa and followed instructions she gave him. However, at times Bongani was momentarily defiant, moving away from Andiswa, particularly when he felt she was going to take something away from him or do a task he doesn’t particularly like.

*Engagement:* Although it took Andiswa some time, she was able to engage Bongani through various techniques such as questioning him and sparking his interest. This sometimes took time and left Andiswa frustrated resulting in her forcing contact on Bongani resulting in him being evasive towards her at times. When Andiswa was able to engage Bongani without physical force, he responded well to her, listening, making eye contact and having simple conversations. They seemed to have fun at certain tasks, such as throwing the ball and singing together with Andiswa praising Bongani and encouraging him. However, at times she jokingly teased him and shouted at him for accidentally messing. Her volatility to change made Bongani a little wary of her and resulted in him being a little cautious of her physical touch and disengaging from her.

*Nurture:* Andiswa attempted to provide Bongani with nurturance, however, her frustration and short temper often got in the way of this with Bongani withdrawing

away from her physical touch. It is apparent Andiswa cared for Bongani and attempted to be warm, engaging and create a comfortable space for him by being responsive towards his needs, praising him, and reigning him in when he got distracted. However, at times in frustration she withheld gratifying experiences from him, and ignored his requests to go to the bathroom or eat something. Bongani showed care and concern towards Andiswa, particularly in the separation task, and it was apparent he appreciated her but he also exhibited behaviours that showed he was wary of her and mistrusting due to her inconsistency.

*Challenge:* Andiswa was able to challenge Bongani by creating tasks that required him to do things for himself, verbalise, and use his weaker arm. At times these tasks were a little too developmentally advanced, such as corresponding a written number with the word which made Andiswa a little frustrated but she was very encouraging and offered praise when he was able to do something within his scope. She was also able to see the difficulty and attempted to make the task a little easier. She allowed Bongani time to try and get the tasks done rather than rushing in and taking over but at times her frustration got to her and she reprimanded him and made forceful moves to direct him.

### **Summary**

Overall, Andiswa and Bongani seemed to have a fairly good but cautious relationship with one another. It was apparent that they cared for each other, with Bongani listening to Andiswa and interacting with her in a positive manner at times and Andiswa praising and encouraging him but Bongani was also careful around her and mistrusting of her actions. Andiswa showed moments of having a short temper and becoming easily frustrated which made her emotionally unavailable and forceful with Bongani and caused him to retreat from her.

*Section 3: Interpretative Phenomenological Analysis (IPA) Theme Tables*

Appendix 5, Figure F  
*Emerging Themes and Sub-Themes for Baseline Data Collection*

<b>Main Theme</b>	<b>Subordinate Themes</b>
1. Making sense of the disability	<p>Understanding the disability</p> <p>Behavioural disability seen as naughtiness</p> <p>Physical health prioritized/ seen as contributing to disability</p> <p>Hope that disability will go away</p>
2. Overcoming traumatic past experiences	<p>Traumatic past experiences and fighting for the child to get him away from neglect</p> <p>He is so much better now that I started taking care of him</p>
3. Immense Responsibility	<p>Unrelenting responsibility – You have to have your eye on him at all times</p> <p>Distrust of other people caring for him – I don't trust anyone with him</p> <p>Responsibilities weighing on her and causing isolation and exhaustion</p>
4. Personal Strength and Support Systems	<p>Neighbours keep an eye on him</p> <p>Family</p> <p>Faith and Prayer- God helping her acceptance</p>
5. Barriers to healthcare	<p>Misunderstanding of reasons to attend the developmental clinic</p> <p>Transport difficulties</p> <p>Clinic dates not suitable</p> <p>No one else to care for other children</p> <p>Child too naughty to take to clinic</p>
6. Positives of Healthcare services	<p>Respect and Kindness</p>

	Other parents with disabled children
7. Discipline and violence	“I spank him” Child showcasing violence towards others

Appendix 5, Figure G  
*Emerging Themes and Sub-Themes for Post Intervention Data Collection*

<b>Theme</b>	<b>Subordinate Themes</b>
1. “He is much better now”	Functional Improvements Fewer health scares
2. Understanding Disability	Disability as a behavioral issue  Empathising
3. Responsibility and Constraints	“I am the one who feels for him and thinks for him”  Sick and Tired but Resilient  Poverty Constraints  No support at home  Duty to be there for him no matter her discomfort
4. Effects of the Service Learning Programme	Improvements  Visits as status boosting  Easing transport difficulties  It gave her a break  Difficulty letting go  Intermediating with clinic

Appendix 5, Figure H  
*Themes Relating to Caregiver Well-being*

	Research as an intervention
5. Support	Feeling valued and understood Spending time with friends as an enjoyment and distraction Spirituality Parents as support- “you are not alone”
6. Fear of the Future	“I pray that God will change him to be a normal child” Longing to find answers
7. Effects of the Developmental Clinic	Helpful Difficulties in accessing clinic

**Baseline Collection Themes**

Baseline Collection Themes	
Overcoming Traumatic Experiences	
Childhood Responsibility	
Child Isolation and Evacuation	
Respect and kindness from therapists	
Support from other parents	

*Themes Relating to Child Functioning*

Appendix 5, Figure J

Appendix 5, Figure I

**Post Intervention Collection Themes**

“I am the one who feels for him and thinks for him”
No support at home
Fear of the future
Poverty constraints
Sick and tired but resilient
Feeling valued and understood
Spirituality
Parent Support Group

*Themes Relating to Caregiver-Child Relationship*

<b>Baseline Collection Themes</b>
Discipline and violence

Appendix 5, Figure K  
*Themes Relating to Caregivers Experience of Care*

<b>Post Intervention Collection Themes</b>
Visits as status boosting
Easing transport difficulties
Gave her a break
Intermediating between caregiver and clinic
Difficult to let go
Research as an intervention

<b>Post Intervention Collection Themes</b>
Empathy

<b>Baseline Collection Themes</b>
Not understanding the Disability
Disability as Naughtiness
Hope for the Future

<b>Post Intervention Collection Themes</b>
Disability as a behavioural issue
Empathy
Longing to find answers
Functional improvements
Improvements attributed to the service-learning programme

**APPENDIX 6**  
**Zintle and Lizo**

*Section 1: Quantitative Data Scores*

Appendix 6, Figure A  
Demographic Questionnaire

<b>Demographic Questionnaire</b>		
<b>Interview Details</b>		
101	Interview number	<i>SBS</i>
102	Date of interview (dd/mm/yy)	<i>09/05/2016</i>
103	Place of interview	1= Home where child resides 2=Other home 3=Clinic/hospital 4= <i>Other (Psychology Department)</i>
104	Person interviewed	1= <i>mother</i> 2=caregiver
105	If caregiver (other than mother), what is relationship to child?	1=Father 2=Grandmother 3=Grandfather 4=Sibling 5=Relative 6=Neighbour 7=Friend 8=Other _____
106	Responsible for how much of child’s care?	1= <i>All the time (day and night)</i> 2=Day only 3=Night only 4= After school care 5=other _____
<b>Caregiver’s Characteristics and Relationship with Child</b>		
201	Date of birth (dd/mm/yy)	<i>25/12/1970</i>
202	Age (years)	<i>44 years old</i>
203	Sex	1=Male 2= <i>Female</i>
204	Race	1= <i>Black</i> 2=White 3=Indian 4=Coloured 5=Chinese 6=Other

205	Home language	1=English 2= <i>Xhosa</i> 3= Zulu 4=Afrikaans 5=Other _____
206	Current marital status	1= <i>Married</i> 2= Living together 3=Divorced 4= Separated 5=Widowed 6= Never married
207	What is the highest grade of schooling that you have completed?	1=None 2=Primary School 3= <i>High school (grade 10)</i> 4=High school (matric) 5=Diploma 6=University degree
208	Do you work?	1=yes, full time 2= yes, part time 3= <i>no, seeking work</i> 4=no, not seeking work
209	Where does your main source of income come from?	1=Regular income from working 2= Occasional income from working 3=Pension 4= <i>Child support grant</i> 5=Disability grant (for self) 6= Disability grant (for child) 7= Foster care grant 8= Maintenance grant 9= <i>Income from husband</i> 10= <i>Income from other family members</i> 11= Other _____ 12. No income
210	Approximate monthly income?	<i>R900.00</i>
211	How many hours a day do you spend with the child?	1= <i>During the week? 12 hours</i> 2= <i>During the weekend?12 hours</i> 3=none
212	How much of the time are you responsible for the child?	1= <i>all of the time</i> 2= During the day only 3= During the night only 4= Only some days
213	During a typical day, how much do you play with	1= <i>During the week? _____</i>

	your child?	2= During the weekend? ____ 3=None
214	Compared to other children is this a difficult child?	<i>1=Yes</i> 2=No
215	Is there someone you can trust to leave your child with when you are busy?	<i>1=Yes</i> 2=No
216	Who is this person?	1=My mother 2=my in-laws 3= my neighbour 4=my relatives 5=my friend <i>6=other (Father of child)</i>
<b>Child's Characteristics and Disability Treatment</b>		
301	Child's date of birth (dd/mm/yy)	<i>08 September 2015</i>
302	Child's age	_____ years <i>8</i> months
303	Child's sex	<i>1=Male</i> 2=Female
304	Type of Birth	<i>1=Singleton</i> 2=Twin 3=Triplet or more
305	Place of birth	<i>1= Hospital</i> 2= Clinic 3= Home 4= Other
306	Method of delivery	<i>1=Natural</i> 2= Caesarian section 3=Breech
307	Child's impairment (more than one can be circled)	<i>1=Moving and walking</i> <i>2=Talking</i> 3= Hearing 4= Seeing 5=Learning 6=Behaviour 7=Other _____
308	Gross Motor Function Classification System	1= Level 1 2=Level 2 3=Level 3 4=Level 4 <i>5=Level 5</i>
309	Was your child born with the disability or did he/she acquire the disability later on?	<i>1=congenital (at birth)</i> 2= acquired If acquired:

		Date: _____ Reason: _____
310	How does your child mostly communicate?	1= Speaking 2= Using gestures/ signs 3= Facial expressions <i>4=Crying</i> 5= Making sounds or noises 6= Does not communicate 7= Unknown
311	Do other people understand what your child is telling you?	<i>1=all the time</i> 2=some of the time 3=hardly at all 4=never
312	Does your child receive a care dependency grant?	1=Yes <i>2=No</i> 3=Applied, still waiting 4=Child not eligible 5=Unknown 6=No, but does receive child support grant
313	Does your child currently attend therapy?	<i>1=Yes</i> 2=No
314	Where does your child receive therapy? (can circle more than one)	1=Hospital <i>2=Clinic</i> 3=Home 4=Other _____
315	How often during the past 6 months has the child attended therapy?	1= More than 6 times <i>2= 6 times</i> 3= 4-5 times 4= 2-3 times 5=1-2 times 6= Not at all
316	How long have you been attending therapy?	1= 6 months or less <i>2= 7-12 months</i> 3= 13- 24 months 5= 2- 4 years 6= more than 5 years
317	How long does it take you to get to the clinic/ hospital from where you stay?	<i>1= 30mins or less</i> 2= 31-60mins 3= 1 hour- 2 hours 4= more than 2 hours
318	How do you usually get to the clinic or hospital for therapy?	1= taxi 2=bus <i>3= by foot</i> 4= by private car (It is your own car? Y / N) 5=other

319	Does your child attend school/ day care?	1=Yes 2= <i>No</i>
<b>Household Characteristics</b>		
401	Number of occupants in the house?	Children: <i>4</i> Adults: <i>2</i>
402	Total income of household per average month?	1= Less than R100 2= R100- R500 3=R500- R1000 4= R1000-R3000 <i>5=R3000-R5000</i> 6= More than R5000 7=Unknown
403	From where does the household earn income? (more than one option may be circled)	1= Regular income from working 2= Seasonal income from working 3= Occasional income from working 4= Pension <i>5= Child support grant</i> 6= Disability grant (adult) 7= Care dependency grant (child) 8= Foster care grant 9= Maintenance grant <i>10= Other (Husband's income)</i> 11= No income at all 12=Unknown
404	Construction material of main house walls?	<i>1= brick, cement blocks</i> 2= wood 3= informal/shack 4= mud 5= other
405	Construction materials of main houses roof?	1= Tiles, cement, bricks <i>2= Corrugated iron, wood, asbestos</i> 3=Thatch 4=Informal/shack
406	Main water supply?	1= Tap in house <i>2= Tap in yard</i> 3= Tap in street 4= Water truck 5= cement well 6= Traditional well 7= Open, unprotected (pond, river, dam) 8= Rainwater tank

407	In the household do you have a functioning: Stove If yes (gas, coal, electricity) Primus or paraffin stove Hot plate Fridge Microwave TV Hifi/stereo/tape/CD player Video Radio Phone (fixed) Cellphone Car/truck Bicycle Kariki cart/sled	<i>1=yes</i> 2=no  1=yes            2=no 1=yes            2=no 1=yes <i>2=no</i> <i>1=yes</i> 2=no 1=yes <i>2=no</i> <i>1=yes</i> 2=no <i>1=yes</i> 2=no 1=yes <i>2=no</i> <i>1=yes</i> 2=no 1=yes <i>2=no</i> 1=yes <i>2=no</i> 1=yes <i>2=no</i>
<b>Judgment form Interviewer</b>		
501	In your opinion is the information accurate?	<i>1=Good</i> 2=Fair 3=Poor
502	Any other information on the child or family that you would like to add?	

## Appendix 6, Figure B

*Clinical Outcomes in Routine Evaluation- Outcome Measure*

CORE-OM							
Zintle							
		Well-being	Problems	Functioning	Risk	All Items	All Items Minus Risk
Data Collection 1	Total Score	7	11	15	0	<b>33</b>	33
	Mean Score	1,75	0,92	1,25	0	<b>0,97</b>	1,18
	Clinical Score	17,5	9,2	12,5	0	<b>9,7</b>	11,8
Data Collection 2	Total Score	7	15	12	0	<b>34</b>	34
	Mean Score	1,75	1,25	1	0	<b>1</b>	1,21
	Clinical Score	17,5	12,5	10	0	<b>10</b>	12,1
Data Collection 3	Total Score	3	8	8	0	<b>19</b>	19
	Mean Score	0,75	0,67	0,67	0	<b>0,56</b>	0,68
	Clinical Score	7,5	6,7	6,7	0	<b>5,6</b>	6,8

Appendix 6, Figure C

*Paediatric Evaluation of Disability Inventory- Computer Adaptive Test (PEDI-CAT)*

PEDI-CAT Scores Lizo			
	Baseline Collection 1 Scores	Baseline Collection 2 Scores	Post Collection 3 Scores
Daily Activities	38	40	38
Mobility	33	39	40
Social/Cognitive	41	39	46
Responsibility	25	29	25

Appendix 6, Figure D

*Emotional Interaction Style (EIS)*

EIS- Assessment of MIM Zintle and Lizo				
		Baseline Collection 1 Score	Baseline Collection 2 Score	Post Collection 3 Score
Structure and Challenge	1. Parents comprehensive ability to structure the situation relative to the child's developmental level	4	4	3,5
	2. Child's general cooperation and ability to focus on the situation	2	2	1,5
Emotional Reciprocity and Initiative	3. Parent's emotional reciprocity and initiative	3,5	4	3
	4. Child's emotional reciprocity and initiative	1,5	2	1,5
Nurture	5. Parental Nurture	3	4	3,5
	6. Child's response to nurture	3	3	3
Playfulness	7. Parent's playfulness	3	4	3
	8. Child's playfulness	1,5	1,5	1
Representation	9. Representation of the child	2	2	2
Overall Score		<b>23,5</b>	<b>26,5</b>	<b>22</b>

Appendix 6, Figure E  
*Measure of Process of Care- 8 South Africa (MPOC-8 SA)*

MPOCE-8 SA Zintle			
	Baseline Data Collection 2	Baseline Data Collection 2	Post Data Collection 3
Score	31	41	36
Percentage	55,36%	73,21%	64,29%

## *Section 2: Marschak Interaction Method (MIM) Clinical Reports*

### **Marschak Interaction Method Case Reports Zintle And Lizo**

**Child:** Lizo

**Date of Birth:** 08/09/2015

**Age:** 8 months

**Caregiver:** Zintle

#### **Background Information**

Zintle reported a very difficult birthing process. The labour had to be induced due to Zintle's hypertension. The second stage of labour took a very long time and eventually Lizo had to be vacuum extracted which left his head misshapen. Lizo's Apgar Scores at birth were very low 4/10; 5/10; 8/10.

After birth it was noted that Lizo was very rigid/stiff and restless. He was termed an HIE baby (hypoxic ischemic encephalopathy) meaning his entire brain was starved of an adequate oxygen supply resulting in brain damage. Soon after his birth he was transported to a hospital in Port Elizabeth for consultation with a specialist doctor. Here he was diagnosed as a level 5 (GMFCS) spastic quadriplegic cerebral palsy and Zintle was told that he would probably not be able to do much for himself in his life. Lizo also suffers from epilepsy and has had seizures from birth.

Lizo started attending the clinic in March of 2016. He is still very small for his age and his body is very rigid with increased muscle tone. Lizo is very developmentally delayed and cannot sit, stand, or babble. He is constantly in an uncomfortable extensor state, struggling to relax the muscles in his neck, upper body and trunk. The Developmental Clinic is also questioning his eyesight, as he tends to constantly look up and to the right.

#### **Assessment Instrument**

**MIM Tasks:** The following is a list of seven tasks that Lizo and Zintle were asked to engage in together: The task instructions were delivered by the research assistant through a microphone in Lizo and Zintle's first language, isiXhosa.

1. Play a familiar game that you would normally play at home.
2. Use the toys on the table and make a game with them.
3. Tell your child a story about when he was younger.
4. Feed your child something that you think he would like on the table.
5. Wipe his mouth and hands and then put cream on him.
6. Leave your child alone in the room for 1 minute.
7. Sing your child a lullaby/song.

### **Data Collection 1**

#### **Observations**

##### **Task Observations:**

*Familiar game:* Zintle engaged in therapy practice with Lizo as a familiar game. She encouraged him to try and look to the left and make eye contact with her. They then

practiced moving arms and legs- Zintle holding Lizo's arms and legs and opening and closing them for Lizo. Zintle maintained very good/close eye contact with Lizo and engaged with him vocally at all times offering guidance, encouragement and praise-even to the smallest of Lizo's movements.

*New game:* Zintle chose a toy from the table with a jelly spikey texture and a light inside of it. Zintle explained to Lizo that she would pick him up so that he could better see the toy. Zintle cradled Lizo in her right arm and used her left arm to bounce the toy in front of his face. She maintained good eye contact with Lizo and engaged with him vocally. Zintle then encouraged Lizo to hold the toy by placing it in his hand- Lizo responded to this by crying. Zintle briefly comforted him and then persisted in trying to get him to hold the toy.

*Story:* Zintle cradled Lizo in her arms and maintained good eye contact with him while she told him the story in an expressive voice. She also used her one arm to pat him on the back and rock him soothingly. Lizo seemed to be breathing quite heavily with a rasping sound in this seated position, however, it did not seem to bother Zintle. Zintle told the story of Lizo's difficult birth- after which she lets out a heavy sigh and pauses. She then continues the story with how big Lizo has grown and she expresses her hopes and love for him by saying, "*You gonna grow and be Mama's boy, mom is gonna love you, dad is gonna love you and your siblings. You gonna grow into a big boy.*" Lizo then wants to cry but she soothes him and tells him not to be naughty. Zintle then tells him more about her hopes and dreams for him saying, "*He's gonna grow into a big boy, and study like other children. You gonna study boy like other kids and get big and old and become a doctor.*" Although this is very positive and encouraging, it may also show how Zintle has not quite come to accept Lizo's disabilities and limitations. Zintle finishes off the story by complimenting Lizo on how handsome he is.

*Feed:* Zintle positions Lizo in her arms and chooses to feed him yoghurt. She engages with him well telling him that she has chosen a yoghurt and making eye contact while she spoon feeds him. Lizo seems to pull a face and make a crying sound when he is first fed the yoghurt and he lifts his left arm up to his mouth to which Zintle tells him not to do. She encourages him to eat the yoghurt and comments on how well he is eating the yoghurt. Lizo continues to lift his arm up to his mouth and Zintle keeps pushing it down, telling him that she is removing his hand that wants to touch everything. She seems to get a little frustrated with his hand coming up at one point and asks if she must smack it and if he wants to feed himself. When Lizo finishes the yoghurt she praises him in a high/happy tone of voice.

*Lotion:* Zintle cradles Lizo in her arms and using her other hand opens the cream and dabs a little onto her fingertips. She continually engages with Lizo making baby sounds, telling him what she is doing and looking at him. She dabs the cream on his face with her fingertips and Lizo seems to find this ticklish and Zintle laughs and smiles. Zintle lays Lizo on the floor so that she can put lotion on both of Lizo's hands. She makes a lot of baby talk, smiles and comments saying, "*Moisturizing your hands. Boy is smiling, smiling with mama. Who's baba smiling at? Smiling because you look handsome.*"

*Leave the room:* Zintle gets up from the floor without making physical contact with Lizo. While she is walking past him she looks at him and say, “Bye, bye, boy. Where’s mom going?” while she makes her way to the door. Once Zintle has left, Lizo seems to move his arms around a little before his head pulls back into an extensor pattern that looks very uncomfortable. He then begins to sound as if he is crying/breathing difficultly. Zintle enters the room again and softly whispers to him (inaudible). She then gets on her hands and knees and looks at him briefly before she turns away and starts cleaning up- only after which she turns to Lizo and repositions him and pulls him closer to her by his legs.

*Sing:* Zintle picks Lizo up off the floor and cradles him in her arms. Lizo begins to cry while she positions him. She continues to talk to Lizo, trying to make eye contact. She asks him how their song goes, and then tells him not to moan but to tell her how the song goes. Lizo continues to cry until mom begins rocking him, patting his back and singing their song. Lizo then goes quiet.

**Domain Observations:**

*Structure:* Zintle was able to provide Lizo with a good amount of structure that was relevant for Lizo’s developmental level and disability. Zintle was able to guide the tasks, correctly position him, and she made an effort to continually talk to Lizo and explain what they were doing in each task. Zintle was also able to set boundaries for Lizo and correct him when he was doing something she thought he should not be doing (e.g. taking hands up to mouth while feeding). At times Lizo seemed unwilling to accept the task at hand and made crying sounds to which Zintle would briefly comfort him and tell him not to be naughty/moan and she would continue with the task- showing that at times she may be quite rigid and too focused on the task.

*Engagement:* Zintle was very engaging with Lizo. She continually touched and spoke to Lizo throughout all of the tasks and made a concerted effort to encourage Lizo to try and make eye contact with her and smile. She was very responsive to Lizo and praised him greatly when Lizo made even the slightest movement or effort. Zintle seemed to be enjoying the tasks, smiling and laughing with Lizo. She responded to him in a very warm, affectionate way with a lot of praise and physical contact. However, at times when Lizo would begin to cry and Zintle would reprimand him for this by telling him no and saying that he should not be naughty. Zintle also teased Lizo at times, first, walking out of the room saying “bye” and asking where she was going without telling him, and then again during the feeding activity when Zintle asked Lizo if she should smack his hand.

*Nurture:* Zintle was very responsive, warm and caring towards Lizo. She was comfortable with physical touch, holding, caring and feeding Lizo. She was also very good at positioning Lizo correctly and helping him with his extensor pattern to keep him comfortable. Zintle was able to recognise Lizo’s emotions and respond to them. She was able to soothe him by patting and rocking him, however, at times she would reprimand him by telling him not to cry. During the stressful separation task, Zintle did not prepare Lizo for her leaving the room, instead, she got up and walked out of the room saying goodbye and asking Lizo where she was going, almost teasingly. Lizo seemed to go into an uncomfortable extensor pattern during this time and made a crying sound. Upon Zintle’s return she whispered to him and looked at him briefly before cleaning up the yoghurt and only then returning to Lizo to reposition him.

Challenge: Zintle was able to set developmentally appropriate tasks for Lizo. Zintle challenged Lizo a little bit during the tasks, she mainly focused on challenging Lizo to try and look to his left hand side, which he struggles with due to his disability. She was quick to praise Lizo with great elation for even the slightest movements and they shared moments of pleasure when he was able to make even a small achievement. During the story task, Zintle was very encouraging of Lizo's future, however, she may have unrealistic hoped for Lizo telling him he will study like other children and become a doctor, as this is not in line with Lizo's disabilities.

### **Summary**

Zintle and Lizo seemed to have a good relationship that is affectively attuned and in synchrony at most times. They looked very comfortable with one another and seemed to enjoy their interactions together. At times Zintle would reprimand Lizo for crying rather than acknowledging his emotions but she would still physically respond in a nurturing manner to restore his mood and reengage him. Although Zintle is a very positive and encouraging parent she still seems to not have fully accepted Lizo's disabilities, and still has large dreams for Lizo that will more than likely be unattainable.

## **Data Collection 2**

### **Observation**

#### **Task Observations:**

*New game:* Zintle places Lizo in a seated position next to her and fully supports him with one arm around him. She chooses a toy car for them to play with saying that if Lizo could choose for himself she thinks he would choose the car. She proceeds to drive the car around on the mat in front of Lizo (unfortunately out of his sight), making different car sounds and telling an elaborate story involving Lizo. During the story Zintle takes on the role of narrating for both herself and for Lizo- creating a conversation between them. Zintle is very expressive in her effort, continually making eye contact with Lizo, and laughing as if enjoying the interaction. She also helps Lizo place his hand onto the car and move it around by himself to try and involve him in the interaction.

*Familiar game:* At first Zintle seemed quite confused by the instruction and couldn't decide what game to play. She finally chose a cause and effect toy with different shapes and colours. She seemed to struggle to get Lizo and the toy into a working position and changed their position up until she cradled him on her lap in her one arm and held the toy in front of him with the other arm, but the toy was still out of Lizo's direct sight. She held his hand and directed it to press the different buttons on the toy. Throughout the interaction Zintle engaged with Lizo by telling him what to do with very basic instructions and she tried to explain and name parts and colours of the toy although she seemed a bit confused by the toy too. Zintle was very encouraging of Lizo and would respond by saying "Wow" when there was an effect from the toy. Zintle also looked over to Lizo to make sure he was in a comfortable position. It seemed as if the toy needed to be pressed quite hard to create an effect and Lizo eventually responded to this by crying out loud to which Zintle responded by saying

“sorry boy sorry” and cradling him, looking at him, talking to him and patting him to soothe him which calmed Lizo down.

*Story:* Zintle starts talking to Lizo but he starts to cry at which point Zintle looks away from him briefly before attending to him by looking at him intently, rocking him and talking to him to try and soothe him. She says “*Oh no why are you so sad? Sorry, sorry.*” and hushes him while patting his back. Lizo responds by stopping crying. When he stops crying Zintle tells the story of how Lizo very rarely cries and so she has to often check on him. She tells him that when he didn’t cry at birth it hurt her but she continued to have hope for him and now he is crying and growing up and achieving her hopes and dreams. Zintle says, “*Now moms baby is all grown and could do stuff that he couldn’t do when he was a baby*”. Lizo begins to fall asleep and Zintle stops the story to try and keep him awake. Throughout the story telling Zintle maintains good, close eye contact with Lizo, using different facial expressions to engage with him all the while cradling him and patting his back.

*Feed:* Zintle acknowledged at the start of the task that she did not think Lizo would want to eat the yoghurt as he was quite moody but she persisted to try anyway. Lizo did not seem to want to eat the yoghurt and moaned quite a bit but Lizo tried to convince and encourage him to eat the yoghurt by constantly talking to him and saying, “*It’s nice, yoghurt is nice*” and “*He’s eating yoghurt... Wow this boy is eating*”. Lizo’s moans seemed to persist and so Zintle stopped feeding Lizo the yoghurt and apologised to him saying, “*You’re sad, I’m sorry*” and reassured him by saying, “*I’ve put it away now. I’ve stopped feeding the baby. I’m sorry*”.

*Lotion:* Zintle cradles Lizo in her one arm so that she has use of both of her hands to rub lotion on Lizo. Zintle takes a little bit of lotion and dabs it onto Lizo’s hands before gently rubbing the lotion onto his face while telling him in a sing song voice “*Moisturise. Moisturise. Don’t you want to moisturise?*” Zintle then takes Lizo’s hands and helps Lizo rub lotion into his own hands and onto his own face while talking as if it is Lizo saying what he is doing. Zintle seems to enjoy this task laughing and making eye contact with Lizo and Lizo seems to be more relaxed too as he no longer cries.

*Leave the room:* Zintle places Lizo on the mat and gets up all the while looking back at Lizo. As she walks out of the rooms she says “*Bye Nana. Byeeee*” watching him and waving at him as she walks away. On her return Zintle walks straight to Lizo and bends down beside him saying, “*Hello, what are you doing when mom is not around?*” Zintle then soon gets up again and goes back to the door to close it. Zintle goes back to Lizo and kneels over him trying to get him to make eye contact with her by clicking at him and saying hello.

*Sing:* Zintle places Lizo on her lap facing towards her and begins singing quite upbeat/happy songs while looking at Lizo and using her hands to move his hands around and bounce him on her knee as if dancing together. Zintle is very expressive in her tone, and seems to smile and have fun while doing this activity. At the end of the activity she give Lizo a big kiss on his head.

#### **Domain Observations:**

*Structure:* Zintle was able to provide Lizo with a good amount of structure, as she was very predictable and logical in her actions- staying with one task and enjoying it with Lizo until its completion. Zintle constantly spoke to Lizo and told him what it was they were doing, even adopting Lizo's persona at times to verbalise what she thought he might say to her if he spoke. Thus she was able to clarify and define Lizo's experiences and involve him in the activities by physically guiding him. When Lizo cried Zintle was also able to help soothe and regulate his emotions and quickly restore a positive interaction.

*Engagement:* Zintle was extremely expressive towards Lizo in her tone and actions, which provided a good amount of excitement, surprise and stimulation. At times Zintle seemed to over stimulate Lizo which resulted in Lizo crying. However, Zintle maintained good eye and physical contact with Lizo and continually checked on him throughout the tasks, which created opportunities for affect attunement and empathic awareness. When Lizo grew distressed Zintle was able to acknowledge this sadness and comfort him by cradling him and soothing him. Their interaction looked quite synchronous despite Lizo's disability and Zintle genuinely seemed to enjoy spending time with Lizo, engaging with him in a playful and loving manner.

*Nurture:* Zintle came across as very warm natured and caring which resulted in an interaction that looked very comfortable despite Lizo's disabilities. Zintle was able to recognise that Lizo was quite tired and did not seem to be himself but she tried to push on for the sake of the video. When Zintle became visibly distressed Lizo would stop the activity, acknowledging Lizo's discomfort and soothing him. Lizo responded well to Zintle's nurturance. At times during the nurturance tasks Lizo would turn the task into a learning opportunity such as in the lotion task she used Lizo's hands to try and get him to rub cream onto himself. During the leave the room activity Zintle prepared Lizo for her departure by saying goodbye but did not take the time to explain where she was going. On her return Zintle went straight to Lizo to check on him before getting up to close the door and then return to him again.

*Challenge:* Zintle was very encouraging of Lizo and utilised the activities as learning possibilities to guide Lizo and teach him things he doesn't know. Often these things were far above Lizo's current abilities but Zintle understood this and would fully support Lizo and guide his hands. Zintle was also very acknowledging of Lizo's efforts, even if they were fully initiated by Zintle, and offered surprise and praise when he achieved them.

### **Summary**

Overall, Zintle and Lizo seemed to be very in tune with one another and comfortable with each other's presence and physical touch. They responded well to each other with Zintle providing good amounts of structure, engagement, nurturance and challenge. Zintle was a very expressive, empathically aware and caring parent that was able to acknowledge Lizo's feelings and react to them in an appropriate manner to restore his mood when he became distressed. Zintle was also open to challenging and teaching Lizo new skills and encouraging him to strive.

### Data Collection 3

#### Observation

##### Task Observations:

*New game:* Zintle places Lizo on the bean bag quite hurriedly which results in him looking quite uncomfortable. She then laughs and says “He doesn’t want to sit down, mommy will put you right here” she then adjusts the bean bag and places Lizo down slowly in a more comfortable position while asking him “are you going to play? Let’s play with this one”. Zintle then moves to the toy table while looking at Lizo, only turning briefly to select a toy saying “mmm, here it is, look, here is a toy”. She places the toy next to Lizo and picks him up while she moves into position and gets comfortable without much focus on him. She then turns her attention to him and gets him into a comfortable position adjusting his head and cradling him in her right arm. Zintle then attempts to place the toy in Lizo’s hand and rattle it for him saying “There is it, look, can you see, mm?” in an excited voice. Lizo continues to look to the right away from Zintle and unable to hold the toy himself. Zintle rattles the toy in front of Lizo’s face watching for a reaction and using her supporting arm around the back of his head to nudge him to try and encourage a reaction. Zintle notices spit on Lizo’s face and reaches for her spit towel, intently looking at him and wiping it away making sure he is clean. She then attempts to spin the toy saying “yoh, yoh oh this man is spinning around, the man is spinning around” in an animated and excited voice, watching his face. She then briefly shakes the toy in front of him and tries to place it in his hand again telling him to hold it and asking “do you want to hold it? Here, hold it yourself. Hold it, look hold it”. She continues to encourage him to hold it but he lets his hand fall and she says “oh you let it go, here hold it yourself...hold it yourself and play” continually encouraging him and trying to get him to hold it by placing it between his fingers and around his hand. She then takes the toy and shakes it out of his line of site (too low), seemingly getting a little frustrated, she then moves it close to his face shaking it in line with his site but when she doesn’t get any reaction she looks dartingly at the table and starts to think of a different game to play, saying “Oh there is a car, don’t you want to drive a car?”

*Familiar game:* Zintle places Lizo on the floor, she picks him up to wipe his face before placing him on the floor again and going to choose another toy. She returns to Lizo and picks him up saying “ok now let’s try another one, here is a telephone” She positions him comfortable in the opposite arm which allows Lizo to look to his preferred side (right) towards her. She pretends to dial the phone telling Lizo “dial on the phone, dial, dial”. She then places the receiver to his ear and animates a conversation talking on behalf of Lizo in a child’s voice. She looks at him intently and makes facial expressions while having the conversation and rocks and moves him with her supporting arm as if he were moving himself in the conversation. The conversation centres around Lizo telling his friend he is at school and playing with all nice things. Lizo yawns and Zintle says “all of this is causing you to yawn”. He then coughs and she lets go of the phone and holds his head to support him, looking at him and making sure he is alright. She then picks up the phone again and says “okay let’s call dad, dial his number yourself, come on dial” and then tells Lizo “it is ringing.” She then has a conversation imitating Lizo and telling his dad “I am at school, I am playing with other kids. It’s so nice here at school.” She continues to pat his back and gently rock him while looking at him and changing her voice and speaking. She then says to Lizo “We’re going to put the phone down now, who else do you want to call?”

looking at him and asking him the question. She then puts the phone away saying “Hey boy, no I don’t want to call anyone. I’m tired now.” She then stops and just watches him placing her hand on his chest.

*Story:* Zintle continues to cradle Lizo in her left arm, he looks at her and she places her right hand on his chest. She tells him the story of when he was young speaking in the third person. She tells him “Lizowas still young, he was a sweet child, very quiet and calm. He just wanted his food, to have his nappy changed by his mom, for his mom to bath him, play with him and feed him”. She takes her right hand off of him holding him only in the left arm and swaying gently, patting his bottom. He seems to cry/moan very softly and she places her hand back on him and then takes his hand in her hand and moves it around while she speaks of herself in the third party saying “his mom would take her child and put him on her chest, she would sleep with her child and put him over here.” She pulls him closer to her to show him and then moves him away and brings him closer again maintaining eye contact and kissing him on the forehead. She tells him “mommy loves her child, Lizo. Even though he is the way he is, Lizo is loved by his mother... it doesn’t matter what he is like”. She then kisses him again and tells him “I love you my boy, ok mommy loves you” and says “you and I get along fine right my boy”. She seems to be a little emotional and then says “mommy is done telling you a story about when you were young.” Then after a moments silence she continues to tell Lizo that she loves him and always will. She then lifts him up and hugs him placing his arms around her neck and shoulders saying “mommy loves you, give me a hug. You are hugging mommy, mommy is hugging her baby” while hugging and swaying him from side to side and patting his back. She then places him in her right arm facing away from her and tells him “You will also be just like the other children one day and be able to sit and walk one day mm” and places a kiss on his forehead. He then start to cry and she says “oh no I am sorry” and cradles him swaying and patting him to soothe him while saying “ah ah ah ah”. When he stops she lets out a big sigh and says “mommy is done telling you a story”.

*Feed:* Zintle takes the yoghurt and places Lizo on her lap saying “Ok would you like to eat Lizo? Are you hungry my boy mm?” and tells him what he is going to eat. She positions him on her lap telling him “Sit here, there you go” and asking him “you want some yoghurt?”. Lizo seems upset and raises his arms pulling a face to which Zintle says “no, no, no... there you go. Open your mouth” and pushes the yoghurt in. She surmises that because the yoghurt is cold he might not be enjoying it and tells him “Oh it’s very nice even though it’s cold.” Lizo doesn’t seem to be enjoying it too much and she has to encourage him to open his mouth and she praises him when he does constantly talking and reassuring. He then places his hand on her hand that is feeding him and she jokingly says “Oh now you want to hold the spoon. You want to feed yourself now, but you don’t even know how to hold the spoon”. He doesn’t want to open his mouth and she asks “are you already full?” but continues to try and feed him. When he doesn’t open his mouth Zintle pauses and looks at him and says “Lizo!” with a frown on her face. This causes him to start crying. She immediately apologises and closes the yoghurt to put it down and start cradling him, gently speaking to him saying “Oh I’m sorry, mommy has stopped”.

*Lotion:* Zintle places Lizo on the floor with his head on the bean bag and turns to get a wipe and the cream. She kneels over him and wipes his face and hands saying “Oh are you mad, we are mad now” and apologising to him. She then sits down and lifts him into her arms to cradle him and takes a little bit of cream which she places directly on his hands and face. She lifts his hands and tries to make him rub his own cream on his hands and rub his face telling him “let’s wipe our hands and face”. Lizo doesn’t enjoy this and starts crying and Zintle apologises, lifting him over her shoulder and holding him to her chest swaying and patting his bottom while saying sorry.

*Leave the room:* Zintle places Lizo on his stomach and adjusts him so that he can push up on his hands while saying “do you want to be left here all by yourself?” She then readjusts him to face towards the door and not away from it and again places his hands underneath him to push up on. She then leaves the room saying “I’ll leave you by yourself mmm” and she says goodbye watching him as she walks out. Lizo watches her walking away pushing himself up on his hands. He seems to push up and drop continually as if hyperflexing and moans a bit while doing this. He then falls over onto his side and lies there. When Zintle returns she makes a big fuss laughing at him and saying “Oh this little man, I knew you would fall over” and leans down to pick him up, looking at him and asking “did you fall over?” and apologising. She wipes his face and picks him up to cradle him, adjusting his clothes and making sure he is comfortable again.

*Sing:* Zintle monitors Lizo to make sure he is comfortable in her arms before she starts singing. She looks at him and rocks him gently back and forth while patting him on his bottom. Lizo watches her face and seems to relax and yawn while she sings to him.

#### **Domain Observations:**

*Structure:* Zintle provided Lizo with a fair amount of structure in the tasks by taking charge and setting out what they should do. She constantly spoke to Lizo to try involve him and co-regulate his experiences. At times Zintle seemed a little too rigid and focused on the task at times which resulted in a slightly disorganised and somewhat forced interaction.

*Engagement:* Zintle was extremely engaging with Lizo who struggled to reciprocate due to his disabilities. She continually spoke to him with excitement, expression and stimulation. She was empathically aware of his emotions and constantly watched him attempting to make eye contact and provide physical stimulation to sooth him. However, at times she would provide a little too much stimulation that upset Lizo. When Lizo became distressed, Zintle was able to acknowledge this and restore his mood by cradling and rocking him.

*Nurture:* Zintle was nurturing towards Lizo, recognising his needs and taking care to make sure he was comfortable during the process. Zintle was very much at ease with holding, feeding and cuddling Lizo. However, at times Zintle placed the tasks ahead of Lizo’s wants, such as encouraging him to eat when he didn’t seem hungry. She also used nurturing tasks for learning such as getting Lizo to rub cream on his own face

which visibly upset him. When Lizo became upset, Zintle was able to recognise his feelings and cradle him and sooth him.

Challenge: Zintle attempted to challenge Lizo throughout the tasks by getting him to hold toys, rub cream on himself, and have some tummy time. During the story telling she placed importance on Lizo showing everyone when he grows up how he will be able to do things like sit. She was very encouraging of him and praised him highly. However, at times Zintle challenged Lizo a little too much which resulted in him crying.

### **Summary**

Overall, Zintle was a highly energetic and engaging caregiver who aimed to challenge Lizo, encouraging him to strive. However, at times she did not effectively attune to Lizo's emotions causing him distress due to too much challenge or engagement. Zintle was able to realise this, apologising to Lizo and providing him with nurturance and care to sooth him. Lizo responded well to Zintle and they were able to show a comfortable and loving relationship with good amounts of structure and nurturance.

**Section 3: Interpretative Phenomenological Analysis (IPA) Theme Tables**

Appendix 6, Figure F  
*Emerging Themes and Sub-Themes for Baseline Data Collection*

<b>Main Theme</b>	<b>Subordinate Theme</b>
1. I did not expect to have a child like this	Shock and disbelief “It hurts, it doesn’t feel good at all” Unfairness
2. Acceptance	Being strong for the child/resilience Helplessness- “Nothing I can do but accept it”
3. Alone with the responsibility	Responsibility and worry that is interruptive to daily life Suffering alone
4. Pillars of support	Prayer/Church Clinic guidance/ acknowledgement/ empowerment Clinic’s community of other caregivers Cousins sister
5. He is growing up now	Positive growth and development Improvement attributed to clinic
6. Affect Attunement / Bonding	A strong/ understanding connection between mother and child Pride in understanding child Worry about misunderstanding

Appendix 6, Figure G  
*Emerging Themes and Sub-Themes for Post Intervention Data Collection*

<b>Theme</b>	<b>Subtheme</b>
1. Developmental Improvements	Growth with difficulties Health improvements “He is trying now”
2. Coming to terms with disability	“It was not easy” Denial of disability Broken expectations
3. Strong bond	Acceptance of disability He is loved I understand him Devotion Self-acknowledgement Getting tired of each other
4. Problems	Worries at home Constraints Responsibility Need to be happy
5. Difficult caring for a child with disabilities	Attention seeking Demanding Tiring
6. Support structures	Family time Spirituality Talking to others
7. Helpful experience of the service-	Gave her a break

learning programme	Enjoyment spending time with them Empowering- “I taught them”
8.Supportive experience of the Clinic	Encouragement Learning experience Acknowledgment
9. Research as cathartic	Speak without shame about disability “It was a release for me”

Appendix 6, Figure H  
*Themes Relating to Caregiver Well-being*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
“I did not expect to have a child like this”	Problems at home
Acceptance	Responsibilities
	Need to be happy
	Family support

Appendix 6, Figure I  
*Themes Relating to Child Functioning*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
“He is growing up now”	Growth with difficulties
Improvements attributed to clinic	“He is trying now”
	Health improvements
	Devotion

Appendix 6, Figure J  
*Themes Relating to Caregiver-Child Relationship*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
A strong connection between mother and child.	“He is loved”.
Pride in understanding child.	“I understand him”.
Worry about misunderstanding.	Getting tired of each other.

Appendix 6, Figure K  
*Themes Relating to Caregivers Experience of Care*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
Clinic as guidance, acknowledgement and motivation.	Encouragement (DOH).
Clinic’s community of caregivers.	Learning experience (DOH).
	Acknowledgement (DOH).
	Enjoyment spending time with students.
	Gave her a break.
	Empowering- “I taught them”
	Research as an intervention.

**APPENDIX 7**  
**Unathi and Mandla**

*Section 1: Quantitative Data Scores*

Appendix 7, Figure A  
*Demographic Questionnaire*

<b>Demographic Questionnaire</b>		
<b>Interview Details</b>		
101	Interview number	<i>SLJ</i>
102	Date of interview (dd/mm/yy)	<i>10 July 2016</i>
103	Place of interview	1= Home where child resides 2=Other home 3=Clinic/hospital 4= <i>Other (Psychology Department)</i>
104	Person interviewed	1= <i>mother</i> 2=caregiver
105	If caregiver (other than mother), what is relationship to child?	1=Father 2=Grandmother 3=Grandfather 4=Sibling 5=Relative 6=Neighbour 7=Friend 8=Other _____
106	Responsible for how much of child’s care?	1= <i>All the time (day and night)</i> 2=Day only 3=Night only 4= After school care 5=other _____
<b>Caregiver’s Characteristics and Relationship with Child</b>		
201	Date of birth (dd/mm/yy)	<i>17/06/ 1989</i>
202	Age (years)	<i>27 years</i>
203	Sex	1=Male 2= <i>Female</i>
204	Race	1= <i>Black</i> 2=White 3=Indian 4=Coloured 5=Chinese 6=Other

205	Home language	1=English 2= <i>Xhosa</i> 3= Zulu 4=Afrikaans 5=Other _____
206	Current marital status	1= <i>Married</i> 2= Living together 3=Divorced 4= Separated 5=Widowed 6= Never married
207	What is the highest grade of schooling that you have completed?	1=None 2=Primary School 3= <i>High school (grade 9)</i> 4=High school (matric) 5=Diploma 6=University degree
208	Do you work?	1=yes, full time 2= yes, part time 3= <i>no, seeking work</i> 4=no, not seeking work
209	Where does your main source of income come from?	1=Regular income from working 2= Occasional income from working 3=Pension 4= <i>Child support grant</i> 5=Disability grant (for self) 6= <i>Disability grant (for child)</i> 7= Foster care grant 8= Maintenance grant 9=Income from husband 10= Income from other family members 11= Other _____ 12. No income
210	Approximate monthly income?	<i>R 1 850.00</i>
211	How many hours a day do you spend with the child?	1= <i>During the week?</i> _____ 2= <i>During the weekend?</i> _____ 3=none
212	How much of the time are you responsible for the child?	1= <i>all of the time</i> 2= During the day only 3= During the night only 4= Only some days
213	During a typical day, how much do you play with your child?	1= <i>During the week? 24/7</i> 2= <i>During the weekend? 24/7</i>

		3=None
214	Compared to other children is this a difficult child?	<i>1=Yes</i> 2=No
215	Is there someone you can trust to leave your child with when you are busy?	<i>1=Yes</i> 2=No
216	Who is this person?	1=My mother 2=my in-laws 3= my neighbour 4=my relatives 5=my friend <i>6=other(Sister)</i>
<b>Child's Characteristics and Disability Treatment</b>		
301	Child's date of birth (dd/mm/yy)	<i>21 March 2013</i>
302	Child's age	____ <i>3</i> ____ <i>4</i> ____ months
303	Child's sex	<i>1=Male</i> 2=Female
304	Type of Birth	1= <i>Singleton</i> 2=Twin 3=Triplet or more
305	Place of birth	<i>1= Hospital</i> 2= Clinic 3= Home 4= Other
306	Method of delivery	<i>1=Natural</i> 2= Caesarian section 3=Breech
307	Child's impairment (more than one can be circled)	<i>1=Moving and walking</i> <i>2=Talking</i> <i>3= Hearing</i> <i>4= Seeing</i> <i>5=Learning</i> <i>6=Behaviour</i> 7=Other _____
308	Gross Motor Function Classification System	1= Level 1 2=Level 2 3=Level 3 4=Level 4 <i>5=Level 5</i>
309	Was your child born with the disability or did he/she acquire the disability later on?	<i>1=congenital (at birth)</i> 2= acquired If acquired: Date:

		Reason:
310	How does your child mostly communicate?	1= Speaking 2= <i>Using gestures/ signs</i> 3= Facial expressions 4= <i>Crying</i> 5= Making sounds or noises 6= Does not communicate 7= Unknown
311	Do other people understand what your child is telling you?	1= <i>all the time</i> 2=some of the time 3=hardly at all 4=never
312	Does your child receive a care dependency grant?	1= <i>Yes</i> 2=No 3=Applied, still waiting 4=Child not eligible 5=Unknown 6=No, but does receive child support grant
313	Does your child currently attend therapy?	1= <i>Yes</i> 2=No
314	Where does your child receive therapy? (can circle more than one)	1=Hospital 2= <i>Clinic</i> 3=Home 4=Other _____
315	How often during the past 6 months has the child attended therapy?	1= More than 6 times 2= <i>6 times</i> 3= 4-5 times 4= 2-3 times 5=1-2 times 6= Not at all
316	How long have you been attending therapy?	1= 6 months or less 2= 7-12 months 3= 13- 24 months 5= <i>2- 4 years</i> 6= more than 5 years
317	How long does it take you to get to the clinic/ hospital from where you stay?	1= 30mins or less 2= 31-60mins 3= <i>1 hour- 2 hours</i> 4= more than 2 hours
318	How do you usually get to the clinic or hospital for therapy?	1= taxi 2=bus 3= <i>by foot</i> 4= by private car (It is your own car? Y / N) 5=other

319	Does your child attend school/ day care?	1=Yes 2= <i>No</i>
<b>Household Characteristics</b>		
401	Number of occupants in the house?	Children: <u>2</u> Adults: <u>2</u>
402	Total income of household per average month?	1= Less than R100 2= R100- R500 3=R500- R1000 4= <i>R1000-R3000</i> 5=R3000-R5000 6= More than R5000 7=Unknown
403	From where does the household earn income? (more than one option may be circled)	1= Regular income from working 2= Seasonal income from working 3= Occasional income from working 4= Pension 5= <i>Child support grant</i> 6= Disability grant (adult) 7= <i>Care dependency grant (child)</i> 8= Foster care grant 9= Maintenance grant 10= Other _____ 11= No income at all 12=Unknown
404	Construction material of main house walls?	<i>1= brick, cement blocks</i> 2= wood 3= informal/shack 4= mud 5= other
405	Construction materials of main houses roof?	1= Tiles, cement, bricks 2= <i>Corrugated iron, wood, asbestos</i> 3=Thatch 4=Informal/shack
406	Main water supply?	1= Tap in house 2= <i>Tap in yard</i> 3= Tap in street 4= Water truck 5= cement well 6= Traditional well 7= Open, unprotected (pond, river, dam) 8= Rainwater tank

407	In the household do you have a functioning: Stove If yes (gas, coal, electricity) Primus or paraffin stove Hot plate Fridge Microwave TV Hifi/stereo/tape/CD player Video Radio Phone (fixed) Cellphone Car/truck Bicycle Kariki cart/sled	<table style="width: 100%; border: none;"> <tr> <td style="width: 50%;"><i>1=yes</i></td> <td style="width: 50%;">2=no</td> </tr> <tr> <td><i>1=yes</i></td> <td>2=no</td> </tr> <tr> <td>1=yes</td> <td>2=no</td> </tr> <tr> <td><i>1=yes</i></td> <td>2=no</td> </tr> <tr> <td>1=yes</td> <td><i>2=no</i></td> </tr> <tr> <td>1=yes</td> <td><i>2=no</i></td> </tr> <tr> <td><i>1=yes</i></td> <td>2=no</td> </tr> <tr> <td>1=yes</td> <td><i>2=no</i></td> </tr> <tr> <td><i>1=yes</i></td> <td>2=no</td> </tr> <tr> <td>1=yes</td> <td><i>2=no</i></td> </tr> <tr> <td><i>1=yes</i></td> <td>2=no</td> </tr> <tr> <td>1=yes</td> <td><i>2=no</i></td> </tr> <tr> <td>1=yes</td> <td><i>2=no</i></td> </tr> </table>	<i>1=yes</i>	2=no	<i>1=yes</i>	2=no	1=yes	2=no	<i>1=yes</i>	2=no	1=yes	<i>2=no</i>	1=yes	<i>2=no</i>	<i>1=yes</i>	2=no	1=yes	<i>2=no</i>	<i>1=yes</i>	2=no	1=yes	<i>2=no</i>	<i>1=yes</i>	2=no	1=yes	<i>2=no</i>	1=yes	<i>2=no</i>
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1=yes	<i>2=no</i>																											
<b>Judgment form Interviewer</b>																												
501	In your opinion is the information accurate?	1= <i>Good</i> 2=Fair 3=Poor																										
502	Any other information on the child or family that you would like to add?																											

Appendix 7, Figure B

*Clinical Outcomes in Routine Evaluation- Outcome Measure (CORE-OM)*

CORE-OM							
Unathi							
		Well-being	Problems	Functioning	Risk	All Items	All Items Minus Risk
Data Collection 1	Total Score						
	Mean Score						
	Clinical Score						
Data Collection 2	Total Score	2	18	17	1	<b>38</b>	37
	Mean Score	0,5	1,5	1,42	0,17	<b>1,12</b>	1,32
	Clinical Score	5	15	14,2	17	<b>11,2</b>	13,2
Data Collection 3	Total Score	4	17	18	0	<b>39</b>	39
	Mean Score	1	1,42	1,5	0	<b>1,15</b>	1,39
	Clinical Score	10	14,2	15	0	<b>11,5</b>	13,9

Appendix 7, Figure C

*Paediatric Evaluation of Disability Inventory- Computer Adaptive Test (PEDI-CAT)*

PEDI-CAT Scores Mandla			
	Baseline Collection 1 Scores	Baseline Collection 2 Scores	Post Collection 3 Scores
Daily Activities		37	35
Mobility		54	35
Social/Cognitive		50	44
Responsibility		34	29

Appendix 7, Figure D  
*Emotional Interaction Style (EIS)*

EIS- Assessment of MIM Unathi and Mandla				
		Baseline Collection 1 Score	Baseline Collection 2 Score	Post Collection 3 Score
Structure and Challenge	1. Parents comprehensive ability to structure the situation relative to the child's developmental level		3	4
	2. Child's general cooperation and ability to focus on the situation		2	2,5
Emotional Reciprocity and Initiative	3. Parent's emotional reciprocity and initiative		3,5	4
	4. Child's emotional reciprocity and initiative		2,5	3
Nurture	5. Parental Nurture		3,5	4
	6. Child's response to nurture		4	4
Playfulness	7. Parent's playfulness		2	3
	8. Child's playfulness		1,5	1,5
Representation	9. Representation of the child		2	2
Overall Score			<b>24</b>	<b>26</b>

Appendix 7, Figure E  
*Measure of Process of Care- 8 South Africa (MPOC-8 SA)*

	MPOC-8 SA Unathi		
	Baseline Data Collection 1	Baseline Data Collection 2	Post Data Collection 3
Score		34	27
Percentage		60,71%	48,21%

## *Section 2: Marschak Interaction Method Clinical Reports*

### **Marschak Interaction Method Clinical Report Unathi and Mandla**

#### **Information**

**Child:** Mandla

**Date of Birth:** 21/03/2013

**Age:** 3 years 5 months

**Caregiver:** Unathi

**Date of MIM:** July 2016

#### **Background Information**

C was born on the 21<sup>st</sup> of March 2013. He is currently 3 years old. He was born as a full term baby weighing 3,5 kg by emergency caesarean section. He was not well after his birth and was sent to a neonatal intensive care unit in Port Elizabeth where he remained for three months.

C was referred to the Grahamstown Developmental Clinic from Queenstown in October 2015. His family has since relocated from [Name] town to {Name} town in order to enable them to attend the Developmental Clinic on a more regular basis. C has a form of undiagnosed cerebral palsy that results in him having increased tone/spasticity in his legs, low muscle tone in his trunk, and fluctuating low and high muscle tone in his arms. C also has cortical blindness caused by damage to the occipital cortex in his brain. This form of blindness is irreversible. Due to his disabilities, C is very much immobile- he is unable to track, roll, sit, vocalise, or reach for objects. He has a Madiba Buggy, which is an off-road wheelchair postural supportive device.

#### **Assessment Instrument**

**MIM Tasks:** The following is a list of seven tasks that C and M were asked to engage in together: The task instructions were delivered by the research assistant through a microphone in C and M's first language, isiXhosa.

1. Use the toys on the table and make a game with them.
2. Play a familiar game that you would normally play at home.
3. Tell your child a story about when he was younger.
4. Feed your child something that you think he would like on the table.
5. Wipe his mouth and hands and then put cream on him.
6. Leave your child alone in the room for 1 minute.
7. Sing your child a lullaby/song.

### **Data Collection 2**

#### **Observations**

##### **Task Observations:**

*New game:* Unathi places Mandla into position in quite a rough manner by picking Mandla up by one arm, pulling and pushing him, and roughly adjusting his clothes- she does not vocalise with him at this time or make eye contact. She then begins the task by choosing a rattle to play with Mandla. She crouches close to him making eye contact and talking softly to him, saying, "let's play". Unathi shakes the rattles very

close to Mandla's face and Mandla seems to blink quite rapidly and looks in the direction of the different rattles, responding to the sound. Unathi laughs at this and encourages Mandla to hold the rattles by placing them in his hands. When Mandla is holding the rattles Unathi acknowledges it briefly by saying "Baba is playing now, he's playing". She then turns her attention to getting Mandla to relax his legs by quickly massaging his knees to make them straight. When they are straight Mandla seems to go into a flexor pattern and drops the rattles which may have been caused by the knees being pushed down too quickly. M ignores this and returns to trying to get Mandla to play with the rattles but when Mandla no longer seems to respond to the rattle Unathi quickly turns the attention to a toy car- driving it along Mandla's chest and making car sounds. When Mandla does not seem to respond to this she quickly turns back to using a rattle, and then again changes the game shortly after that to play with a ball. She seems to give very brief and non-descriptive instructions like; "let's play", "take this one", "let's take the car", and "play" rather than engaging with Mandla and explaining what they are doing and praising him.

*Familiar game:* Unathi lifts Mandla onto her lap in quite a disorganised manner with his head flopping back. Unathi places Mandla on her lap facing away from her and takes the ball once again to play with him. She tries to get him to take the ball but when he doesn't respond she shifts her attention to trying to get him to relax and open his legs by pulling them apart and saying "open your legs" and "relax your legs". In the process of doing this Mandla's upper body is pushed back behind her arm in what looks to be a very uncomfortable position. She finally realises and laughs at this and then repositions him quite roughly and begins to bounce the ball saying, "let's play some ball". Unathi watches Mandla's face to see his responses to the ball as she bounces it. When Mandla doesn't seem to respond she tries a series of different activities with the ball- placing the ball in his hands to try and get him to hold it, squeaking it in front of his face, and bouncing the ball on Mandla's forehead. When Mandla doesn't seem to respond to any of this Unathi seems to get despondent and puts the ball away sighing and saying "Don't you want to play? Let's sing then". Unathi sings very softly to Mandla and tries to get him to open his hands to clap them and encourages him by saying "come let's sing". Unathi pulls Mandla into her quite hard to get his attention and he looks at her making eye contact but then looks away again. Unathi again gets despondent again saying "don't you want to play?" and then looking away and taking her hands away from him.

*Story:* Unathi told Mandla a very brief story. Unathi cradled Mandla in her arms and tells him "I'm gonna tell you a story". She looks at his face and starts to tell him about when he was a baby. The story seems to focus on Mandla's negative aspects, she says, "you used to cry a lot...when you took a bath you would cry a lot and we would fight... when eating you'd cry... when brushing your teeth you cried... you liked crying, you still like crying". While telling the story she holds Mandla's hand rubbing it and shaking it up and down, she also squeezes his cheeks together and points to his mouth. During the story Unathi tends to laugh a little while telling it and when Mandla seems to smile, Unathi laughs and smiles back at him. Towards the end of the story Unathi says to Mandla that he is "much better now" laughing and speaking about things he like "you would cry but when I fed you yoghurt you would not cry" and "one thing you liked was being sang to". Unathi seems to be very desperate to get Mandla's attention and when he looks away for a long time she pulls him in closer to her, and even tries to forcefully turn his head to look at her.

*Feed:* Unathi engages with Mandla telling him that he is going to eat now and explaining that she has chosen the yoghurt and asking “you like eating yoghurt?” Unathi continues to gently talk to C throughout the feeding task, telling him when to open up his mouth and praising him on how well he is eating saying, “*wow this baby is eating... he’s eating so well...good boy*”. She also refers to Mandla as “*mommy’s baby*” and “*mommy’s C(name)*” during this time rather than just by his name as was previously done. They both seem to enjoy this task; Unathi takes her time and gladly chats to Mandla throughout and Mandla enjoys the food.

*Lotion:* Unathi continues to cradle Mandla in her lap. She takes a little lotion and rubs it in her hands before rubbing it onto Mandla’s face. She does this quite quickly and without much thought. She softly talks to Manda throughout the process and tells him “Wow...he looks so handsome.” She then quickly rubs some lotion onto each of his hands. Mandla makes a burping sound and Unathi reacts by saying, “Wow he’s burping now, this is a big boy, he burps”. She then lays him down on the ground next to her.

*Leave the room:* Unathi gets onto her knees and looks at Mandla, making sure he is comfortable and telling him “*I’m leaving you now right*” before she gets up and leaves the room. Once left alone Mandla seems to just lie where he is left quite comfortably, letting out a sigh. When M returns she goes straight to Mandla saying, “*Hello, what are you doing?*” and checks on him. Unathi seems to find something Mandla’s his face that she tries to remove. Mandla seems to find this ticklish and smiles and Unathi smiles back and continues to tickle him with her finger after which she holds his hand and shakes it while whispering to him.

*Sing:* Unathi lifts Mandla up into her arms with his head on her shoulder and his face looking at hers. She then sings to him “*quiet, quiet baby mom is coming*” repetitively while patting him on the back and looking at him. Mandla seems to enjoy it and looks very relaxed.

### **Domain Observations:**

*Structure:* In the earlier tasks Unathi really struggled to structure activities and carry them out in a cohesive manner. Instead, she would become frustrated easily and change up the task at hand in quick succession as her focus shifted which created a somewhat disorganised interaction with Mandla becoming despondent. Often the tasks that she requested were also beyond Mandla’s abilities and there was a notable lack of rewarding success for slight gains. However, when it came to later tasks that M seemed more comfortable with, such as feeding, she was able to provide a good amount of structure that resulted in a trustworthy and predictable atmosphere for Mandla to enjoy himself.

*Engagement:* Unathi seemed to struggle to engage with Mandla at times possibly due to his severe disabilities. She came across as quite quiet and reserved and struggled at times to verbalize excitement, surprise or praise. She attempted to make eye contact with Mandla but would exhibit signs of frustration when he did not reciprocate: calling his name repeatedly, pulling him into her quite hard to try and get him to look at her, and at times giving up on a task with an exhibited sigh of frustration. When Mandla did reciprocate, either positively by smiling or negatively by blinking a lot

with the rattle, Unathi would give the same response by laughing and smiling at him not necessarily taking into account his possible aversion for the activity. Her physical engagement with him was also quite rough at times and unsynchronized making their interaction look quite uncomfortable. When Unathi did a familiar task such as feeding Mandla she seemed to be more comfortable and engaged with Mandla in a more positively attuned manner with excitement and praise.

*Nurture:* Unathi actively offered nurturing towards Mandla and constantly looked after his needs by adjusting his clothes and position, and openly speaking to him throughout their interaction. She seemed to be very comfortable in tasks that involved daily nurturing activities such as feeding Mandla. However, at times she was quite rough and hurried in her nurturing towards him and seemed uncomfortable with holding him and moving him. In the absence task Unathi briefly prepared Mandla for her leaving the room by making sure he was comfortable and telling him of her intentions. On her return she was able to go straight to Mandla and check on him.

*Challenge:* Unathi seemed to be aware of Mandla's developmental abilities and could appropriately challenge Mandla in the given tasks. She focused on trying to get him to hold objects and relax his stiff muscles. However, her instructions were quite brief and repetitive and her ability to praise Mandla when he achieved these goals even slightly was somewhat absent at times as she only acknowledged them and did not necessarily praise them. When Mandla had already fully mastered a task such as self-swallowing in the feeding task she praised him highly for this. Unathi seemed to get a little frustrated with Mandla when he would not engage with her when she challenged him which resulted in her giving up on the task at hand.

### **Summary**

Overall, Unathi came across as quite a quiet and reserved carer that struggled to openly engage with Mandla emotionally. Unathi seemed to battle with certain tasks, particularly the free play tasks, but she seemed more comfortable in the daily nurturance tasks such a feeding which may be a result of how often she engages with Mandla in these different tasks. When Unathi wasn't able to engage Mandla she became quite frustrated and discouraged to continue with the task, thus she was not encouraging towards Mandla and offered very little praise. Unathi also seemed to rush through activities at times when she felt uncomfortable. This may be due to a lack in self-esteem regarding her parenting abilities, particularly seen in her abilities outside of her comfort.

## **Data Collection 3**

### **Observations**

#### **Task Observations:**

*New game:* Unathi places Mandla on the floor in front of her and supports him with one hand while she selects appropriate toys for him with the other hand. She chooses toys that make a sound, particularly a rattle and a squeaky ball. She then sits back and positions Mandla on her lap comfortably, cradling his head in her arm and adjusting his legs and his clothes. Unathi then waves the rattle close to Mandla's face trying to get him to look from side to side. She softly talks to him saying, "Take it boy. Here you go boy. Take it boy" repetitively and calling his nickname to get his attention. She moves the rattle from side to side watching where he is looking. When he doesn't respond as much as she expects Unathi readjusts him, straightening his clothes and

tries the ball, squeaking it on either side of his face saying “what do you want to play with?” She then places the rattle in his hand saying “here take this one, don’t you want to take this one? You don’t want to play” and holds the rattle there shaking his hand for him to rattle. She moves the rattle closer to her in his hand and calls his name to which Mandla responds by looking at her directly. Unathi smiles and laughs gently. She then attempts to use the ball again squeaking it. She adjusts the hand with the rattle in and then let’s go of it for Mandla to hold it by himself. His hand drops down. She squeaks the ball on either side of his head watching for his reaction and leaning in to see if he looks at it but he doesn’t. Unathi drops the ball again and uses the rattle once again in the same manner. When he doesn’t respond she starts stroking his cheek with the rattle and Mandla looks at her again. Unathi smiles and laughs at him continuing to stroke his cheek until he looks away.

*Familiar game:* Unathi adjusts her position, placing Mandla on a heaped blanket with his head raised slightly. She then asks him “do you want to play” and kneels over him and begins stretching his legs encouraging him by continually saying “stretch your legs, stretch your legs” in a soft but playful tone while watching his facial reactions. She stretches his legs in and out and when he relaxes and stretches, she offers praise saying, “the baby is stretching, there you go”. She can tell this is somewhat uncomfortable for him and he groans so she says “one more time” and stretches him again. She then moves toward his arms explaining that he needs to stretch his arms now. She continues to kneel over him, watching his expression with keen eye contact and talking to him while she massages his arms. She also monitors the rest of his body and adjusts his legs straight when they flop to the side. She praises him and rubs his back when he stretches well. Unathi then rubs his body which Mandla seems to find ticklish. She laughs with him, smiling. Mandla then seems to cough up some phlegm so Unathi gets up to get a cloth to clean his mouth and clothes.

*Story:* Unathi repositions Mandla on her lap and cradles him in her arms comfortably. She again wipes his face to make sure it is all clean. She looks intently at him while she cradles him and strokes his face and tells him about when he was a baby and all the things he didn’t like to do like bathing or eating. She holds his hand and looks deeply at him while telling the story and then she takes his hand and strokes his face while speaking to him. She reminisces how he only wanted her when he was a baby and how only she could get him to eat or sleep and he only wanted to sleep in her arms saying “You didn’t even like sleeping but your mommy would make you sleep. You didn’t want anyone else, you just wanted your mommy”. She then tells him how he has grown up now and now he doesn’t mind anyone holding him. Mandla seems very relaxed and almost sleepy watching Unathi speak and resting against her.

*Feed:* Unathi repositions Mandla to a more seated position and looks at him and asks him “What do you want to eat. You don’t want something to drink?”. She then selects a yoghurt and easily opens it and begins feeding him in a well practiced manner. She softly speaks to him and cradles him throughout the feeding process. She tells him when to open his mouth and spoons it in gently, cleaning any spillage and making sure he gets everything in. Mandla seems to enjoy it. She encourages him saying “come on eat my boy” and praises him by saying “oh my baby is eating!”. She continually chats throughout the process and watches him intently.

*Lotion:* Unathi takes a wipe and folds it to gently clean around Mandla's mouth and nose. She then wipes her hands and his hands too. She then puts cream on her hands rubbing them together to warm it up. She then rubs it on his face and hands. Throughout the process, she explains to Mandla what she is doing and where she is putting the cream- speaking very softly to him and looking at him.

*Leave the room:* Unathi uses the bean-bag and a blanket to make a soft bed for Mandla to lie on. She positions him on it comfortably, facing towards the door and wipes his face, gently patting him before she leaves. Upon re-entering the room Unathi places her phone on the table and walks around Mandla. She then leans over him with her face close to his and picks him up smiling and saying "Who are you with in here? Are you by yourself boy?" and chatting to him, smiling and laughing. Mandla smiles a big smile at her while she lifts him up into her arms and then sits and positions him in her lap, adjusting his clothes and making sure he is comfortable. She then reaches for the blanket and says "let me cover you with a blanket, are you covered?" and questions "are you cold boy?" checking that he is positioned well in her arms and ensuring that he is comfortable.

*Sing:* Unathi tells Mandla "Ok so you will sleep now, its nap time now" and she looks at his face and begins singing while cradling him and rhythmically patting his back. Mandla seems to relax and his eyes grow heavy wanting to sleep. While she is singing Unathi looks at Mandla's body and repositions him slightly to make sure he is comfortable, pulling him closer to her and resting his head on her chest while she hugs him with both hands. Unathi snuggles her face close to Mandla touching his cheek with hers. She then goes back to looking at him and sways from side to side still singing and rhythmically patting his back. She then wipes his ear and strokes his cheeks while watching him. Mandla looks to have fallen asleep. Unathi keeps singing and patting his back.

**Domain Observations:**

*Structure:* Unathi provided Mandla with a moderate amount of structure. She took charge of the activities and provided a consistently safe a predictable environment for him. At times Unathi was not very vocal towards Mandla about the activities and could have offered more directions and commentary to involve him, provide an understanding and further co-regulate his experiences. However, Mandla exhibited a good level of physical and emotional security, accepting the structure and exhibiting a comfortable relationship.

*Engagement:* Unathi was extremely soothing and calming towards Mandla which seemed to be an appropriate way of interacting with him. However, Mandla didn't respond to all of the cues Unathi used in attempt to engage him and she seemed to get a little disheartened by this. She could have possibly been a little more encouraging, enthusiastic and playful at times to draw him into the interaction a little more.

*Nurture:* Unathi was very nurturing towards Mandla. She was warm, soothing, and very comforting towards him and she was very attuned to his needs. Unathi seemed very comfortable holding and, cuddling and feeding Mandla. She made an effort to keep him warm, clean and in a comfortable position throughout the tasks.

*Challenge:* Unathi seemed to be aware of Mandla's developmental level and disabilities. She attempted to challenge him by getting him to hold the toy and by practicing therapeutic stretches that he found to be difficult. When approaching these tasks she did so with little enthusiasm or playfulness and struggled to engage Mandla, however, she was acknowledging of him when he was able to reciprocate.

**Summary**

Overall, Unathi provided a safe, comfortable and soothing environment for Mandla catering to all of his needs and truly caring for him. She was very nurturing towards Mandla and provided him with a good amount of structure in the tasks. However, Unathi came across as very soft spoken and quiet which resulted in her struggling to engage Mandla and challenge him in an encouraging and playful manner.

*Section 3: Interpretative Phenomenological Analysis (IPA) Theme Tables*

Appendix 7, Figure F  
*Emerging Themes and Sub-Themes for Baseline Data Collection*

<b>Theme</b>	<b>Subordinate Theme</b>
Growth with Limitations	Growing Fine Limited abilities Functional Improvements
Clinic	Helpful Enjoy being there Encouraging
Caregiver well-being	Acceptance- "I am fine but I was not fine." Worry for illness No time to self Happy seeing child accepted by others
Good Relationship	"We get along well all the time" Enjoy spending time together Pride in parenting

Appendix 7, Figure G  
*Emerging Themes and Sub-Themes for the Post Intervention Data Collection*

<b>Theme</b>	<b>Subordinate Themes</b>
Development	Physical Growth Improvements “He is happy” Hard knowing he cannot do anything
Well-being	Worries about children’s health “Sometimes I just feel sad” “I am fine now” Life changing responsibility
Service-learning programme was nice	Accepted by others Gave her a rest Empowering- “I taught them”
Developmental Clinic- a lifeline	Improvements attributed to Developmental Clinic Helpful learning experience Support of other parents
Relationship	Happiness together Knowing each other
Support	Talking to a friend Talking to self

Appendix 7, Figure H  
*Themes Relating to Caregiver Well-being*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
Acceptance- “I am fine but I wasn’t fine”	“I am fine now”
Worry for illness	Child makes her happy
No time to self	Life changing responsibility
Happy seeing children accepted by others	“Sometimes I just feel sad”
	Worries about health

Appendix 7, Figure I  
*Themes Relating to Child’s Functional Abilities*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
Growing fine	Improvements
Limited abilities	Limited abilities
No time to self	He is happy
Functional improvements	

Appendix 7, Figure J  
*Themes Relating to Caregiver-Child Relationship*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
We get along well	Happiness together
Enjoyment in spending time together	Knowing each other
Proud to be his parent	

Appendix 7, Figure K  
*Themes Relating to Experience of Care*

<b>Baseline Collection Themes</b>	<b>Post Intervention Collection Themes</b>
Clinic helpful	Service-learning programme as nice
Enjoy being there	Accepted by others
Encouraging	Gave her a rest
	Empowering
	Improvements attributed to Clinic
	Helpful learning experience
	Support of other parents