

OCCUPATIONAL THERAPY FOR CHILDREN WITH  
SEVERE CEREBRAL PALSY IN GOVERNMENT  
HEALTHCARE FACILITIES IN THE WESTERN CAPE:  
AN OVERVIEW OF CURRENT SERVICES

By

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## DECLARATION

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Signed by candidate

Lauren Fuller

26 January 2021

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## ABSTRACT

**Background:** There is a high worldwide prevalence of cerebral palsy, a neurological condition which impacts most areas of life of children and their families. Evidence shows that occupational therapy is effective in enhancing the child's function, participation and quality of life, especially when provided at a young age and with high intensity. Literature provides additional recommendations for occupational therapy to follow a holistic and family-centred approach, considering participation in context, rather than an individual medical focus. These notions place pressure on the strained South African healthcare system, where human and physical resources, as well as contextually-relevant evidence for practice, are limited. The aim of this research was, therefore, to obtain a baseline description of the occupational therapy services being provided to children with severe cerebral palsy, across all government healthcare facilities of the Western Cape province.

**Methods:** A quantitative, cross-sectional descriptive study was conducted, using a self-designed questionnaire. The questionnaire was developed using recognised survey principles in order to maintain research rigour, reliability and validity of results, and guidelines from previous studies of a similar nature. The questionnaire was available to participants in duplicate online and hard copy formats. The anonymous, self-report questionnaire obtained profiles of the participating occupational therapists and their departments, descriptions of current service provision (assessments, goal-setting and interventions), perceived factors influencing service selection, and an understanding of services therapists felt they should be providing more of. No sampling took place and responses were invited from all occupational therapists employed by the provincial health department. All recruitment and correspondence took place via email or telephone. Recruitment and data collection took place over a period of 16 weeks, with each participant having a maximum of two weeks to submit their responses, after which a maximum of three reminders were sent. Numerical data were analysed using non-parametric descriptive statistics and categorical data were presented in terms of frequencies and percentages. Ethical principles adhered to included respect, confidentiality, anonymity, beneficence, non-maleficence and justice.

**Results:** There was a response rate of 53%, with all provincial health districts and levels of care represented amongst participants. Assessments frequently involved observations of the child

in activities (85%) and interviews with their caregiver (98%). Goals formulated, with some input of caregivers, related to occupational performance components (91%) more often than occupational performance (77%), and largely aimed to maintain the child's condition (68%), rather than improve development or functional participation (47%). A range of interventions were provided, but appointments were infrequent (median: 1 per month), mainly took place in clinical environments (100%), and waiting periods for assistive devices and orthotics were common. Opportunities for direct therapy and interventions in the child's daily context were limited, and home programmes and caregiver education were heavily relied upon indirect intervention methods, frequently implemented by 100% and 91% of participants respectively. Key factors influencing the selection of services included resource availability (62%), therapists' training (62%) and the level of care at which they worked (59%). Therapists felt they were meeting some of the children's needs, and required the support of the multidisciplinary team to meet more of their needs effectively.

**Conclusion:** This study provides insight into occupational therapists' roles in the government healthcare sector in the Western Cape province, and highlights the degree of alignment of services with policy and elements of best practice. Some merits are clear, in terms of the combination of direct and indirect services provided and the involvement of families in therapy processes. However, there remains a shortfall in terms of effective holistic, evidence-based, family-centred, and early and intensive approaches. This study, therefore prompts revision of strategies to implement existing policies promoting quality services for people with disabilities and align occupational therapists' training with evidence-based practice and holistic frameworks and approaches. Further research is recommended, particularly a qualitative consideration of the contextual factors influencing service provision, in order to better understand and address the barriers to meaningful and effective services for this population within the context of Primary Healthcare. With these recommendations, quality service provision, leading to participation and quality of life outcomes for children with severe cerebral palsy and their families, may be enhanced.

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## DEFINITIONS OF TERMS

### **Assistive device (AD)**

Any items or products that increase functional independence in mobility or any other daily activity (Zupan & Jenko, 2012).

### **Cerebral palsy (CP)**

A lifelong non-progressive movement disorder, resulting from abnormal brain development or injury to the brain prenatally or during early childhood, which leads to limitations in activity and function (Goldstein, Rosenbaum, & Leviton, 2005). For the purpose of this study, **severe cerebral palsy** refers to an extent of cerebral palsy where impairments are classified on Level IV and V of the Gross Motor Function Classification Scale. Individuals require maximal assistance in aspects of daily life and functioning (Palisano, Rosenbaum, Bartlett, & Livingston, 2008; Towsley, Shevell, & Dagenais, 2011).

### **Child/children**

For the purpose of this study, children are considered to be individuals 0 – 12 years old.

### **Family-centred approach**

An approach to service that facilitates improved functional goal-setting unique to families, through collaborative decision-making and co-ordination of interventions, involving the child, their caregivers and families (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2010).

### **Health districts**

Geographically demarcated regions which prescribe drainage areas to healthcare services and ensure distribution and accessibility of priority and financially viable services across the province (Coetzee, 2018; Department of Health, 2017; Kautzky & Tollman, 2008).

### **Intervention**

The implementation of planned activities by occupational therapists, with the goal of achieving outcomes related to occupational performance and participation of individuals or groups. This may include **actions** that are direct treatments with the individual to remediate function or enhance health, or **indirect** actions, which alter or adapt their environments to make way for improved performance and participation (Bass, Baum, & Christiansen, 2017).

### **Levels of care**

Within the primary healthcare approach, services vary according to location and types of facility in order to improve accessibility of appropriate services to communities. These include primary level services (community services, healthcare clinics, community health centres and district hospitals), secondary level services (at secondary or regional hospitals) and tertiary level services (at tertiary, provincial, national hospitals and specialist facilities) (Coetzee, 2018; Cullinan, 2006).

### **Models of disability**

Sets of assumptions and ontologies that frame understandings and approaches to disability matters. Examples are the medical and social models (Kielhofner, 2009; Marks, 1999).

### **Occupational participation**

Engagement, including thinking, doing and feeling, in activities that are desired and/or contribute to one's wellbeing (Kielhofner, 2009).

### **Occupational performance**

The act of 'doing,' brought about by engaging the individual's underlying performance components within a specific context (Baum & Law, 1997; Law et al., 1990).

### **Occupational performance area**

Groupings of activities or occupations of a similar nature or purpose. Recognised occupational performance areas include leisure or play, self-care or activities of daily living, and work or productive activities (Baum & Law, 1997; Law et al., 1990).

### **Occupational performance components**

Underlying skills and abilities that contribute to an individual's occupational performance, including physical, cognitive, sensory and emotional elements (Baum & Law, 1997; Law et al., 1990).

### **Occupational therapy models of practice**

Proposed structures of evidence-based concepts, principles and systems, which act as frameworks for occupational therapists' thinking and acting (Kielhofner, 2009; Pendleton & Schultz-Krohn, 2017).

### **Primary Healthcare (PHC)**

The approach to healthcare adopted in South Africa, aiming towards equitable and just societal well-being through addressing individual needs together with the broader determinants of health in a comprehensive manner. Services include health promotion and prevention, treatment, rehabilitation and palliative care, encouraging inter-sectoral collaboration, community participation and appropriate technology (Coetzee, 2018).

### **Services**

Any significant interaction, procedure or process in which the occupational therapist is involved in the management of the child with cerebral palsy. Specifically, for this study, this refers to the actions taken to complete the main steps in the Occupational Therapy process, which involves establishing needs through holistic assessments, setting goals for therapy, and interventions to enhance participation (Bass et al., 2017; Baum & Law, 1997; Pendleton & Schultz-Krohn, 2017).

## ABBREVIATIONS

AD	Assistive Device
CIMT	Constraint-induced Movement Therapy
CP	Cerebral Palsy
DoH	Department of Health
FSDR	Framework and Strategy for Disability and Rehabilitation
GMFCS	Gross Motor Functioning Classification System
HREC	Human Research Ethics Committee
ICF	International Classification of Functioning, Disability and Health
LMIC	Low- to middle-income countries
MAES	Movement Analysis Education Strategies
NDT	Neurodevelopmental Therapy
NHRD	National Health Research Database
NRP	National Rehabilitation Policy
PHC	Primary Healthcare
QoL	Quality of Life
SA	South Africa

# CHAPTER 1: INTRODUCTION

## 1.1. INTRODUCTION

This chapter positions the study, through describing disability and healthcare, particularly for children with severe cerebral palsy (CP), in the Western Cape province of South Africa (SA). The chapter concludes with the research purpose, question, aim and objectives.

## 1.2. CONTEXT OF THE STUDY: DISABILITY AND HEALTHCARE IN SOUTH AFRICA

SA has a longstanding history of societal division, marked by variances in lived experiences and service availability across population groups and regions. Division has been observable according to, amongst others, racial, gender, religious, sexuality and disability groupings (National Planning Commission, 2011). Politically, most attention has been on correcting racial inequalities post-Apartheid. While this remains important, minority groups, such as people with disabilities, appear to be on the fringes of priority plans (Price, 2016). It is estimated that 7.5 percent of the population have disabilities - a significant figure when considered in light of their exclusionary experiences (Statistics South Africa, 2014).

Segregation of people with disabilities historically involved long-term institutionalisation, little contact with families and culture, and lack of opportunities for integration or autonomy (Horsman, Suto, Dudgeon, & Harris, 2010; Meekosha, 2011). Echoes of this historical status quo are evident when disability matters are not prioritised in governmental agendas and service provision. Disabled children globally continue to experience marginalisation, discrimination, negative stigma and isolation (United Nations General Assembly, 2007; Banks, 2018). This exclusion, together with the functional limitations resulting from their impairments, amounts to significant participation challenges and effects on quality of life (QoL), for children and their families (Annamma, Connor, & Ferri, 2013; Ben-Moshe & Magana, 2014; Burch & Patterson, 2013; Pal, 2011).

These ongoing challenges may partly result from discrepancies in the frameworks considered when defining disability. While other models of disability exist, the medical and social models are best known (Marks, 1999). The medical model highlights that participation challenges are inherent and related directly to the bodily impairments of the individual. The social model

recognises these impairments, but emphasises the barriers that one's context imposes on participation (Albert, 2004; Thomas, 2002). These foundational ontologies, therefore, oppose one another. A lack of uniformity and integration of these models, in terms of needs and priorities, appears to remain within government departments, resulting in varying approaches to service provision, in terms of sector involvement and resource allocation (Albert, 2004; Marks, 1999).

Most of the South African population relies on the government healthcare sector (Levin, 2006) which is based on a Primary Healthcare (PHC) approach. With this approach, improving the accessibility and affordability of appropriate quality healthcare services is prioritised. The service level model is utilised, involving primary, secondary and tertiary level facilities, to facilitate access and streamline referrals (Coetzee, 2018; Cullinan, 2006; Kautzky & Tollman, 2008).

The South African government has been pressured to take action on disability matters in order to better reflect an equitable and inclusive nation. The South African Bill of Rights (1996) speaks to the requirement for people with disabilities to have equal access to healthcare and social development resources, aligning with the United Nations Convention of the Rights of People with Disabilities (United Nations General Assembly, 2007). Inclusion and service provision have been addressed through efforts of individuals, organisations and policy developments (Department of Health, 2015; World Health Organization, 2011). The development of policies, such as the Integrated National Disability Strategy (Department of Health, 1997), National Rehabilitation Policy (NRP) (Department of Health, 2000) and the Framework and Strategy for Disability and Rehabilitation (FSDR) in SA (Department of Health, 2015) are valuable in relation to health and rehabilitation services for disabled groups.

However, little traction has been gained to sustainably mobilise quality disability service provision in particular (Department of Health, 2015; Kautzky & Tollman, 2008). Practically, there are limited guidelines regarding management of specific disabilities within healthcare institutions, creating inconsistencies in approaches (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014). Limited resources and experienced health professionals, in combination with the high prevalence of disability and long-term therapy needs of these individuals, explain the inadequate availability of holistic multidisciplinary services, especially in rural areas (Levin,

2006). Permanent positions, where therapists can grow their skills and build effective departments, are ideal, and where this is lacking, the sustainability and trust towards therapy services amongst communities is challenging (Levin, 2006). Physiotherapy appears to be the most available, while occupational and speech therapy and orthopaedic support is limited (Burton, 2015; Donald et al., 2015; Donald et al., 2014; Jesus, Landry, Dussault, & Fronteira, 2017). Thus, while there are developments towards inclusion and improving healthcare, the availability and quality of therapy services for vulnerable groups of people with disabilities may still be inconsistent and of concern.

### **1.3. BACKGROUND TO THE STUDY**

CP is a prevalent childhood disorder, which significantly impacts the individual and their family's QoL (Levin, 2006; World Health Organization, 2011). Evidence shows that allied health, and specifically occupational therapy, is beneficial to individuals with CP, with best outcomes shown when intervention is provided early, in a holistic and family-centred manner (Darrah et al., 2010; Majnemer et al., 2013; Palisano et al., 2012; Saleh et al., 2008). Without opportunities for therapy, children may not reach their functional potential and develop secondary complications. These conditions together result in high levels of dependence, societal exclusion and reliance on long-term healthcare (Bantjes, Swartz, Conchar, & Derman, 2015; Dodd, Imms, & Taylor, 2010a; Saleh et al., 2008).

### **1.4. RESEARCH PROBLEM**

There appears to be a challenge within the South African context for children with disabilities to receive appropriate early, and ongoing, therapy. With most of the population relies on public healthcare services, specific concerns relate to those in rural communities, where access is largely limited to primary level facilities (Department of Health, 2017; Kautzky & Tollman, 2008).

With their high long-term therapy needs, attention and resources for children with severe CP are lacking despite the existence of valuable disability policies. There appears to be a discrepancy between policy, academic evidence for good therapeutic practice, and service implementation (Coetzee, 2018; Cullinan, 2006; Pretorius & Steadman, 2017). While the International Classification of Functioning, Disability and Health (ICF) and occupational therapy

models prescribe contextualised services, most services take place in clinical settings and are focused on body functions and structure rather than overall participation (Kruijssen-Terpstra, Ellens, et al., 2016; Peer & Pollard, 2012; Saloojee, Rosenbaum, & Stewart, 2011).

There are, therefore, concerns that resource allocation, therapy protocols and practice are not aligning adequately with children's holistic needs and priorities reflected in policies and frameworks; calling for investigation and attention.

## **1.5. RATIONALE**

This research was an initial step towards discovering how to better improve function, participation and QoL of children and their families, and thus decrease the burden on healthcare systems. Since there is no local literature regarding best practice and current practice, this study was valuable in uncovering a baseline description of current occupational therapy services for this population, as well as factors influencing the selection of services. The research thus illuminates merits and needs within current services, and contributes towards reflection on the application of therapy and policies with this population.

## **1.6. PURPOSE OF RESEARCH**

The purpose of the study was to describe services, and the factors influencing the selection thereof. This insight may prompt revision of intervention programmes and resource allocation at various service levels and locations. Additionally, initial recommendations could be made regarding training of therapists and revision of policies and implementation strategies. Long-term, this may positively impact the function, participation and QoL of these children and their families as well as the strain on the healthcare system, through more efficient and meaningful service delivery.

## **1.7. RESEARCH QUESTION**

What occupational therapy services are being provided to children with severe CP across government healthcare facilities in the Western Cape?

## **1.8. AIM**

To describe the occupational therapy services being provided to children with severe CP, across all government healthcare facilities in the Western Cape.

## **1.9. OBJECTIVES**

- To determine basic profiles and distribution of occupational therapists within government healthcare facilities (geographically and across levels of care).
- To describe the types and frequency of occupational therapy services being provided to children with severe CP.
- To identify factors influencing occupational therapists' service selection for children with severe CP.
- To identify additional services occupational therapists feel they should be providing to children with severe CP.

## **1.10. SUMMARY**

People with disabilities remain excluded from societal participation. Their position on the fringes of society is perpetuated by the strained government healthcare system struggling to provide ongoing intensive therapeutic services, particularly required by those with severe conditions, such as children with severe CP. While occupational therapy has the potential to improve their function, participation and inclusion, the reality of insufficient quality services poses negative implications for the QoL of these children and their families. Local research into service provision for this vulnerable group is limited. This study thus aims to provide a baseline description of current occupational therapy services within the context of the Western Cape province.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1. INTRODUCTION**

This chapter focuses on the functional and participatory effects of severe CP on children, and their resulting healthcare needs. It discusses the evidence for the role of occupational therapy in meeting these needs, as well as barriers and facilitators to effective intervention within the South African government healthcare system.

Literature was reviewed following a search of the following databases: EBSCOHost, Academic Search Premier, Africa-Wide Information, CINAHL, ERIC, Health Source, MEDLINE, PsycINFO, Primo, Scopus, Google Scholar and OTSeeker. Search terms included occupational therapy, therapy, children, paediatric, cerebral palsy, severe cerebral palsy, treatment, intervention, service, home programme, assessment, evaluation, goals, needs, role, function, participation, government healthcare, South Africa, Western Cape, low- to middle-income country and developing country.

### **2.2. CEREBRAL PALSY AS A LEADING CHILDHOOD CONDITION REQUIRING LIFELONG HEALTHCARE SERVICES**

CP is a leading childhood disorder worldwide and estimates are that one out of every 100 South African children present with it (Farooqi, 2005; Levin, 2006). This is five times higher than the global prevalence (Couper, 2002; Donald et al., 2014; Paneth, Hong, & Korzeniewski, 2006). Goldstein et al. (2005) describe CP as a lifelong non-progressive movement disorder, resulting from brain injury or abnormal development prenatally or during early childhood. Considering the aetiology of CP, and the challenges within government healthcare sectors in low- to middle-income countries (LMIC) in managing perinatal complications adequately, the stark differences between the national and international statistics are likely to be possible (Arens, Molteno, Marshall, Robertson, & Rabkin, 1978; Donald et al., 2014; Wilmshurst et al., 2011).

Accompanying the physical impacts, many children present with additional associated neurological conditions, including intellectual disability, epilepsy and sensory impairments (Goldstein et al., 2005; Wilmshurst et al., 2011). Most common amongst children with severe CP, these conditions result in complex functional challenges. Families frequently need to adapt

their home and lifestyle, behaviourally and socially, and adjust their developmental expectations and care planning for their child (Logar, 2012). Furthermore, African studies by Venter (2007), Wilmshurst et al. (2011) and Burton (2015) report that many families face negative social stigma, denial, shame and misconceptions regarding the cause of CP. These experiences commonly delay diagnosis and treatment, parental acceptance of their child (Krüger & Sello, 2008; Logar, 2012; Pretorius & Steadman, 2017) and encourage trends towards traditional healers being the first avenue for families (Burton, 2015). When families make use of healthcare services, challenges with trained specialists, resources and life-long management planning are common throughout Africa (Wilmshurst et al., 2011).

Amongst health professionals, the Gross Motor Functioning Classification System (GMFCS) is a common means of describing disability severity. This system's numerically-named levels are based on functional abilities and quality of movement. For example, individuals on Level I can perform all mobility functions independently, with decreased speed and co-ordination. However, those on Level V have significantly limited active mobility and require specialised attendant-propelled mobility devices. In most cases, children remain on the same level throughout their lives, as progress in function to change their classification is very rare (Palisano et al., 1997).

The GMFCS encourages health professionals to focus on children's functional abilities in their daily context, and provides a medium for communicating with families and formulating realistic goals. Additionally, the GMFCS may be useful to managers in classifying individuals' needs and assist in resource management (Palisano et al., 1997). For researchers, this system can also be instrumental in defining populations of interest.

A systematic review by Donald et al. (2014) concluded that the proportion of children on GMFCS Levels IV and V appears to be larger in Africa than Europe and North America. Similarly, van Toorn, Laughton, Van Zyl, Doets, and Elsinger (2007) stated that spastic quadriplegia is the most common subtype in LMIC, while spastic diplegia and hemiplegia are more common in developed countries. Once again, the higher prevalence of more severe conditions may be due to challenges in healthcare systems in adequately managing postnatal complications (van Toorn et al., 2007) and providing adequate early intervention (Donald et al., 2014; Venter, 2007).

### 2.3. THE HEALTHCARE NEEDS OF CHILDREN WITH SEVERE CP

Individuals with CP have increased support and healthcare needs throughout their lifespan. Their needs vary over time, yet are relatively similar across families with similar experiences (Bertule & Vetra, 2014; Geiger, 2015). Particularly, children with severe conditions have higher support needs and intensive multidisciplinary healthcare requirements (Bertule & Vetra, 2014; Colver, Fairhurst, & Pharoah, 2014; Dodd, Imms, & Taylor, 2010b; Geiger, 2015; Palisano et al., 2008; Saleh et al., 2008).

There are frequently times when health professionals and families' perceptions of priorities differ, and Bertule and Vetra (2014) and Geiger (2015) emphasise that, to ensure that services are effective, economical and collaboratively implemented, the views of both health professionals and caregivers are important to consider. Usually, concerns regarding participation, inclusion and QoL are common amongst both families and health professionals (Chiarello et al., 2010; Kruijsen-Terpstra, Verschuren, et al., 2016). Considering the backdrop of an already divided and exclusionary society, it is acknowledged that health professionals and society may carry varied perceptions and attitudes towards disability, and a number of assumptions regarding participation for children with CP are often at play (Albert, 2004; Thomas, 2002).

While speaking largely to participation in productive activities and education, Adolfsson, Johnson, and Nilsson (2018) and Maxwell (2012) discuss prerequisite environmental conditions that participation depends on. These include availability, accessibility, affordability and acceptability of the activity. Children often require adaptations and support from an assistant in their activities when these contextual factors do not favour participation, and compound their inherent functional difficulties (Bailes, Gannotti, & Fenchel, 2017; Majnemer et al., 2013; Palisano et al., 2012; Perat, 2012a; Venter, 2007). Interestingly, these environmental conditions echo the National Department of Health's (DoH) striving to offer affordable, accessible, acceptable and appropriate services for people with disabilities (Department of Health, 2000; Hayles, Jones, Harvey, Plummer, & Ruston, 2015). Should society, families and the healthcare system abide by either a medical or social model, efforts would be insufficient. Offering both opportunities for meaningful participation in activities and healthcare in this manner, therefore calls for complex problem solving and the implementation of well-integrated biopsychosocial approaches (Albert, 2004; Department of Health, 2000).

Parents also highlighted needs beyond traditional medical and therapeutic concerns. Peripheral to therapy, parents require information about their child's condition, future and service availability (Bertule & Vetra, 2014; Geiger, 2015). South African health professionals are mandated to provide appropriate information to patients (Department of Public Service Administration, 2003), ensuring this need of families is met, no matter which health professional or level of healthcare they are accessing.

Parents additionally express the need for psychosocial support. Often, the additional planning, energy and time for daily activities, especially when limited social support is available, places substantial burden on caregivers (Pretorius & Steadman, 2017). Financial assistance was also raised as a concern, as children with CP require specialised care, transport and equipment. These peripheral services may facilitate participation in both activities and receipt of healthcare services, and are thus considered vital (Bertule & Vetra, 2014; Donald et al., 2015; Krüger & Sello, 2008; Ngubane & Chetty, 2017).

This is by no means an exhaustive list of needs, since individuals' unique social, physical and temporal contexts elicit different needs (Bronfenbrenner, 1979; Dunn, Brown, & McGuigan, 1994). This emphasises the complex and diverse service approaches required to enhance participation and QoL for children with severe CP and their families.

## **2.4. OCCUPATIONAL THERAPY FOR CHILDREN WITH SEVERE CP**

Occupational therapists have a potentially broad role to play with children with severe CP, considering their interest in participation in meaningful occupations. Roles may be of a clinical nature, and may extend to addressing social inclusion and advocacy (Bantjes et al., 2015; Colver et al., 2014; Werner, 1987). While discussion of each of these roles and services holds value, the underlying models of practice that occupational therapists employ will first be considered.

### 2.4.1. Frameworks, approaches and models of practice

The ICF is an interdisciplinary system of thought which broadens healthcare beyond body functions and structure, highlighting how their interrelationship with environmental factors impacts on overall participation (Saleh et al., 2008; World Health Organization, 2011). This is echoed by many occupational therapy models, including the Ecology of Human Performance (Dunn et al., 1994), the Model of Creative Ability (De Witt, 2014) and the Person-Environment-

Occupation Model (Law et al., 1996). Foundationally, these models explain how the congruence in the relationships between the person, their occupations and environment affect health and wellbeing (Law et al., 1996; Palisano, Snider, & Orlin, 2004).

Insights from these frameworks prompt health professionals to align approaches with elements of both the social and medical models of disability (Albert, 2004; Thomas, 2002). Regarding children with CP specifically, Perat (2012b) agreed that functioning depends on the interaction between bodily condition and unique environments. That is, children with the same physical condition will participate differently, depending on their context. Occupational therapists therefore need to conduct thorough assessments and activity analyses in context, in order to guide effective, focused interventions (Dunn et al., 1994).

With these theoretical bases, occupational therapists' roles remain to improve participation, QoL and wellbeing. With environments, and thus families, having been highlighted, the family-centred approach comes to mind. With this approach, more organic and variable therapy roles emerge (Law & Darrah, 2014; Palisano et al., 2004).

When utilising the ICF to evaluate the efficacy of family-centred therapies, Law and Darrah (2014) and Palisano et al. (2004) explained that families usually select goals within the activity and participation elements, rather than specific body functions and structure. Considering the variety of occupations making up children's lives, children with CP generally participate in fewer leisure activities than typically developing children (Reedman, Boyd, Trost, Elliott, & Sakzewski, 2019). Additionally, activity participation, and thus therapy goals, vary according to the severity of their condition. Goals for children on GMFCS Levels I to III often relate to the quality and quantity of active functioning, while participation of children with severe CP is often of a passive nature. Focal interventions typically relate to the prevention of decline and maintenance of their condition, through caregiver education, adaptations, basic care and positioning (Bailes et al., 2017; Benevides, Carretta, Ivey, & Lane, 2017).

Regarding types of activities, parents seldom highlight leisure, mobility and productivity as priorities, rather focusing on self-care (Chiarello et al., 2010). The prioritisation of feeding and eating particularly may reflect that basic growth and health status are considered more important than activities relating to QoL and meaningful participation. While self-sufficiency and some independence were considered important for all children, other self-care activities

were often too complex for children with severe mobility challenges and other commonly associated conditions (Chiarello et al., 2010).

Occupational therapists agree that participation can be facilitated through various means. This includes adaptations, preventing further disability, creating opportunities, altering environments or restoring abilities (Dunn et al., 1994), through direct or indirect therapy (Dodd et al., 2010a; Steultjens et al., 2004). The researcher suggests that one's understanding of 'participation' may be challenged when it comes to children with severe CP, ceasing to strive towards independence or quality of engagement, and rather making room for engagement in more passive or assisted manners (Hammell, 2010).

#### 2.4.2. Therapeutic strategies, skills and interventions

Majnemer et al. (2013) highlights the global lack of literature regarding service structures and interventions for children with CP. Similarly, two systematic reviews found that evidence for the effectiveness of specific interventions is still poor (Novak et al., 2013; Steultjens et al., 2004). It is, however, asserted that occupational therapists have vast options of intervention modalities, which can be summarised into five categories, all working towards enhancing participation (Dodd et al., 2010a; Palisano et al., 2012; Steultjens et al., 2004).

Firstly, treatment of sensorimotor components includes hands-on techniques using movement activation and inhibition, often employed with younger children for enhancing developmental progress and their quality of participation (Dodd et al., 2010a; Palisano et al., 2012; Steultjens et al., 2004). Examples of these contact therapies include neurodevelopmental therapy (NDT), constraint-induced movement therapy (CIMT), sensory integration and bimanual training (Novak et al., 2013; Palisano et al., 2004; Saleh et al., 2008). The researcher suggests that rehabilitation professionals' roles in pain management be added to potential direct sensorimotor interventions, especially for children with severe CP. Pain is experienced by many children who are unable to walk or have existing contractures, and is a recognised inhibitor to participation (Adolfsson et al., 2018; Nilsson, Johnson, & Adolfsson, 2016).

The second group of interventions, skills training, involves activity analyses and adaptation of tasks or environments to match children's abilities (Dodd et al., 2010a; Palisano et al., 2012; Steultjens et al., 2004). This allows for observable changes in participation (Dunn et al., 1994),

and is often considered in combination with the third means of intervention, namely the use of assistive devices (ADs) (Dodd et al., 2010a; Palisano et al., 2012; Steultjens et al., 2004). While ADs vary in terms of being high- or low-tech, they can be beneficial to improve mobility, positioning, communication, self-care or leisure participation (Costigan & Light, 2010; Zupan & Jenko, 2012).

A fourth intervention is orthotics, especially common for children with severe CP (Dodd et al., 2010a; Palisano et al., 2012; Steultjens et al., 2004). Although splinting in the presence of hypertonicity is contentious, the main goal is to maintain muscle length and range of movement. Achieving this improves hygiene, comfort and function (Jackman, Novak, & Lannin, 2014; Ranjan, Das, & Singh Cheema, 2011) which, in turn, all impact active or passive participation.

Fifth, a method of ensuring sustainability of interventions involves caregiver training, counselling and empowerment (Dodd et al., 2010a; Novak et al., 2013; Palisano et al., 2012; Steultjens et al., 2004). Because of the long-term nature of the condition, this is necessary in most cases (Bertule & Vetra, 2014). Basic stimulation by caregivers in routine life is effective, in comparison to no intervention between direct interventions with therapists. In addition, family-directed identification of needs and goals improves when they feel involved and understand the purpose of therapy (Dodd et al., 2010a; Novak, Cusick, & Lannin, 2009; Palisano et al., 2012).

Whilst occupational therapists use clinical reasoning to select services, comprehensive approaches involving combinations of the above methods are encouraged. Outside of these clinical interventions and roles, the family-centred approach reminds one to consider the impacts that CP has on family units, and thus potential additional roles that occupational therapists may play (Dodd et al., 2010b).

#### 2.4.3. Sustainable and integrated services

Caregivers report significant impact on their own physical and emotional health and QoL. The taxing physical demands of the continual care required may be compounded by social stigma, isolation, lack of time for their own self-care or leisure, and the personal blame often experienced (Ahmadizadeh, Rassafiani, Khalili, & Mirmohammadkhani, 2015; Bertule & Vetra,

2014). Furthermore, many caregivers remain unemployed to care for their child at home. Feeling overwhelmed with the responsibility for their child's care is common and this, together with their financial requirements, poses significant stress on caregivers (Dambi & Jelsma, 2015; Geiger, 2015; Ngubane & Chetty, 2017). Attention should be paid to caregivers and their environment, especially considering the expectation of them implementing home programmes amidst already pressured and complex daily routines (Saloojee et al., 2011).

Considering the overall complexity of barriers to participation, the involvement of other health professionals is vital to ensure integrated services. With skills for holistic assessment, occupational therapists may be instrumental in facilitating referrals and managing cases (Darrah et al., 2010; Ngubane & Chetty, 2017; Perat, 2012b). Other professionals often involved include physiotherapists, specialist doctors or paediatricians, speech therapists, social workers, dieticians, special education systems, or specialists involved in complementary and alternative therapies (Bischof, Basu, & Pettifor, 2002; Dodd et al., 2010b; Fong et al., 2008; Palisano et al., 2012; Saleh et al., 2008; Salghetti & Martinuzzi, 2012).

While Kruijssen-Terpstra, Ellens, et al. (2016) and Sakzewski, Ziviani, and Boyd (2014) did not specifically set out to investigate what influences occupational therapists' service selection, they noted that personal paradigms, culture and perceptions of their role may contribute. They further suggest that their place and extent of training, specifically-developed skills, location of work, type of team and years of experience contribute to clinical reasoning. Irrespective of reasons for selecting services, sustainable and well-integrated interventions, and striving towards improved participation for the child and caregivers, should always remain central, through remaining aligned with the ICF and occupational therapy models (Kruijssen-Terpstra, Ellens, et al., 2016; Palisano et al., 2012; Saleh et al., 2008).

## **2.5. SERVICE TRENDS AND THE CONCEPT OF BEST PRACTICE IN THE SOUTH AFRICAN CONTEXT**

Since the quantity and combination of therapy considered 'ideal' or 'sufficient' amongst this population is difficult to define, the development of protocols and intervention programmes is challenging. There are, however, a number of agreed-upon conditions which may be valuable when considering the services in SA.

### 2.5.1. Early intervention and intensive approaches

Early intervention is vital to improve functional developmental outcomes and prevent secondary conditions, especially for those with severe CP (Bailes et al., 2017; Majnemer et al., 2013; Molteno, Arens, Marshall, & Robertson, 1980; Palisano et al., 2012; Perat, 2012a). A high frequency and intensity of therapy is also recommended, however Palisano et al. (2012) and Bailes et al. (2017) explain how this often varies according to family preference, facility protocols, policies, disability severity, service availability, caseloads, individual goals, therapy approaches and the child's tolerance.

In South Africa, the ratio of health professionals to children is well below international standards, leading to significant strain on service provision. This is especially concerning in rural areas, despite the national recommendation of decentralised services (Coetzee, 2018; Cullinan, 2006; Donald et al., 2015; Jesus et al., 2017). It is therefore understandable that, considering the prevalence of CP, therapists face challenges in providing adequate early, frequent and intense services (Pretorius & Steadman, 2017).

Anecdotally, it appears not uncommon for occupational therapists in the government sector to meet teenagers with CP who have never received intervention. This essentially raises their therapy needs, resulting from complex secondary conditions and chronic participation limitations (Levin, 2006). With therapy often limited to infrequent appointments and, in some cases, once in their lifetime, every interaction is important, and typically includes a combination of the aforementioned intervention strategies (Levin, 2006; Venter, 2007). Few therapists, especially in rural areas, have training in specialised treatment modalities. Thus, the combination of challenges concerning training and infrequent appointments, have resulted in superficial hands-on treatments and provision of home programmes without proper monitoring becoming the norm (Donald et al., 2014; Krüger & Sello, 2008; Levin, 2006; Pretorius & Steadman, 2017).

### 2.5.2. Family-centred, integrated and combination approaches

Darrah et al. (2010) and Majnemer et al. (2013) highlight family-centred care, functional and meaningful goals and planning for continual integrated lifespan therapy as important elements for appropriate therapies. These all appear to align with the guidelines of holistic occupational therapy conceptual frameworks and the ICF (Palisano et al., 2004). Saloojee et al. (2011)

recommends holistic approaches which comprises a combination of contact therapy, ADs, caregiver support and education. These, in addition to assistance with referrals and accessing social support services, should be packaged within a caring and respectful attitude towards family units.

The family-centred approach, and particularly caregiver education and assistance with social support services, may be especially important locally, since children are often cared for by unemployed and uneducated caregivers, rather than within schooling or institutional systems (Dodd et al., 2010b; Levin, 2006; Saloojee et al., 2011). Local families report valuing the family-centred approach and having an active role in therapy. However, challenges and inconsistencies were also communicated, including difficulties with ensuring informed decision-making amongst caregivers, as well as availability of relevant caregivers to attend appointments (Kruijssen-Terpstra, Verschuren, et al., 2016; Ngubane & Chetty, 2017).

Empowerment of parents, through providing information and developing partnerships with health professionals, appears to be a global necessity. Sadly, compliance, participation and ongoing attendance at therapy is often poor where caregivers perceive their needs as not being recognised or met, or do not understand therapy processes (Kruijssen-Terpstra, Verschuren, et al., 2016; Ngubane & Chetty, 2017). This may further set them up for poorer prognoses or outcomes (Venter, 2007).

Despite occupational therapists' insight into health conditions and the contextual factors impacting participation and performance (Dunn et al., 1994; Law et al., 1996), opportunities to operationalise integrated interventions remains somewhat limited. This may be because the profession is traditionally situated in the medical field, and most therapists remain based at healthcare institutions, where person-focused, decontextualised therapy is often endorsed and prioritised (Department of Health, 2000; Kruijssen-Terpstra, Ellens, et al., 2016; Naidoo, Van Wyk, & Joubert, 2016; Saloojee et al., 2011). Attempts to traverse the elements of the ICF are challenging since, locally and abroad, few sessions take place in the context where the child usually participates. This commonly leads to inadequate recommendations for environmental adaptations and misunderstanding in their application by families (Darrah et al., 2010; Saloojee et al., 2011). It is suggested that this imbalance in considering the ICF elements and occupational therapy models is insufficient in meeting complex needs, and a holistic view of

participation is required to meet the health promotion, prevention, curative and rehabilitative goals of PHC (Department of Health, 2015; Reedman et al., 2019).

### 2.5.3. Occupational therapy in under-resourced environments

The implementation of occupational therapy services in LMIC needs to be considered against historical and political backdrops, which may raise tension regarding international evidence and service standards (Conchar, Bantjes, Swartz, & Derman, 2016; Levin, 2006; Perat, 2012b). Additionally, ineffective referral pathways and inconsistent co-ordination of services appear to remain, despite policies and the various levels of service in place (Burton, 2015). It is thus understandable that therapists would like to do more to meet children's needs, without having the means or gaining sufficient multidisciplinary support (Levin, 2006; Saleh et al., 2008; Werner, 1987).

South African occupational therapists report facing a lack of resources, and need to employ creativity to provide services, within the boundaries of recognised treatment principles, for example, when fabricating and adapting ADs (Levin, 2006). Distribution of human resources is also concerning (Kautzky & Tollman, 2008), despite some improvements regarding access to therapy in rural areas, following the implementation of mandatory community service for all new graduates. Levin (2006), Kautzky and Tollman (2008) and Mahlathi and Dlamini (2015) express concerns of inequitable access to quality services, as there is an annual contractual turnover of therapists, and inexperienced therapists often work with little support. Apart from this, the demographics of health professionals often misalign with the communities they serve. This raises complex dynamics in terms of culture and worldviews affecting the quality and acceptance of services within communities, as well as the ability to provide services in appropriate languages, as mandated in the Batho Pele principles (Department of Public Service Administration, 2003; Levin, 2006).

Proposed improvements for access to occupational therapy with this population is the decentralisation of services, which involves repositioning a cohort of skilled professionals at primary level facilities to work with community members trained in disability and rehabilitation (Petersen, Lund, Bhana, Flisher, & The Mental Health and Poverty Research Consortium, 2012). Task-shifting is anticipated to become a growing focus, where mid-level workers conduct tasks in homes at community level. While this aligns well with a family-centred and holistic approach,

it may also potentially facilitate gaining trust, easing referrals, improving communication and building a culture of collaboration – essential elements within PHC (Donnelly, Leclair, Wener, Hand, & Letts, 2016; Naidoo et al., 2016).

Aligned with this, Burton (2015) identified that training caregivers has great potential for sustainable therapeutic input. This is complemented by Dambi and Jelsma (2015) who reported the positive outcomes of local community-based therapy services. Relative to community-based services, and apart from positive therapeutic outcomes, caregivers were also more satisfied and compliant with services. Unfortunately, this is one of the few studies regarding the efficacy of such interventions or experiences of families in LMIC (Donald et al., 2015; Donald et al., 2014; Pretorius & Steadman, 2017; Saloojee et al., 2011).

There remain unmet therapy needs of children with CP in higher-income countries (Benevides et al., 2017; Jackson, Krishnaswami, & McPheeters, 2011). The local realities thus raise questions as to what services are taking place with the vulnerable population of children with severe CP. While research relating to occupational therapy for these children appears to be increasing, most research aims to establish evidence for specific interventions. Overviews of service trends have been investigated with other population groups in specific contexts, such as the studies by Jones, Drummond, and Vella (2007) and Swinson et al. (2016), which described services for children with acquired brain injury and patients with dementia respectively. However, research into current practice and service overviews for children with CP has not occurred locally to date, with only the Canadian research by Saleh et al. (2008) having similar objectives.

There is a high demand for occupational therapists to implement evidence-based practice and establish their role, but incongruencies between evidence and practice remain common (Buchanan, 2011; Kruijsen-Terpstra, Verschuren, et al., 2016; Peer & Pollard, 2012). Developed countries are known to have more established healthcare systems, with respected professional scope and protocols. This is understandable considering occupational therapy in SA is still in its infancy (Venter, 2007). However, with SA being 26 years post-Apartheid, and the profession over 70 years old, it seems timely to investigate the quality and quantity of services for this vulnerable population, in order to gain a credible understanding of present realities (Crouch, 2010; Peer & Pollard, 2012).

## 2.6. SUMMARY

With CP as a leading childhood disorder that has significant effects on the participation of individuals and their families, their needs and healthcare requirements warrant consideration. Evidence shows that early, intensive, holistic and family-centred interventions are most effective to maximise function and opportunities for participation. Importantly, therapy should align with the ICF and occupational therapy practice models, ensuring sustainable interventions relating to the child, their environment and their occupations. While evidence is varied, occupational therapists have a range of therapeutic strategies at their disposal to meet these needs. However, many South African therapists face challenges in aligning their practice with international evidence and notions of best practice, and rely heavily on home programmes and caregiver interventions. The absence of current literature on service practices for children with severe CP in LMICs indicates that it is timely and necessary to investigate this further.

## CHAPTER 3: METHODOLOGY

### 3.1. INTRODUCTION

This chapter outlines the procedure followed to complete the research. The research approach and design are named and justified, followed by descriptions of the population and sampling. Details are provided regarding the development of the data collection instrument, as well as the steps of recruitment, and data collection, analysis and management. The chapter concludes with an account of the ethical considerations.

### 3.2. RESEARCH APPROACH AND DESIGN

A quantitative research approach was taken, employing a cross-sectional descriptive design. A quantitative approach allowed for collection of focused, systematic, large-scale objective data through standardised procedures (Kaplan, 2004). A cross-sectional descriptive design was selected since no variables were manipulated and data related to characteristics as they existed at a particular point in time (Leedy & Ormrod, 2019; Ruel, Wagner, & Gillespie, 2016).

This was appropriate when seeking a quantitative overview of current services, as did the studies by Jones et al. (2007), Saleh et al. (2008) and Swinson et al. (2016).

### 3.3. STUDY POPULATION AND SAMPLING

#### 3.3.1. Population

This research aimed to acquire complete data regarding occupational therapy services for children with severe CP, provided within government healthcare facilities in the Western Cape. Therefore, the population included all occupational therapists providing services to children with severe CP, employed by the Western Cape DoH. This included all levels of care (primary, secondary and tertiary), across all provincial health districts (Eden and Central Karoo, Overberg, Cape Metro, West Coast and Cape Winelands). The population therefore included educated, literate professionals with at least a 4-year degree in occupational therapy. All were proficient in English, as it is a recognised primary language of most training and reporting.

Potential participants were identified through contacting an occupational therapist in a prominent management role at a large tertiary institution, who also chairs the leading

occupational therapy forum in the Cape Metropole. As a result of these roles, she held databases of occupational therapists employed within each district in the province. Through these lists, it was evident that there were positions for 63 occupational therapists within the Western Cape DoH, who potentially provide services for children with severe CP. This excluded those working at specialist facilities (such as psychiatric hospitals) and those in larger tertiary institutions not allocated to work with paediatrics.

#### 3.3.1.1. Inclusion criteria

Occupational therapists providing services to children with severe CP, currently employed by the Western Cape DoH were included. They needed to have worked in their facility for at least two months. The rationale for the latter parameter was based on the assumption that it takes time to establish an understanding of one's department, caseload and service trends. Responses from occupational therapists who had recently been employed may not accurately reflect services.

#### 3.3.1.2. Exclusion criteria

There were no exclusion criteria.

#### 3.3.2. Sampling method and sample size

With the relatively small population (N=63), it was appropriate to conduct a population-based study (Leedy & Ormrod, 2019; Ruel et al., 2016), with responses invited from everyone fulfilling the criteria. Considering occupational therapists needed to have worked in their facility for at least two months, and that databases were potentially outdated, additional snowball sampling was considered to account for coverage errors (Ruel et al., 2016). In cases where there was a new employee who did not fulfil the inclusion criteria, contact with the previous occupational therapist in that position was planned, in order to account for their services.

The SurveyMonkey (2000) online sample size calculator was used to calculate the number of responses required to represent the population. Working with a 95% confidence interval and 0.05 precision, a minimum of 55 participants was needed.

### 3.4. INSTRUMENTATION

A self-administered survey allowed for collection of large-scale objective data of several constructs at once, reduced bias and maximised reliability (Borque & Fielder, 2003; Burns et al., 2008).

Since the research context was unique and no such similar survey was known to have taken place, there was no existing instrument that could be used. A self-designed questionnaire was thus developed using recognised design principles and processes, following guidelines described by Burns et al. (2008) and through consultation with research of a similar nature. Notably, while Saleh et al. (2008) also had interest in children with CP, their methodology differed in that participants needed to respond regarding services they would select for defined case examples, rather than their overall current practice trends. The content regarding assessments, goals and interventions, was thus similar, but the development of a unique instrument and data collection process reflected that of Jones et al. (2007) and Swinson et al. (2016) more closely.

#### 3.4.1. Administration methods

While internet surveys have the best response rates amongst professionals (Borque & Fielder, 2003), this was not accessible for all occupational therapists in the population, as they did not all have internet access at their places of work. Electronic and paper-based surveys are also efficient, cost-effective means of gathering data over large geographical areas, while minimising social desirability bias because of their self-report, anonymous nature (Borque & Fielder, 2003; Ruel et al., 2016; Streiner, 2008).

Convenience and ease of utility was prioritised to maximise participation, thus two identically-worded formats of the questionnaire were developed. The online and Microsoft Word versions resembled one another as closely as the parameters that Google Forms and Microsoft Word allowed for. A further option was available for telephonic interviews using the questionnaire as a standardised guide.

### 3.4.2. Instrument development

The principles and process outlined by Burns et al. (2008) was consulted for the questionnaire development. Steps involved item generation, item reduction, formatting of items, composition, and testing.

#### 3.4.2.1. Item generation and item reduction

In order to maintain focus, coherence and cohesion throughout the instrument, core constructs needed to be identified (Burns et al., 2008). Considering Burns et al.'s (2008) recommendations, the research objectives were used as guidelines to develop constructs of interest, also considered to be the variables for this research. These constructs were translated into five categories, namely:

- A. Profile of occupational therapist
- B. Profile of occupational therapy department
- C. Occupational therapy services
- D. Factors influencing service selection
- E. Perceptions of quality of service

It is notable that the category of 'Occupational therapy services' was the most important in relation to the research question and aim. From the outset of the study, there had been discussion between the researcher, her supervisors and an occupational therapist working in government healthcare regarding whether 'services' should only reflect intervention and treatment, or include other steps in the therapy process. The occupational therapy process is recognised to consist of multiple steps, including evaluation (often referred to locally as 'assessment') and interventions, in relation to goals regarding occupational participation (Bass et al., 2017; Baum & Law, 1997; Pendleton & Schultz-Krohn, 2017). Since this implies that the selection of interventions cannot be understood out of the context of assessment and goal-setting, it was agreed that 'services' be considered as any significant and meaningful interaction with the child and their caregivers that contributes to this process. Assessments, goal-setting and interventions thus formed sub-categories within Category C.

Key ideas for items relating to each category were extracted from literature regarding the occupational therapy role with children with severe CP and studies of a similar nature (Borque & Fielder, 2003; Burns et al., 2008; Jones et al., 2007; Saleh et al., 2008; Streiner, 2008).

Specifically, in relation to Category C, details regarding the practicalities of implementing each modality and action described in literature formed the key elements of items.

The initial set of ideas had a large number of items (128), which raised concern for the length of the questionnaire. Items in Category C were reduced from 106 to 88 based on the researcher and primary supervisor's clinical experience, selecting only those most relevant within the South African context (Borque & Fielder, 2003; Streiner, 2008). Some repetition, that had evolved from overlapping key elements of various categories, was also eliminated in this process.

Length of the questionnaire was important to consider in terms of the ethics regarding taking up valuable time of therapists in the government sector, as well as potential non-response, respondent fatigue and premature abandonment (Ruel et al., 2016). While Draft 1 (Appendix 1) of the questionnaire remained lengthy (110 items), it was agreed to refine this through the testing process described in Section 3.4.2.4.

A summary of the categories and items remaining in Draft 1 is in Figure 1.

#### *3.4.2.2. Formatting of items*

Items listed were formulated into clear questions, each comprising of unidimensional concepts and no more than 20 words (Alwin & Beattie, 2016; Burns et al., 2008). Neutral wording was selected to avoid leading responses (Alwin & Beattie, 2016; Ruel et al., 2016).

Questions in Category A and B (profiles of the occupational therapist and the facility they represented), required both closed- and open-ended questions. As a relatively minor focal area of the research, these were objective, non-threatening and quick to answer, aiding in encouraging participation through building initial rapport with participants (Marsden & Wright, 2010).

In order for the time taken to complete Category C (occupational therapy services) not to be too lengthy, and adequately obtain standardised quantitative responses, closed-ended questions with identical ordinal and nominal scales were used wherever possible.

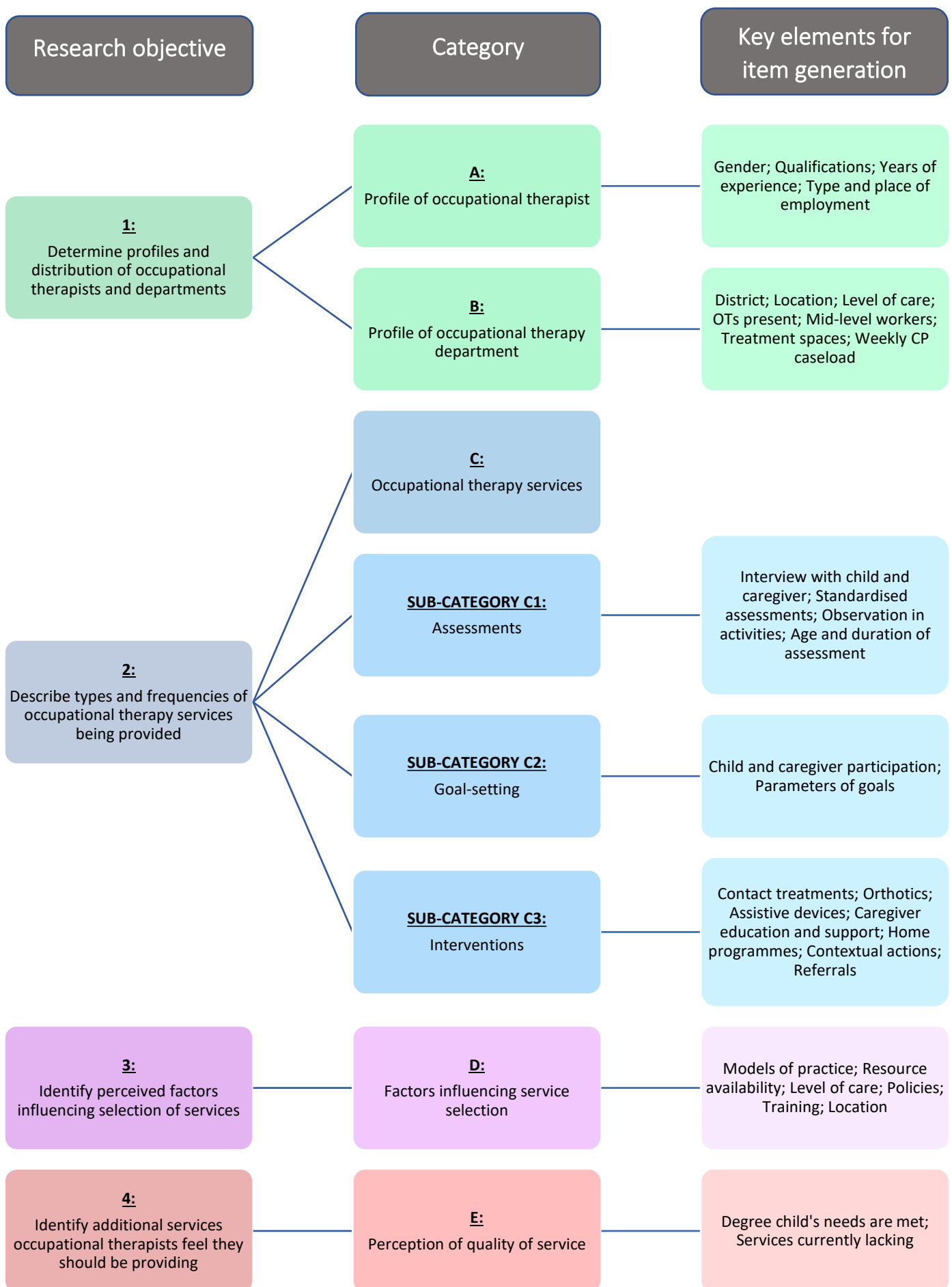


Figure 1 Summary of items included in Draft 1

Response options were comprehensive and mutually exclusive. No more than seven options were provided, in order to maintain participants' ability to comprehend options and make selections with ease, while still allowing for finer differences to be expressed (Borque & Fielder, 2003; Streiner, 2008). An option for participants to select if they did not know about a listed action or modality was included, to facilitate truthful responses and reliability, by preventing selection of another option for the sake of completeness (Ruel et al., 2016). Supplementary optional open-ended questions were asked, allowing space for explanation where relevant.

In Draft 1, open-ended questions were used for questions in Category D and E, so as not to lead participants towards assumed or expected factors influencing their service selection. However, considering this was the last section of the questionnaire, the risk for respondent fatigue and poor responses to open-ended questions was recognised (Borque & Fielder, 2003), and identified as an area to monitor during testing.

#### *3.4.2.3. Questionnaire composition*

In order for the large number of items to be included efficiently, the item groupings and organisation needed careful consideration (Burns et al., 2008).

A simple introductory page was designed, to provide information and allow participants to anticipate the process of the questionnaire. This included the expected duration and instructions for completion, definitions of key terms, a figure outlining the various sections of the questionnaire and the researcher's contact details (Burns et al., 2008).

Sections 1 and 2 (Categories A and B), gathered descriptive demographic and practical elements relating to the participant and the facilities in which they worked. These aligned with the first and second objective of the research. Sections 3, 4 and 5 (Category C) formed the majority of the questionnaire and related to services provided, namely assessments, goal-setting and intervention; as per the second objective of the study. Section 6 (Category D and E) elicited responses relating to the third and fourth objective of the study, gaining insight into factors influencing services selection and therapists' perceptions of services.

The questionnaire concluded by thanking participants for their participation and reminding them of the condition regarding implied consent upon submission.

Sections were given applicable headings for clarity, and started on new pages in both the online and Microsoft Word versions. The design was kept professional and simple, having a plain, neutral background, clear font and adequate font size. Each question was in its own row and alternating shading was used to facilitate following across lines in the Microsoft Word version (Borque & Fielder, 2003; Marsden & Wright, 2010). Bold and capital lettering was used minimally and in a consistent manner to emphasise specific elements and differentiate similar questions from one another, without causing unnecessary distraction (Borque & Fielder, 2003; Marsden & Wright, 2010).

All sections used consistent numbering and formatting conventions, with clear instructions to skip questions when not applicable, based on a previous response (Borque & Fielder, 2003; Fowler, 1995). Additional definitions of terms were included as footnotes or within questions, where the understanding of terms needed to be uniform or were possibly unknown to participants.

Sufficient space was provided for open-ended questions, varying space sizes to guide participants regarding the extent of detail requested (Fowler, 1995; Marsden & Wright, 2010).

#### *3.4.2.4. Testing the instrument*

An important step in the development of self-designed instruments is the testing stage, by gaining input from independent experts. This allows researchers to establish rigour, in terms of face and content validity, reliability of responses, as well as utility elements across each format of the questionnaire (Borque & Fielder, 2003; Burns et al., 2008; Leedy & Ormrod, 2019). Three stages of testing occurred, with changes based on feedback made between each stage. This process is summarised in Figure 2.

The questionnaire was tested by eight participants. These participants were individuals who would not form part of the eventual population of the research, but had sufficient similarities to prospective participants in order to relate to the questionnaire in a similar manner. It was therefore required that, in order to gain valuable feedback, at least half of the pilot participants had either extensive experience with children with CP, and would thus relate closely to the content of the questionnaire, or additional post-graduate experience in the research arena.

Since only an English questionnaire was developed, the researcher ensured that English was not the primary language of practice of at least two of the participants, in order to gain more than one perspective as to whether a translated version or additional definitions of terms may be necessary for such participants. Since the online version was anticipated to be the primary means of administration, the last criteria was for most participants to complete this version, but at least one Microsoft Word version was to be completed.

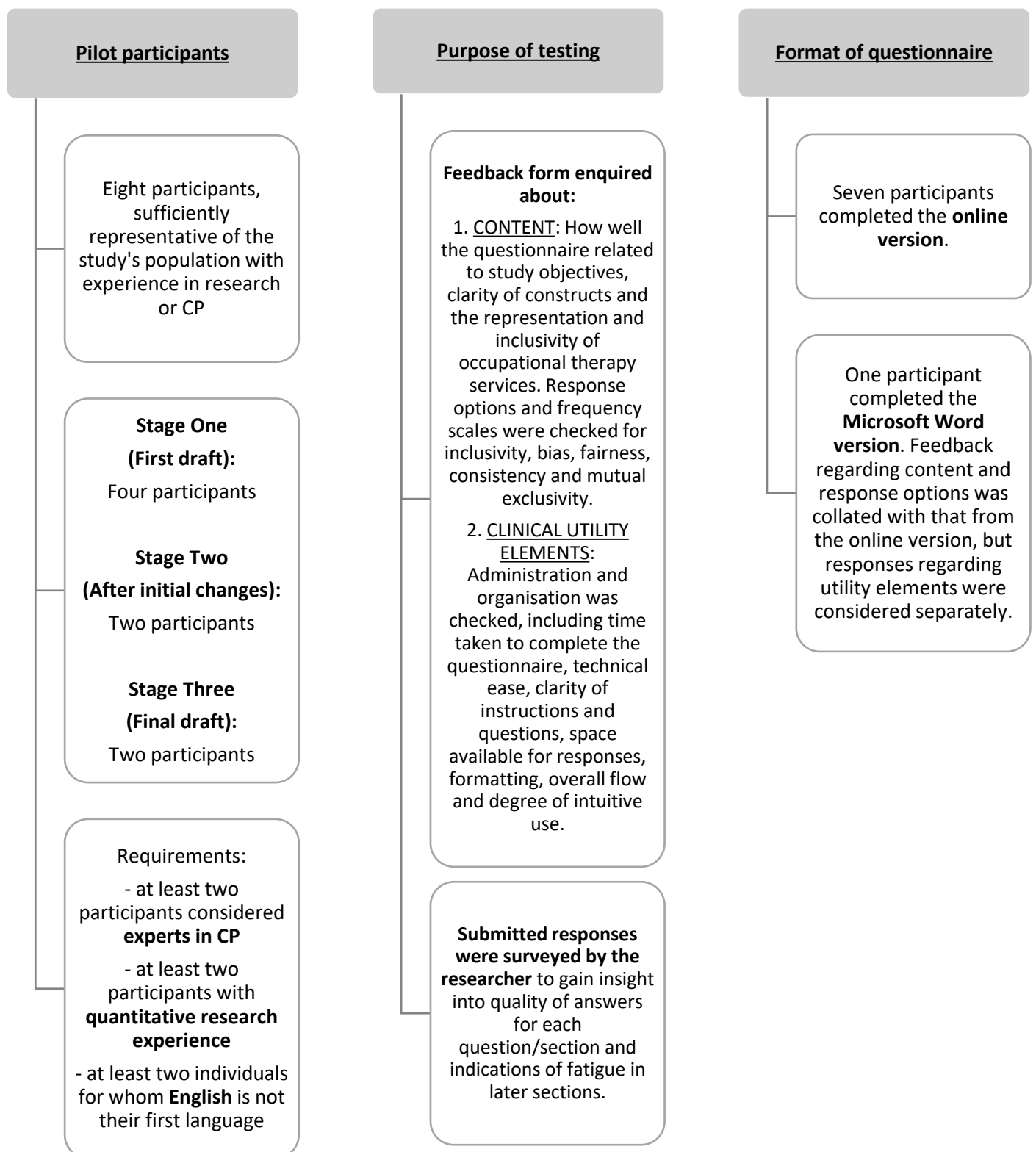


Figure 2 Outline of the questionnaire testing process

Guidelines and an example from Ruel et al. (2016) were used to develop a feedback form (Appendix 2), to ensure focused feedback covering all areas of interest. Of interest to the researcher was the validity and reliability of the questionnaire's content, as well as its utility properties (Ruel et al., 2016).

Content and construct validity were assessed according to how well content related to the objectives of the study, occupational therapy terminology and theory, and government healthcare service trends. Reliability was considered in terms of response options provided, how questions were interpreted and adequacy of definitions of terms. Inter-rater and test-retest reliability was not required, due to the self-report and once-off cross-sectional nature of data collected. Inquiry into participants' practical experience explored elements of the questionnaire's utility. To address concerns of the questionnaire's length, input from pilot participants regarding relevance of questions, in relation to the research objectives and their experience, would effectively justify further removal of specific items.

The formal feedback was supplemented by the researcher reviewing participants' responses to the questionnaire to assess if questions had been understood in the manner intended, and identify areas of redundancy or repetitive ideas being elicited (Burns et al., 2008).

A complete compilation of feedback and changes, as well as an audit trail of the testing process, can be found in Appendix 3 and Appendix 4 respectively. However, a summary of key feedback and how it was dealt with at each stage is summarised below.

#### *3.4.2.4.1. Feedback from Stage One testing*

Three participants completed the online questionnaire and one completed a Microsoft Word version. Overall positive feedback was provided regarding the clarity of structure, organisation and formatting of both versions, so no changes were made in this regard.

Completion time ranged from 20 to 30 minutes, so it was recognised that some items needed removal, however no specific indication of redundant or repetitive items was evident. Participants highlighted questions that needed clearer wording or provision of examples and instances where additional response options were required in order to answer accurately (Appendix 3, Question 1C, 1D and 3F). These suggestions were adhered to, but items mentioned by one participant that were not considered vital to change were flagged for monitoring in the next testing stage.

#### *3.4.2.4.2. Feedback from Stage Two testing*

Two participants completed the online questionnaire, taking 25 and 30 minutes respectively. A few questions that were agreed not to add vital information were removed to shorten the questionnaire (Appendix 3, Questions 2A and 3C).

Suggestions for changes were fewer in this stage, but one participant questioned the focus of the study and the inclusion of assessment, goal-setting and intervention processes, as opposed to only interventions or treatment. This was discussed with the research supervisors relative to the study objectives and definition of terms, and decided that including all of these areas aligned with this study's use of the word 'services,' thus was not changed.

Similar to Stage One, it was observed that the responses in the last section of the questionnaire, although complete, remained brief and there was recurring feedback regarding the clarity of these questions (Appendix 3, Question 4). It was, therefore, at this stage that they were changed to have response options in the form of a rating scale, with space for optional additional explanations.

#### *3.4.2.4.3. Feedback from Stage Three testing*

Two participants completed the online questionnaire. One had difficulties with her internet connection, so time recorded to complete was inaccurate, and the other took 29 minutes. Since this was still relatively lengthy and there was no clear way to reduce items while still fulfilling the research objectives, there was concern for therapists' willingness to participate. It was decided to instate an incentive which would be sufficient to encourage participation, but not risk coercion (Borque & Fielder, 2003; Marsden & Wright, 2010).

Responses to Section 6 were much improved and no further items required rewording or additional response options – indicating that prior changes had been effective. While one participant made valuable suggestions to increase opportunities for explanations of responses, this was not deemed appropriate. Maintenance of the quantitative nature of data was important, thus additional questions for the sake of obtaining interesting information, was avoided.

#### *3.4.2.5. Final draft of instrument*

No structural changes were made through the testing process, and the final version contained the sections previously outlined in 3.4.2.2, with a progress bar, and numbered pages on the

Microsoft Word version, added for convenience. Throughout testing, it was reported that the questionnaire took between 20 and 30 minutes to complete. The final questionnaires in both Google Forms and Microsoft Word formats are found in Appendix 5 and Appendix 6 respectively.

The areas where most significant changes were made between draft and final versions were in Sections 5 and 6. Sub-questions eliciting details regarding interventions were omitted in Section 5, while Section 6 was changed to contain rating scales and optional open-ended sub-questions, rather than solely open-ended questions as initially drafted. This allowed for responses at the end of the lengthy questionnaire to remain of adequate quality, maintain focus and elicit quantifiable data (Marsden & Wright, 2010).

Variables, scales and data elicited in the final version of the questionnaire are summarised in Appendix 7. The final questionnaire had 112 items, distributed as follows:

Section 1:	7 items
Section 2:	7 items
Section 3:	21 items
Section 4:	7 items
Section 5:	55 items
Section 6:	15 items

### **3.5. PROCEDURE**

#### **3.5.1. Gaining access and recruitment**

Upon examining databases of occupational therapists employed by the Western Cape DoH, it was evident that they had not yet been updated for the present year, as there were inaccuracies in the listing of therapists completing their community service and those who had recently been employed. Thus, a manager was contacted within each district or sub-district to verify their staffing lists in January and February 2020. Snowball sampling was not required as all therapists met the inclusion criteria by the time recruitment commenced.

At the time of recruitment (March 2020), SA was entering the COVID-19 pandemic, and a number of restrictions regarding research and access were in place. Two facilities declined the

initial application for research via the National Health Research Database (NHRD) due to limited capacity, and approval for a further seven remained unobtainable, due to bans on non-essential research applications. This reduced the population of 63 eligible occupational therapists, to 54 who could be invited.

Increasing the sample size was important to reduce bias. Response rate was therefore of priority, and the researcher made personal contact with each of these 54 potential participants, to build trust and motivate participation (Burns et al., 2008; Leedy & Ormrod, 2019; Ruel et al., 2016). While it was initially intended to attend team or district meetings to address groups and invite participation, this was not appropriate or permissible during the pandemic. Thus, engagement with each occupational therapist was initiated via email or telephone to introduce the researcher and the research. It became evident that a number of therapists had been 're-purposed' during the height of the pandemic and were no longer working in their usual roles or locations. This created unpredictability, delays and the need to be sensitive and flexible in order to remain ethical towards the priorities of the healthcare sector at the time. Recruitment continued until June 2020, thus spanned a period of approximately four months.

Accompanying initial contact, an information sheet (Appendix 8), including explanations of the research purpose, procedures, risks and benefits, was emailed to potential participants. Information regarding the incentive was also provided, by informing them that all participants would be entered into a lucky draw for a prize (namely, a latest occupational therapy textbook), in order to encourage responses (Marsden & Wright, 2010). Where willingness to participate was expressed, participants were required to select their preferred format of completion, and the link to the online form or a Microsoft Word version was provided. Together with this, a request to complete the questionnaire within 14 days, as well as a unique response code, was provided to each participant, in order to ensure anonymity, yet monitor responses and facilitate the lucky draw.

To maximise convenience for participants, an informed consent form was not required and completion of the questionnaire implied consent. This was made clear in the information sheet and at the start and end of the questionnaire. This was considered acceptable since participation posed no significant risk and participants were qualified professionals who could comprehend and understand research processes sufficiently.

### 3.5.2. Data collection

The time-frame for data collection was extended due to the COVID-19 pandemic, and responses were received from mid-March 2020 until 30 June 2020, thus spanning a period of 16 weeks.

Participants were requested to return the questionnaire within 14 days. The initial intention was to follow up on non-responders after 16 days, by sending a reminder email or telephoning them and emphasising the benefits and value of their participation (Borque & Fielder, 2003; Ruel et al., 2016; Streiner, 2008). However, as a result of the pandemic, many occupational therapists were not providing their usual services or having access to their regular workspaces. Provision was therefore made for responses to be delayed and reminders were sent in more sensitive and flexible manners, as was deemed appropriate and ethical. A maximum of three reminders were sent to each participant.

A participant inventory (Appendix 9) was kept, detailing the unique response code for each participant, dates of various interactions, and date and format of completion (Ruel et al., 2016). If participants communicated unwillingness to participate at any point, this was marked clearly on the inventory in order to monitor and report response rate (Borque & Fielder, 2003). Return of the questionnaires occurred through online submissions, or emailing of Microsoft Word versions.

The winner of the incentive prize was drawn through a random selection of a number on an online website, which was then tracked to the participant in that row in the Excel spreadsheet of raw data. This process was witnessed by the research supervisors to ensure it was valid and fair. The winner was contacted via email to receive her prize. All participants were emailed, giving a word of thanks, informing them that a winner had been drawn, and that a summary of the research would be available on request.

## **3.6. DATA MANAGEMENT**

The unique response codes given to participants ensured that no personal details were filled in on the questionnaires. This ensured anonymity, and from the time that submission of their questionnaire was recorded on the participant inventory, there was no link back to their name or facility.

Upon return of the Microsoft Word format questionnaires, raw data were captured verbatim by the researcher, and checked by an assistant, on the Google Form. All responses were imported and downloaded to a Microsoft Excel spreadsheet using the automated function of Google Forms. Data were checked and cleaned by the researcher and supervisors (Ruel et al., 2016) and imported to Statistical Package for the Social Sciences (SPSS) version 26.0 (IBM Corp, 2019) for analysis.

Original completed questionnaires in the Microsoft Word format were held on a password-protected computer to which only the researcher had access. Google Forms responses were maintained electronically on this platform, naturally also password-protected. These original records will be maintained for five years.

### **3.7. DATA ANALYSIS**

Numerical and categorical data were analysed by calculating descriptive statistics using SPSS.

Due to the relatively small number of responses (n=34, of total 40 sent out), data was assumed to not be normally distributed, thus non-parametric descriptive measures were the main means of analysis and reporting numerical data.

Categorical data were analysed in terms of frequencies and percentages. In cases where doing so would not risk losing the sensitivity of the descriptive data, the response options of 'never' and 'rarely,' as well as 'sometimes' and 'usually' were collapsed into categories of 'seldom' and 'frequently' respectively, thus reducing the frequency scale from five-points to three-points.

For open-ended questions, inductive content analysis was done in Microsoft Excel. Codes were created in order to capture the essence of similar responses. These were analysed and patterns identified, to form broader category groupings, captured by meaningful phrases or recognised occupational therapy concepts (Saldaña, 2015). This was done in consultation with the research supervisors to ensure that responses were not misrepresented and there was consistency in understanding of terminology (Ruel et al., 2016; Saldaña, 2015). The ICF was consulted in terms of overarching potential categories, and facilitated grouping where possible. These categories were then analysed as other categorical data and the frequency of codes is reported.

### **3.8. ENSURING SCIENTIFIC RIGOUR**

Careful documentation was kept throughout the research process to ensure transparency, replicability, and to ease the process of identifying study limitations (Ruel et al., 2016).

Making the purpose of the study clear to participants and encouraging honest responses mitigated the risk of participants' potential sense of being personally evaluated. This, together with ensuring anonymity, improved reliability by avoiding social desirability in responses (Marsden & Wright, 2010). The questionnaire was formulated according to respected guidelines and testing. Furthermore, space was provided for additional comments to ensure that participants did not feel obliged to answer in a coerced or dishonest manner if only closed-ended, limited options were available (Ruel et al., 2016).

Sampling bias was minimised by encouraging responses from everyone in the population, allowing for holistic and credible representation of findings for the defined group. Anonymity and confidentiality were ensured by using numbered questionnaires, safe data storage and never representing a single participant's response set as a unit, which may have led to their identity being known, but rather presenting findings through statistical means. There was minimal risk for challenges with recall, as all items related to their current first-hand practice (Fowler, 1995).

Caution was also taken when presenting the findings, guarding against deception through over-generalising the results. Additionally, a true representation of the findings was endeavoured to be presented, by employing objectivity without manipulation, even if they did not align with the researcher's assumptions or literature (Locke, 2000; Ruel et al., 2016; Saldaña, 2015).

### **3.9. ETHICAL CONSIDERATIONS**

This study only commenced when approval was granted by the Human Research Ethics Committee (HREC) of the University of Cape Town (UCT) (reference 702/2019). Permission was also sought from the Western Cape DoH prior to data collection, through the platform of the NHRD (reference WC\_201910\_023). These permissions were stated on the information sheet for the participants to be aware of. The HREC letter of approval and an example of a facility approval letter from the NHRD are available in Appendix 10 and Appendix 11 respectively.

The researcher considered ethics involved in survey research, following principles outlined in the Belmont Report (United States, 1978), and complied with the Declaration of Helsinki (World Medical Association, 2001), as follows.

#### 3.9.1. Respect, confidentiality and anonymity

Respect for persons (United States, 1978) was maintained through the use of an information sheet (Appendix 8) and the voluntary nature of the study. The information sheet was transparent in terms of the purpose, risks and benefits of the study, expectations and role of participants, their right to withdraw their responses at any stage without reprisal, the researcher and HREC contact details, as well as procedures in place to protect anonymity (World Medical Association, 2001). Once a participant agreed to participate, they were assigned a unique response code, to prevent their personal details being provided in the questionnaire. From the time they submitted their responses, there was no longer a link between their responses and personal details.

Since participants were educated professionals who were familiar with research processes, and the study posed minimal to no risks to participants, there was no need for a separate informed consent form, and participation in the questionnaire implied consent. This was emphasised on the information sheet and at the start and end of the questionnaire. Participants were invited to engage with the researcher about the questionnaire or research process should they desire (United States, 1978).

#### 3.9.2. Beneficence and non-maleficence

No significant risks to participants were identified. Since participants would likely complete the questionnaire while at work, contact time with patients may have been at stake. However, permission was first obtained from facility managers, and participation would only take 20 to 30 minutes.

Participants would likely gain short-term benefits from self-reflection while answering the questionnaire, as was verified by a participant during the testing of the questionnaire. Long-term, both occupational therapists and children may indirectly benefit from participation in the research. Considering values of the profession include advocacy, increasing evidence for

practice and taking leadership steps towards policy development (Hammell, 2013), the relatively short time taken to complete the questionnaire was considered acceptable.

### 3.9.3. Justice

Regarding justice (United States, 1978), there were no concerns notable. Participants were treated fairly, by all receiving the same correspondence and maximum number of follow-up communications. No participants received compensation for their participation, apart from the winner of the lucky draw. All participants were informed of this incentive, and the selection was through a controlled and witnessed random draw. Furthermore, because participants were from all service levels and districts, results represented all, and future benefits should consider all.

### 3.9.4. Reporting

Appreciation was shown through sending an email of thanks to participants as well as informing them of the availability of a summary of the findings. The intention is to further disseminate the findings through submitting an article to peer-reviewed journals, sending a summary to relevant disability organisations and presenting at paediatric, neurological or occupational therapy association meetings or congresses.

## **3.10. SUMMARY**

This chapter describes the quantitative cross-sectional descriptive research that was conducted. A questionnaire was developed according to respected principles and underwent testing procedures to establish rigour. This was distributed amongst occupational therapists employed by the Western Cape DoH, in either a Microsoft Word or online format, according to their preference. Self-reported objective responses were thus obtained regarding their service provision, fulfilling the four research objectives. Quantitative data were managed and analysed according to recognised practices. Coding and categorisation were carried out with open-ended responses and categorical data was reported in terms of frequencies and percentages. Non-parametric descriptive measures were used for numerical data. Ethical principles were adhered to and approval was obtained from the HREC and NHRD.

## CHAPTER 4: RESULTS

### 4.1. INTRODUCTION

This study aimed to describe the occupational therapy services provided to children with severe CP, across all government healthcare facilities in the Western Cape. Objectives included determining basic profiles and distribution of occupational therapists, describing the types and frequencies of services, identifying factors influencing service selection and identifying additional services that should be provided.

As outlined in Figure 3, this chapter reports the response rate and then follows the sections of the questionnaire - describing participant and facility profiles, occupational therapy services, factors influencing services and perceptions of adequacy of services.

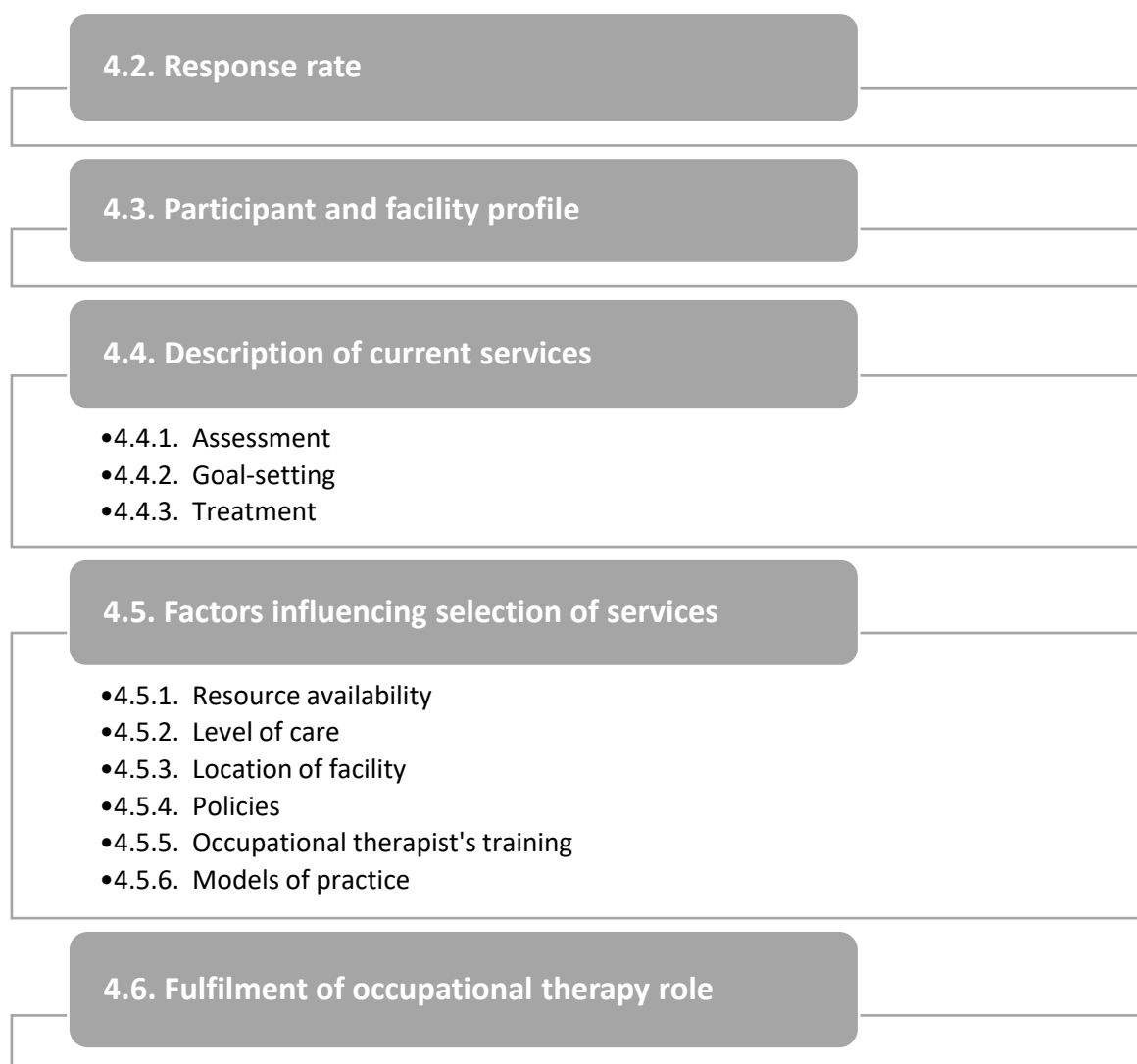


Figure 3 Outline of presentation of results

## 4.2. RESPONSE RATE

Of the 63 occupational therapists in the population, 54 were invited to participate, 40 questionnaires were sent out and 33 responses were received by the deadline (30 June 2020). One additional response was received 10 days later and was included in the analysis. Responses were screened and were all eligible and complete. As summarised in Figure 4, the total number of responses was 34 (n=34) - a response rate of 53%.

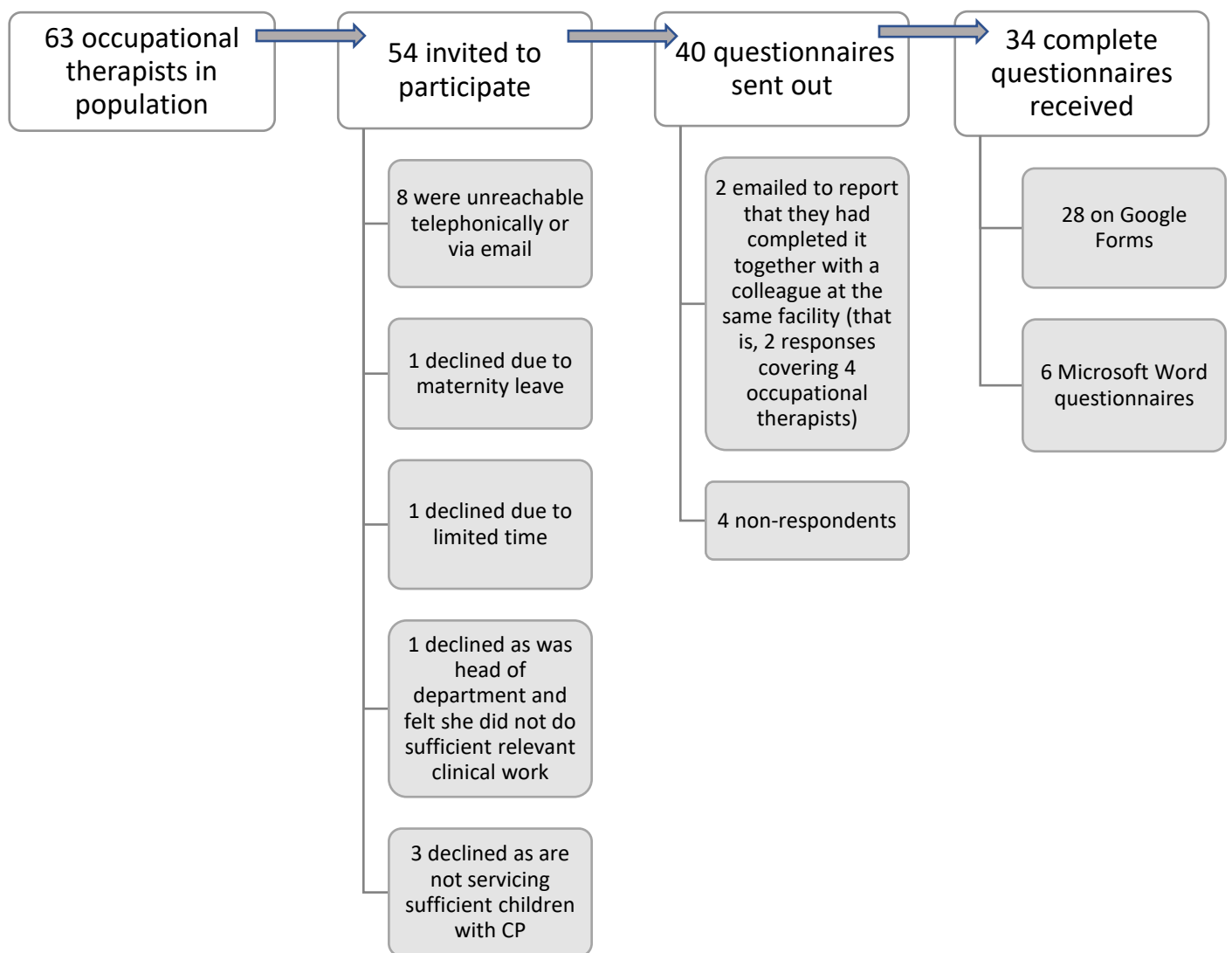


Figure 4 Summary of data collection process and responses

Response rate varied across the five provincial health districts. Figure 5 shows the distribution of occupational therapists, according to those who could not be invited as permission was not received (indicated in red), those who were invited but did not participate (indicated in orange), and those who participated (indicated in green).

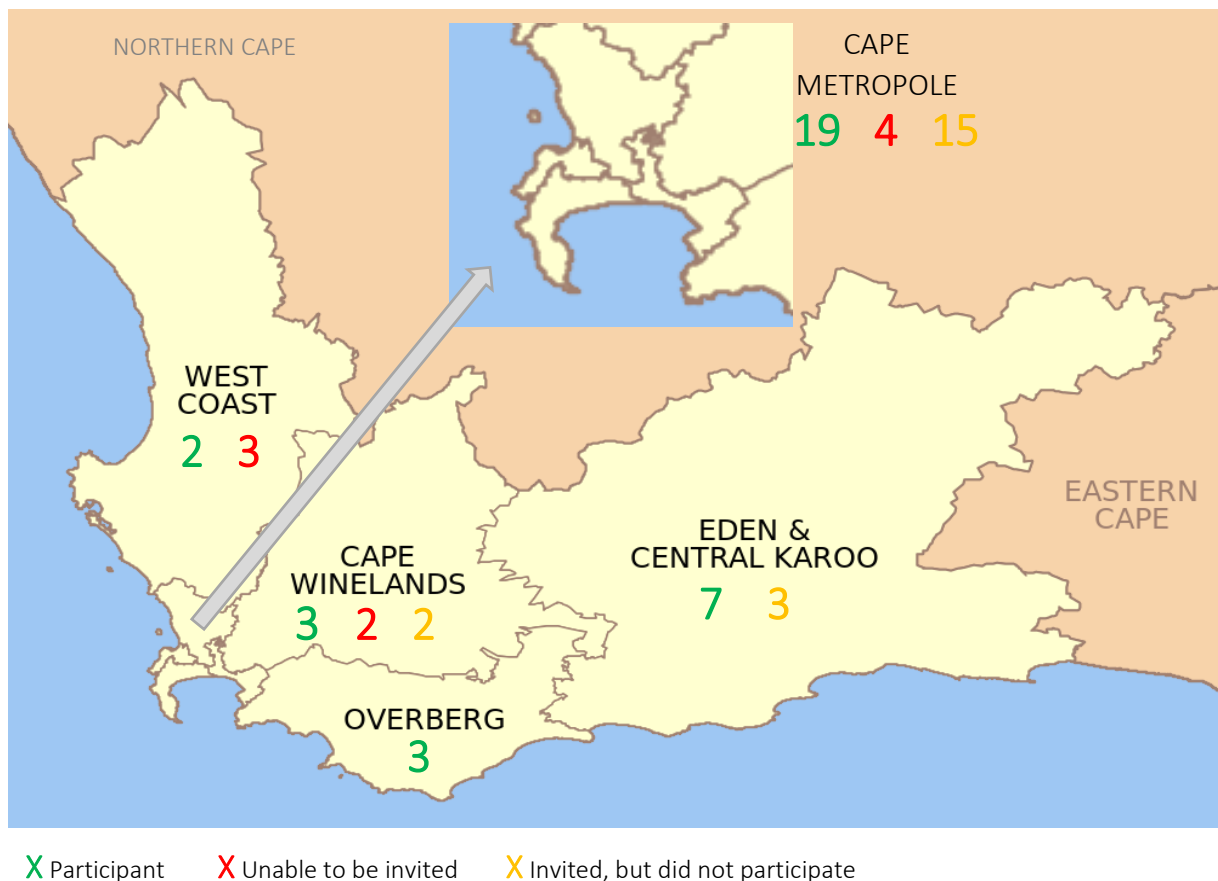


Figure 5 Distribution of participants and population

Compulsory questions were answered by all participants. Some optional open-ended questions had omissions, as detailed in Appendix 12. Data from each question were analysed according to the number of responses received, as highlighted in the applicable sections.

### 4.3. PARTICIPANT AND FACILITY PROFILES

Table 1 details the participant and facility profiles. Years working as an occupational therapist ranged from less than one (2019 graduate) to 39 years (median: 10 years), with a median of 7.5 years with children with CP specifically. Three participants (8.8%) had less than a year of experience and were completing their community service, and most of the remaining participants were employed in permanent (n=29, 85.3%) and full-time (n=31, 91.2%) positions.

Two thirds of participants were positioned in urban areas (n=23, 67.7%), and half worked in the Cape Metropole health district (n=18, 52.9%).

Nineteen (56%) participants were the only occupational therapist in their facility, with the maximum in one department being seven. There was an even spread of participants servicing a single facility and those who had responsibilities over a number of facilities, with five (14.7%) of the latter providing services at more than one level of care. There were few mid-level workers within occupational therapy departments (median = 0, range: 13), and less than half (n=16, 47.1%) had designated spaces for their services.

In terms of caseloads, all participants saw 10 or less children with CP per week.

Table 1 Profiles of participants and facilities

(n=34)

VARIABLE	MEDIAN (IQR; Min-Max)
Years since graduating as an OT	10 (11.3; 0 – 39)
Years of experience with children with CP	7.5 (7.5; 0 – 20)
Number of OTs in department	1 (1; 1 – 7)
Number of mid-level workers in department	0 (1; 0 – 13)
	<b>NO. (%)</b>
<u>Sex</u>	
<i>Female</i>	33 (97.7)
<i>Male</i>	1 (2.9)
<u>Highest Occupational Therapy qualification</u>	
<i>4-Year Bachelors degree</i>	30 (88.2)
<i>Masters degree</i>	4 (11.8)
<u>Type of position held</u>	
<i>Full-time employee</i>	31 (91.2)
<i>Part-time employee</i>	3 (8.8)
<u>Employment status</u>	
<i>Permanent employment</i>	29 (85.3)
<i>Contract/locum employment</i>	2 (5.9)

<i>Community service OT</i>	3 (8.8)
<u>Facilities serviced</u>	
<i>Work at a single facility</i>	17 (50)
<i>Work across a number of facilities</i>	17 (50)
<u>Health district served</u>	
<i>Cape Metropole</i>	18 (52.9)
<i>Eden and Central Karoo</i>	7 (20.6)
<i>Cape Winelands</i>	4 (11.8)
<i>West Coast</i>	2 (5.9)
<i>Overberg</i>	3 (8.8)
<u>Location(s) of facilities served</u>	
<i>Urban</i>	23 (67.7)
<i>Semi-urban</i>	3 (8.8)
<i>Rural</i>	8 (23.5)
<u>Level(s) of care served*</u>	
<i>Primary</i>	24 (70.6)
<i>Secondary</i>	12 (35.3)
<i>Tertiary</i>	4 (11.8)
<u>Nature of treatment space(s) available**</u>	
<i>Designated space(s) for occupational therapy services</i>	16 (47.1)
<i>Shared space(s) with other health professions</i>	24 (70.6)
<u>Approximate weekly caseload of children with severe CP</u>	
<i>0 – 5</i>	28 (82.4)
<i>6 – 10</i>	6 (17.6)

\* Five participants worked at more than one level of care

\*\* Six participants used both designated and shared spaces

#### 4.4. DESCRIPTION OF CURRENT SERVICES

The three main services areas, namely assessment, goal-setting and intervention, are presented below.

#### 4.4.1. Assessment

The median age at which children were first assessed by occupational therapists was two years old (IQR: 2.3; Min-Max: 0-12), and sessions had a median duration of 60 minutes (IQR: 16; Min-Max: 20-120).

The four assessment methods included in the questionnaire are presented in Figure 6. *Interviews with the child's caregiver* and *observations in activities* were the primary means of assessment, frequently employed by 97.8% (n=33) and 85.3% (n=29) of participants respectively. Frequency of *interviews with the child* varied, and *standardised assessments and checklists* were seldom used, with a third of participants never using these (n=10, 29.4%).

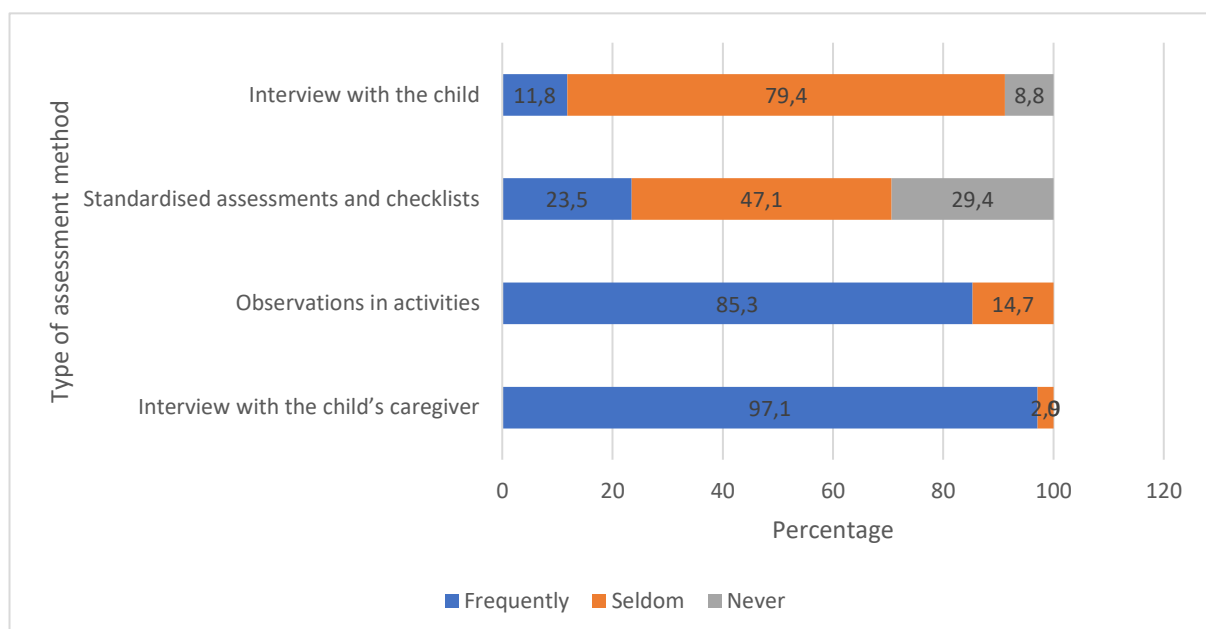


Figure 6 Frequency of various assessment methods used

Regarding other assessments used, participants mentioned home visits (n=2, 5.9%), requesting videos or photographs of home environments (n=2, 5.9%), and seeking collateral information from medical folders or multidisciplinary team members (n=4, 11.8%).

Factors influencing the selection of each assessment method were revealed through content analysis of open-ended questions (Questions 3.1.2., 3.1.3., 3.2.2., 3.2.3., 3.3.3., 3.3.4., 3.4.3. and 3.4.4.), and largely aligned with the components of the ICF (World Health Organization, 2011).

#### 4.4.1.1. Interviews with the child's caregiver

All participants agreed that interviews with caregivers were effective means of assessment. 34 described benefits and 32 reported challenges.

Participants appreciated that interviews provided opportunities to develop relationships with families, which facilitated formulating common goals (n=6, 17.6%), and improved buy-in to interventions (n=3, 8.8%).

*“Caregiver interviews also help put the family at the centre of their child’s care plan. It is essential for carryover to know what the family would like to get out of therapy intervention and what their priorities are.”* (Participant 0316)

It was strongly noted that caregivers tended to know the child well, and provided accurate ‘real-life’ accounts of the child’s abilities and challenges (n=28, 82.4%).

*“They usually live with the child and are usually involved with their moment-to-moment care. Thus, they can verbalise the child's level of functioning and needs better than any other source.”* (Participant 0304)

Participants explained the greater understanding they gained through caregivers.

*“It gives us an understanding of how the family view the child's abilities and a window into what the child does at home. Often children do more at home than they will do at the clinic!”* (Participant 0316)

Interviews elicited valuable ‘holistic’ information about:

- home environments and family dynamics (n=5, 14.7%),
- caregivers’ challenges and needs (n=5, 14.7%), and
- caregivers’ insights and expectations (n=6, 17.6%).

One participant (2.9%) mentioned client-centred practice as a benefit, while three participants (9.4%) were concerned that interviews elicited subjective accounts of the caregiver’s priorities, rather than those of the child.

While interviews were reflected largely as an effective means of assessment, a number of challenges were also described.

*“The language barrier is always difficult...I find it difficult to get useful info from them...I have to call a translator which can take time.”* (Participant 0603)

*“At primary healthcare level, time is limited, so assessment and treatment occur simultaneously. Caregivers usually don’t like to answer questions as they have most likely already answered all the questions asked by someone else.”* (Participant 0318)

These quotes highlight challenging *environmental factors*. This includes the differences in language and culture between the therapist and caregiver (n=16, 50%), and having limited time available (n=3, 13%). A perceived repetition of the process of interviews with other health professionals also limited caregivers’ willingness to engage (n=2, 6.3%).

An additional social environmental challenge was that children often attended appointments with different caregivers (n=5, 15.6%), resulting in caregivers sometimes not knowing the child well enough to answer questions, as well as inconsistency in understanding of information and processes.

Challenging *personal factors* and *participation restrictions* included that caregivers often appeared to have unrealistic expectations or poor insight into the child’s condition (n=13, 40.6%). Similarly, 15.6% (n=5) reported the negative impact of some caregivers’ attitudes, towards the therapist or healthcare system in a general sense. Three participants (9.4%) stated that low educational levels of caregivers limited effective interviews. Some participants said that caregivers gave inaccurate reports on the child’s abilities (n=4, 12.5%), as explained in the example:

*“Caregivers sometimes give inaccurate information based on their hopes and goals for the child. They do not always fully understand the questions the therapist asks, and often overstate the child’s abilities.”* (Participant 0701)

#### 4.4.1.2. Interviews with the child

Only one third of participants (n=11, 32.4%) said that interviews with the child were an effective means of assessment. Challenges, reported by 33 participants, included aspects in all components of the ICF, while 30 reported what made these interviews effective.

Challenges to interviews, relating to the child's *body functions and structure* and *personal factors*, were that they were too young (n=3, 9.1%) and had cognitive impairments (n=15, 45.5%), which limited opportunities for meaningful interactions. In contrast, six participants (20%) viewed interviews as positive opportunities to evaluate the child's cognitive abilities.

The greatest *activity limitation and participation restriction* was that the children had communication difficulties, expressed by 72.7% of participants (n=24). This challenged both their ability to comprehend questions and adequately express themselves.

*"Children who are GMFCS Level 4 or 5 also have cognitive and language impairments which makes a verbal interview very difficult. For the children who are able to communicate, it is usually with an AAC [Augmentative and Alternative Communication] device or with a parent who can understand their often dysarthric speech."* (Participant 0316)

Additionally, three participants (9.1%) mentioned that children tended to be fearful or uncooperative, resulting from not having an established relationship with the therapist. As above, some participants viewed this in a different light, in that interviews could be the mechanism to establish the desired rapport (n=2, 6.7%).

*"Developing a trusting relationship with the child takes time. One has to spend time on winning the child over before assessing."* (Participant 0319)

*Environmental factors*, such as limited time (n=3, 9.1%) and inappropriate spaces in the healthcare facility (n=1, 3%) were also highlighted. The language difference between the child and therapist posed an additional barrier for four participants (12.1%).

On the other hand, there were a number of aspects perceived to make interviews with the child an effective means of assessment.

Eight participants (26.7%) highlighted how interviews facilitated improved client-centred practice, by intentionally involving children in an active manner. Interviews allowed participants to understand the child's lived experience, personal needs, goals and preferences (n=13, 43.3%), which sometimes led to improved motivation, participation and compliance in therapy (n=3, 10%).

*“Some children can clearly verbalise their needs and levels of comfort or discomfort. In such cases, it is the most useful source of information.” (Participant 0304)*

*“The patient is then involved in shared goal-setting. The patient can determine what his/her most significant barriers and enablers are. Therapy will be client-centred and meaningful. A top-down approach can be used in therapy. It will improve compliance.” (Participant 0407)*

13.3% of participants (n=4) summarised interviews as opportunities to gain a holistic understanding of the child, and others specifically highlighted the ability to:

- observe their socialisation and relationships with caregivers (n=6, 20%),
- demonstrate unknown abilities of the child to caregivers (n=1, 3.3%),
- obtain subjective pain reports (n=2, 6.7%), and
- obtain a personal account of their functional and disability experience (n=6, 20%).

#### 4.4.1.3. Observations in activities

Observations occurred mainly in the performance areas of play and leisure (n=34, 100%) and self-care (n=23, 67.6%), with few observations in school-related or productive activities (n=7, 20.6%). Participants mentioned other activities that do not fall directly into these performance areas as elements observed, including handling, interactions and relationships with families (n=1, 2.9%), testing and trialling of ADs (n=1, 2.9%) and mobility and positioning (n=3, 8.8%).

One person omitted this question, but it was clear that observations occurred overwhelmingly in healthcare facilities, with home environments seldom accessed directly (Figure 7). Two participants (6.1%) reported using video calls to observe the child at home.

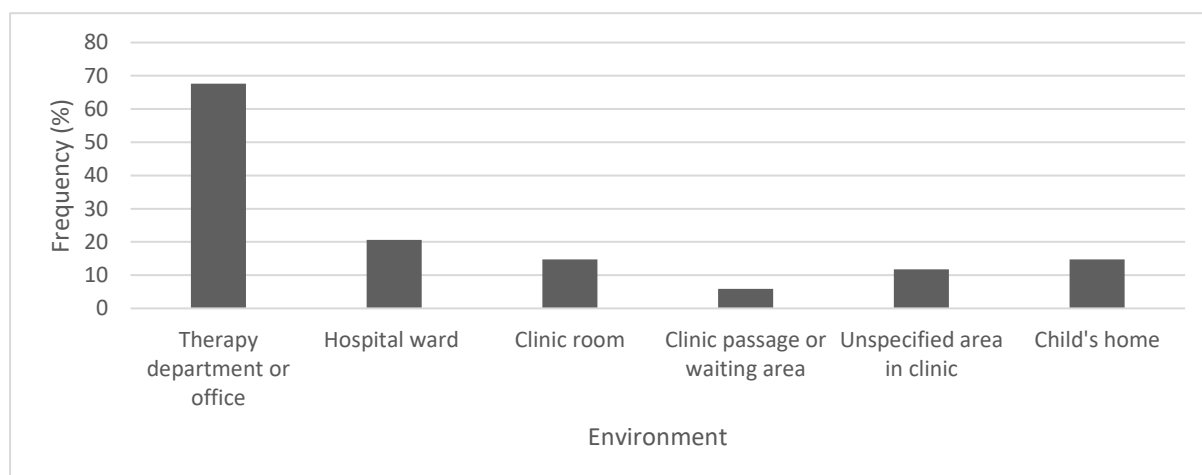


Figure 7 Environments used for observational assessments

Two participants (5.9%) explicitly stated that there were no challenges with observations. The overall positive perception of this assessment method, particularly in resource-scarce settings, is captured in the following quote:

*“With a trained eye, observation is THE tool to use in community settings where resources are low.”* (Participant 0603)

*Activity and participation factors* were the most significant facilitators of its effectiveness. Over a third of participants (n=12, 35.3%) stated that observations were efficient because a lot of information could be gained in a short period of time. Other responses alluded to this, by describing the information that could be gained, including opportunities to:

- gain a direct understanding of functional abilities and limitations (n=24, 70.6%),
- conduct task or activity analyses and explore grading and adaptations (n=5, 14.7%),
- observe interactions, attitudes and skills of caregivers (n=4, 11.8%),
- validate information provided by caregivers (n=1, 2.9%),
- uncover areas of performance that would not have been considered during interviews (n=1, 2.9%), and
- facilitate the transition into intervention (n=2, 5.9%).

Involving the child in fun, stimulating and social activities appeared to be an additional benefit (n=5, 14.7%). Considering the challenges of interviewing children, one participant (2.9%) relayed how using activities as a means allowed them to engage directly in a manner that did not require them to speak the same language.

Factors that made observations challenging, reported by 33 participants, were largely *environmental*. While language barriers were not mentioned as a challenge in this case, cultural barriers were (n=1, 3%). Similarly, nearly half of the participants (n=14, 42.4%) expressed the healthcare facility environment to be ‘inappropriate’ due to distractions, minimal privacy, and a sense of unfamiliarity or discomfort, affecting children’s behaviour and the assessment outcomes.

*“In the setting that I provide the therapy, it is very difficult to maintain the client’s attention to the activities because of the distractions (medical equipment around). Parents/caregivers are also involved in the sessions and often talk about the child’s*

*engagement at home in comparison to in the session. So then I (the therapist) also get distracted at times.” (Participant 0324)*

A further environmental concern was exposure to different toys or resources to what the child had at home, and the effect that this had on the accuracy of the assessment, captured in the quote below.

*“It may not be a true reflection of the child's ability as he may be presented with foreign toys in a foreign environment.” (Participant 0305)*

Once again, participants (n=6, 18.2%) highlighted limited time due to a pressured workload. Additionally, since observations require simultaneous engagement, observation and record-taking, with a child that typically requires significant hands-on support during activities, four participants (12.1%) highlighted that this challenge was exacerbated specifically when limited assistance was available.

*Personal factors* of the child, caregiver and therapist were mentioned. Limiting factors related to the child's motivation and the severity of illness or disability (n=7, 21.2%). The only challenges relating to the caregiver were that they sometimes displayed an expectation of meaningful intervention, as opposed to 'just' observation of their child, or that they assist the child more than the therapist would have liked them to (n=2, 6.1%). The potential subjectivity in observation and interpretation, especially when inexperienced, were limiting factors relating to the therapist (n=5, 15.2%).

#### 4.4.1.4. Standardised assessments and checklists

Only one third of participants (n=11, 32.4%) said that standardised assessments and checklists were effective means of assessment. When standardised assessments or checklists were used, a range was apparent, although this question was only answered by 24 participants.

The most common assessments were the Gross Motor Function Classification Scale, Manual Ability Classification System, Witwatersrand Developmental Profile, Ashworth Scale (regarding muscle tone) and the START (Striving Towards Achieving Results Together) Assessment (Figure 8).

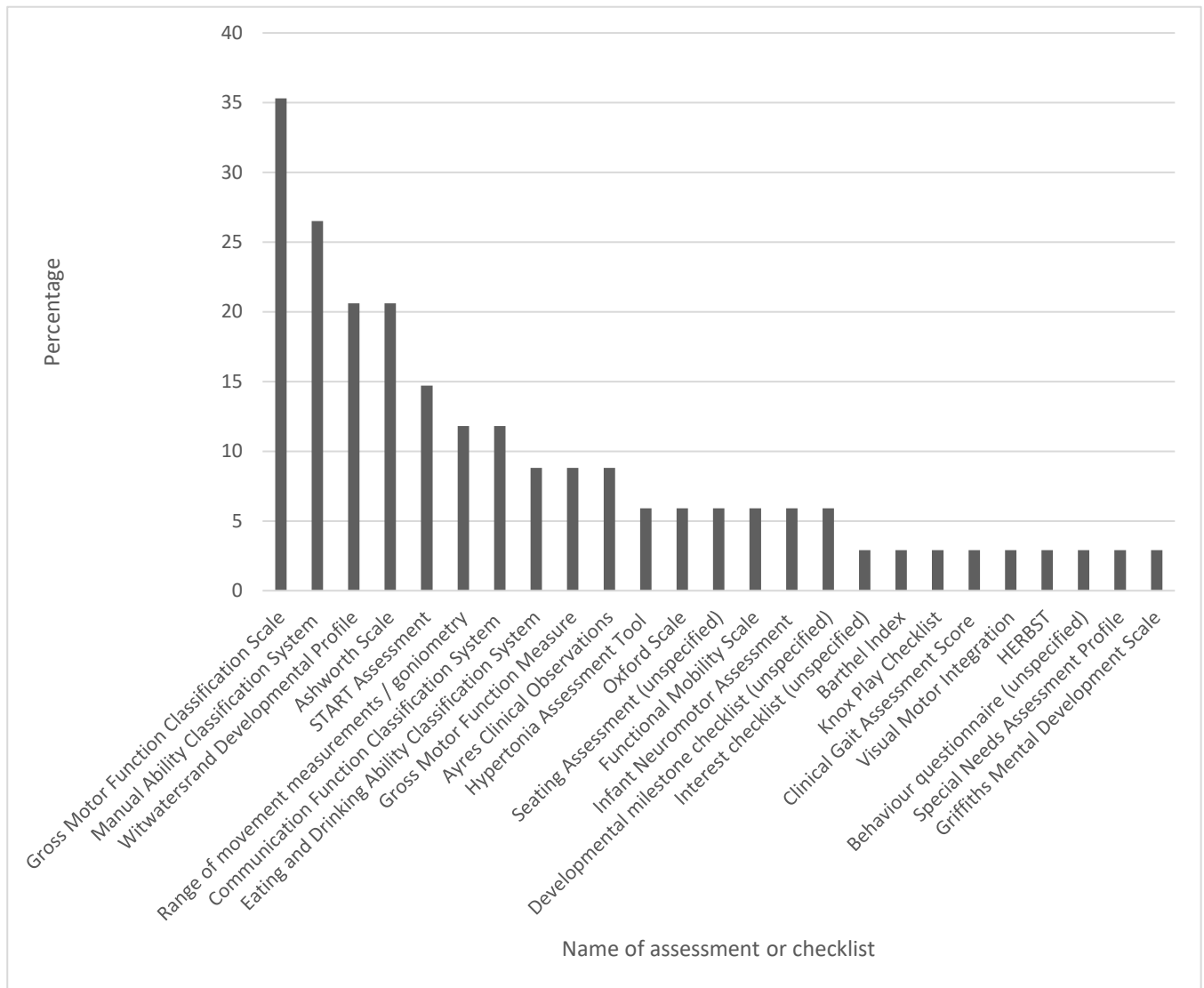


Figure 8 Frequency of various standardised assessments and checklists used

Challenges, especially *environmental factors*, which discouraged the use of standardised assessments and checklists, were reported by 30 participants. The language barrier and ‘inappropriate’ environment of the facility were again mentioned, although each only by one participant (3.3%). The limited time available was a clear barrier (n=14, 46.7%).

*“Some are very lengthy for our busy clinic environment. We generally have 40 mins [minutes] to see a child and there's a lot to get through in that time.”*

(Participant 0316)

Resource limitations were further environmental challenges. Access to training, space, computers, internet connection and equipment were lacking (n=5, 16.7%). Minimal availability of appropriate assessments was common (n=8, 26.7%), and some participants explained that

many assessments had not been confirmed to be appropriate for the South African context (n=4, 13.3%).

*“Most are standardized internationally and therefore difficult to use in our setting (terminology, cultural and socio-economic differences).”* (Participant 0407).

Over half (n=16, 53.3%) were concerned that assessments available were not suitable for children with severe CP, because of their low functional level and comorbidities, or because the tests were not stimulating enough to maintain their engagement.

*“The child's functional level is normally below the standardized scoring criteria.”*  
(Participant 0602)

*“Not always stimulating for the child, you need to be hands-on with the child and thus paperwork is difficult to manage in the session.”* (Participant 0314)

Others were simply unsure of which assessments may be suitable (n=5, 16.7%).

Aspects that made using standardised assessments effective, explained by 31 participants, related to the inherent nature of the tests themselves. Reported benefits of standardised assessments were that they:

- provide a clear and objective measure of functional performance and/or components (n=11, 35.5%),
- facilitate opportunities to accurately reassess and monitor change (n=15, 48.4%),
- provide opportunities to compare results to evidence-based norms and classify children into categories (n=6, 19.4%),
- assist in predicting developmental trajectories, and direct goal-setting and intervention strategies (n=6, 19.4%),
- create a common language for reporting (n=3, 9.7%), and
- guide therapists in what to assess and prioritise to ensure holistic assessment (n=7, 22.6%).

#### 4.4.2. Goal-setting

Goal-setting was most frequently led by the therapist and caregivers (n=22, 64.7%), and children were seldom involved. The scope of goals frequently related to prevention and

maintenance of their condition and functioning, with progress, improvement and development considered less often (Table 2).

Goals related to performance components somewhat more frequently than occupational performance (Table 2). Performance components related overwhelmingly to physical components (n=34, 100%), with only 22 participants (64.7%) highlighting cognitive, sensory or other components. A full list of performance components listed is available in Appendix 13. It is notable, however, that some participants (n= 14, 41.2%) responded with movements, tasks or activities, rather than strictly performance components. These activities or tasks listed included transfers, bed mobility or rolling, hand function, self-soothing, transfers, basic concepts and posture.

*Table 2 Goal-setting*

	ALWAYS	USUALLY	SOMETIMES	RARELY	NEVER
<u>Active involvement in goal-setting</u>					
<i>Caregiver involved</i>	18 (52.9)	14 (41.2)	2 (5.9)	0 (0)	0 (0)
<i>Child involved</i>	0 (0)	1 (2.9)	6 (17.6)	22 (64.7)	5 (14.7)
<u>Scope of goals</u>					
<i>Prevention / maintenance</i>	11 (32.4)	12 (35.3)	10 (29.4)	1 (2.9)	0 (0)
<i>Progress / improvement / development</i>	7 (20.6)	9 (26.5)	15 (44.1)	3 (8.8)	0 (0)
<u>Focus of goals</u>					
<i>Occupational performance</i>	9 (26.5)	17 (50)	7 (20.6)	1 (2.9)	0 (0)
<i>Occupational performance components</i>	12 (35.3)	19 (55.9)	1 (2.9)	1 (2.9)	1 (2.9)

#### 4.4.3. Intervention

For the purpose of this study, occupational therapy intervention was seen to comprise of direct and indirect interventions.

#### 4.4.3.1. Direct interventions

Treatments mostly took place in clinical environments at healthcare facilities. Sessions had a median length of 45 minutes and most took place on an individual basis, but frequency varied from once every two months to daily when the child was an inpatient (Table 3).

Table 3 *Direct interventions*

VARIABLE	MEDIAN (IQR; Min-Max)
Frequency of sessions (per month)	1 (0; 0.5 - 20)
Length of sessions (minutes)	45 (15; 15 – 60)
Proportion of group sessions (percentage)	0 (0; 0 – 80)
	<b>NO. (%)</b>
<u>Treatment environment*</u>	
<i>Occupational therapy department</i>	21 (61.8)
<i>Shared therapy or rehabilitation gym</i>	2 (5.9)
<i>Hospital ward</i>	3 (8.8)
<i>Consultation room in clinic</i>	6 (17.6)
<i>Outreach facility (such as day-care centre)</i>	2 (5.9)
<i>Child's home</i>	1 (2.9)

\*Some respondents reported more than one environment

Direct interventions included hands-on treatment sessions and the provision of ADs and orthotics.

##### 4.4.3.1.1. *Hands-on treatments*

Figure 9 displays the frequency of use of various types of hands-on treatments. Nearly three quarters of participants (n=25; 73.5%) frequently implemented NDT/Bobath therapy, massage and stretching and functional activities as a means of treatment. Where activities were used as a means to treat performance components, activities were mostly in the performance areas

of play and leisure (n=33, 97.1%) and self-care (n=32, 94.1%). Treatments provided least included CIMT, Movement Analysis Education Strategies (MAES) and electrical stimulation, and therapists were least familiar with bimanual training, MAES, CIMT and proprioceptive neuromuscular facilitation. Other treatments mentioned were reflex integration techniques (n=1, 2.9%), mirror therapy (n=1, 2.9%), sensory stimulation (n=1, 2.9%) and mobility training (n=1, 2.9%).

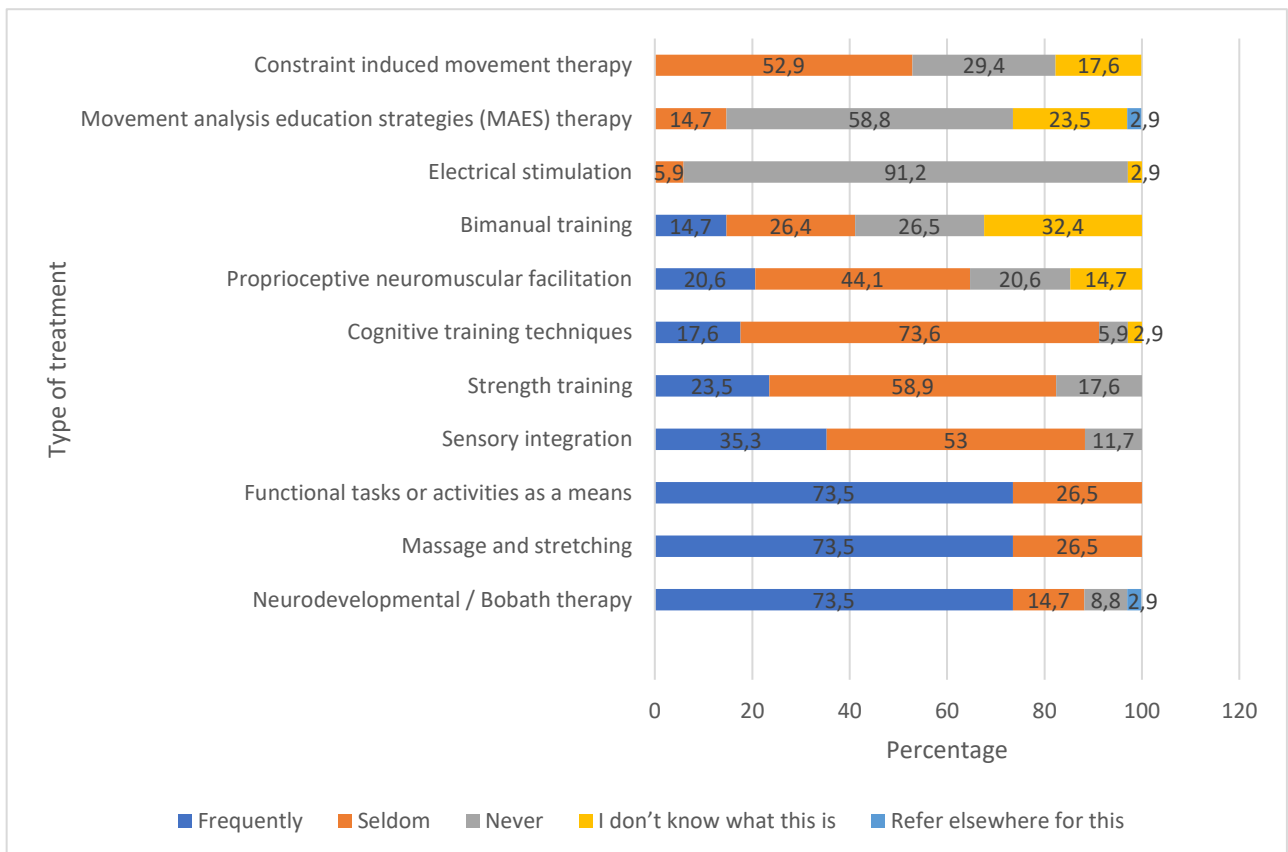


Figure 9 Frequency of hands-on treatments

#### 4.3.3.1.2. Assistive devices and orthotics

ADs considered in this research were mobility aids, positioning devices and ADs for functional tasks. Orthotics of interest were rigid and soft splints for upper and lower limbs. Responses showed that there was a relatively even distribution of ADs and orthotics being prescribed and issued across the levels of care, although they were somewhat more frequently prescribed at primary or secondary level, and then issued at tertiary level (Figure 10).

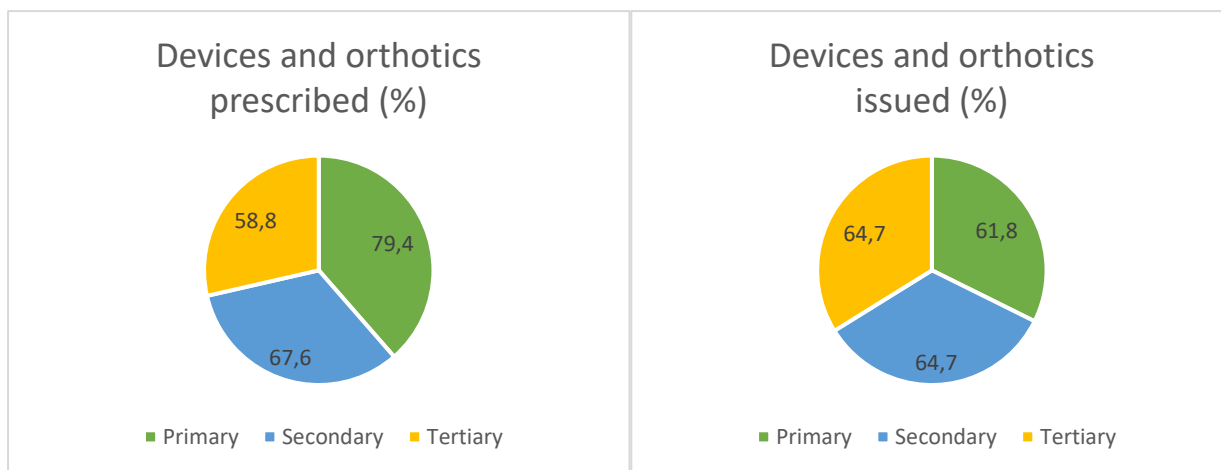


Figure 10 Level of care where ADs and orthotics were prescribed and issued

In Figure 11 it is clear that mobility aids were prescribed most frequently, with almost two thirds of participants 'always' or 'usually' prescribing them. Prescription of other positioning devices, devices for functional tasks and orthotics had more variance.

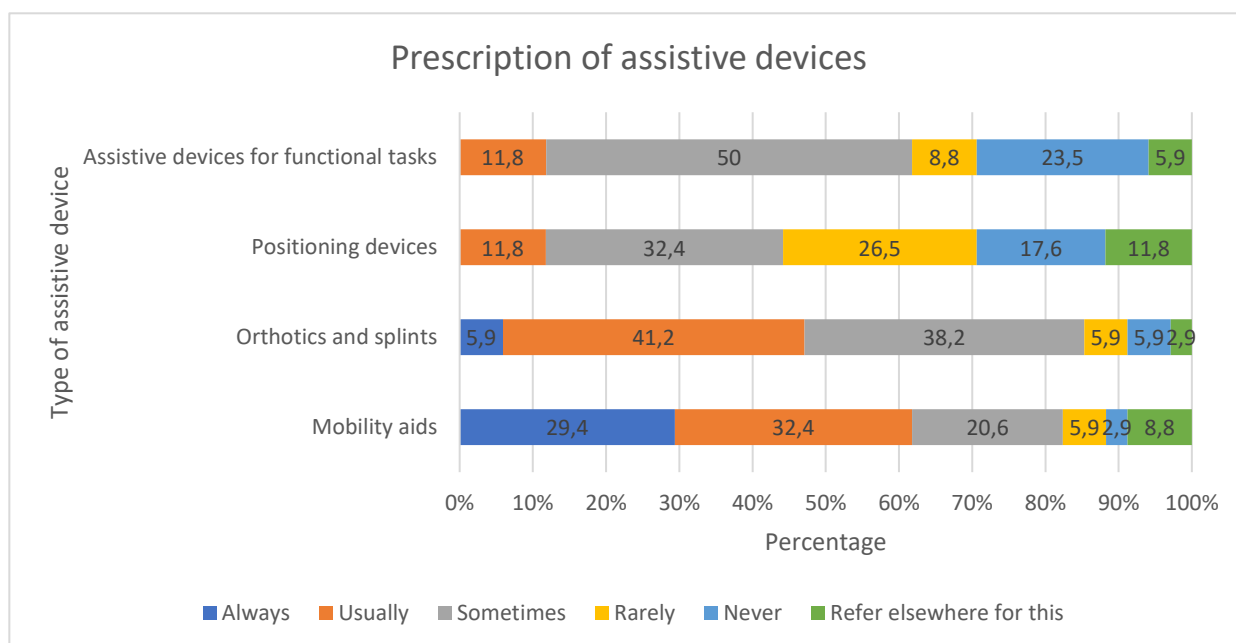


Figure 11 Frequency of prescription of assistive devices and orthotics

Figure 12 displays the frequency with which various devices and orthotics were provided. Mobility aids (indicated by purple bars) most commonly prescribed were wheelchairs and buggies<sup>1</sup>. Other positioning devices (indicated by light blue bars) such as standing frames and

<sup>1</sup> A 'Buggy' is a locally designed and manufactured specialised wheelchair, providing full-body support for children requiring significant postural support, available on the national tender.

side-lyers were commonly prescribed by less than half the participants. Participants also identified prone wedges, vehicle positioning seats and cardboard standing frames (differentiated from commercial devices) as devices they issued.

The variety of ADs prescribed for functional tasks (indicated by dark blue bars) was far greater. Devices were listed by 26 participants and were mostly used in self-care activities, such as eating or bathing. Only one AD mentioned is used specifically for play and leisure activities (Velcro attachments for toys), but a number could be used for tasks across various performance areas, such as built-up grips, splints, universal cuffs, AAC devices and non-slip mats.

Regarding orthotics (n=31), shown by the green bars, lower limb rigid splints were most commonly issued, commonly prescribed by two thirds of participants, followed by upper limb soft splints being provided by just over half. The issue of upper limb rigid splints was slightly fewer, but lower limb soft splints were rarely issued.

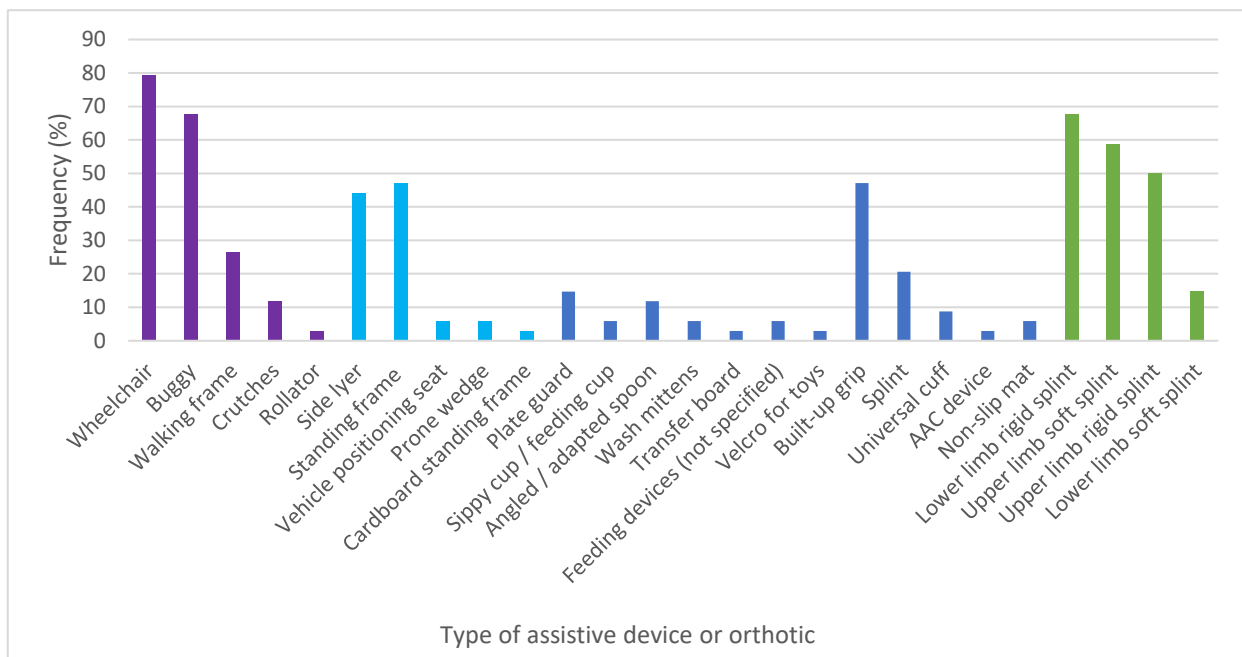


Figure 12 Frequency of the issue of various assistive devices and orthotics

Questions regarding estimated average waiting periods, frequency of review and ages that these devices and orthotics were first issued were poorly answered (see Appendix 12). There appeared to be a great variance in some cases, as summarised in Table 4, but it was evident

that devices were seldom available to issue immediately, and that children were most often first issued with devices as a toddler.

Table 4 *Waiting periods and ages assistive devices and orthotics were issued*

VARIABLE	NUMBER OF RESPONSES (N)	MEDIAN (IQR; Min-Max)
<u>Waiting period (months)</u>		
<i>Mobility devices*</i>	14	2.5 (3; 0 – 6)
<i>Positioning devices</i>	14	4.5 (4; 1 – 12)
<i>ADs for functional activity</i>	19	0 (1; 0 – 6)
<i>Orthotics / splints**</i>	11	0 (8; 0 – 12)
<u>Age of first issue (years)</u>		
<i>Mobility devices</i>	24	2.5 (2.25; 1 – 6)
<i>Positioning devices</i>	15	4.5 (3.24; 1 – 8)
<u>Frequency of review (months between reviews)</u>		
<i>Mobility aids</i>	22	6 (1.5; 3 – 12)

\* Some participants provided additional explanations rather than a single estimated average. Waiting periods for specialised mobility aids ranged from 6-24 months (n=7), but some reported no waiting periods for crutches, walking sticks or walking frames (n=4).

\*\*Some participants provided additional explanations rather than a single estimated average. For upper limb splints that they made themselves, median waiting period was 1 month (IQR: 4, Min-Max: 0-4). Too many participants provided responses regarding more specialised orthotics in a range format, so a median and IQR could not be determined, but the range of waiting periods was 2 weeks to 6 months.

#### 4.3.3.2. Indirect interventions

Indirect interventions included caregiver education, home programmes, psychosocial support, visits to homes or day-care centres, other community actions and referrals to other health professionals.

Most participants frequently provided caregiver education and home programmes, while psychosocial support, community visits and community actions were implemented less frequently (Figure 13).

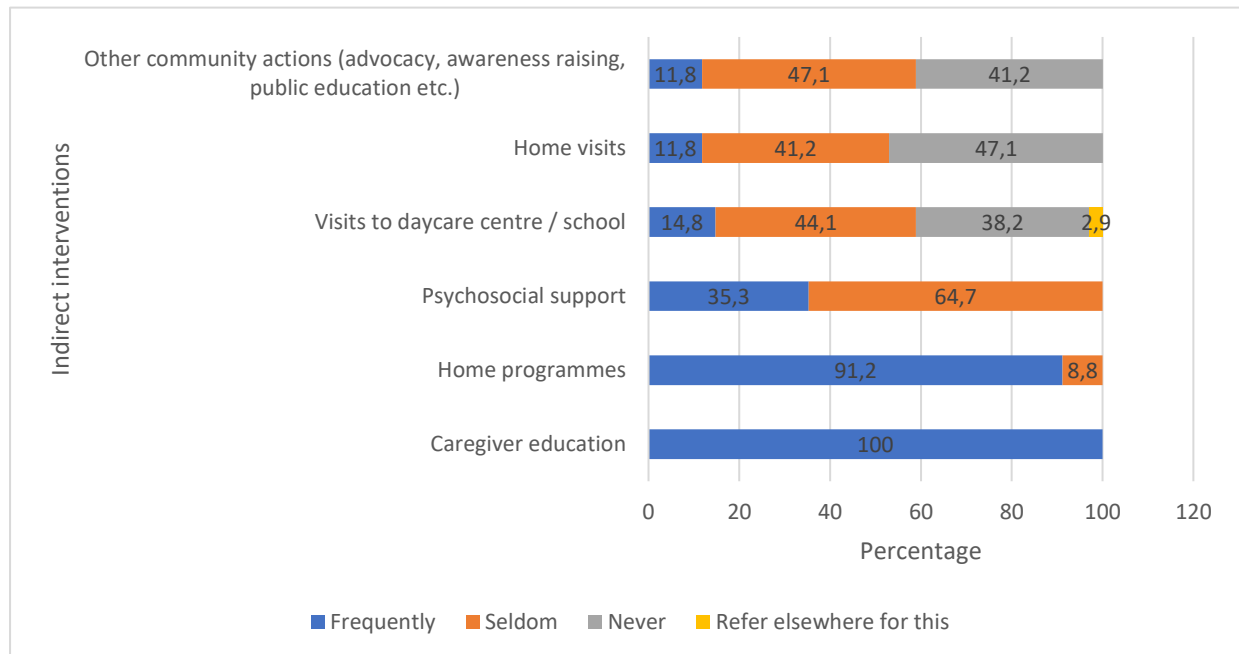


Figure 13 Frequency of the implementation of indirect interventions

Regarding the content of *caregiver education*, 33 participants provided detail. Many indicated the inclusion of information regarding the therapy process (n=27, 81.8%), treatment goals and regimes (n=28, 84.8%), diagnosis and prognosis (n=30, 90.9%) and home programme content (n=32, 97%). Fewer included education regarding caregiver burnout (n=13, 39.4%).

Exploring *home programmes* revealed a range of contents (n=33), with positioning and play and stimulation activities, standing out as key elements for caregivers to implement at home. A full list of contents listed is available in Appendix 14.

The caregiver responsible for the implementation of these home programmes was most often the child's mother (n=32, 94.1%) or grandmother (n=24, 70.6%). Aunts (n=8, 2.5%), fathers (n=7, 20.6%), foster parents (n=4, 11.8%), grandfathers (n=3, 8.8%), whole family units (n=3, 8.8%), neighbours (n=1, 2.9%), siblings (n=1, 2.9%) and staff members at care facilities (n=1, 2.9%) were also mentioned.

Caregiver *psychosocial support* was mostly provided individually (n=27, 79.4%), with only a few engaging with groups together (n=7, 20.6%).

When implemented, *other community actions* involved disability awareness (n=8, 23.5%) and health promotion activities (n=5, 14.7%). Mechanisms of these pursuits included training of stakeholders (non-governmental organisations, care facilities, staff or service providers) (n=7, 20.6%), partnerships with associations for the physically disabled (n=4, 11.8%), events (open days, roadshows and fun walks) (n=4, 11.8%) and unspecified community outreach (n=4, 11.8%).

*Referrals* to the multidisciplinary team were most commonly made to speech therapists (n=23, 67.7%), physiotherapists (n=22, 64.7%), the special education system (n=22, 64.7%) and paediatricians (n=22, 64.7%). Audiologists, orthopaedic surgeons, and other specialists were referred to the least (Figure 14).

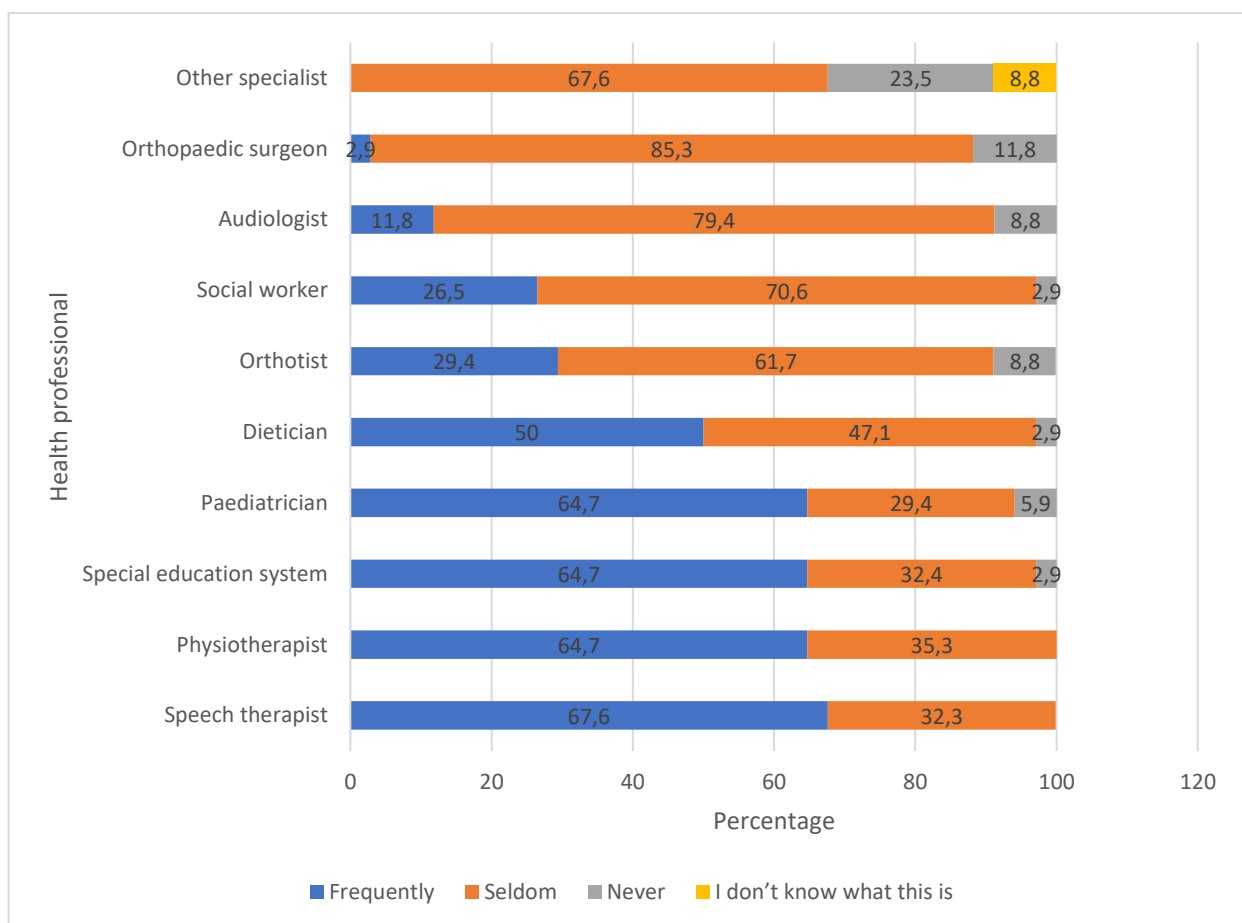


Figure 14 Frequency of referrals to health professionals

## 4.5. FACTORS INFLUENCING SELECTION OF SERVICES

Exploring environmental factors provided insight regarding service selection. Resource availability was the most salient factor, with all participants indicating that this impacts service selection (61.8% frequently, 38.2% seldom) (Figure 15). The occupational therapist’s training also impacted most participants’ selection. While the physical location of the facility played a role, the level of care of the facility was more influential. Policies only frequently played a role in service selection for six participants (17.7%), with a quarter (n=9, 26.4%) expressing that they were never influenced by policy or did not know what this was, implying that this factor was negligible.

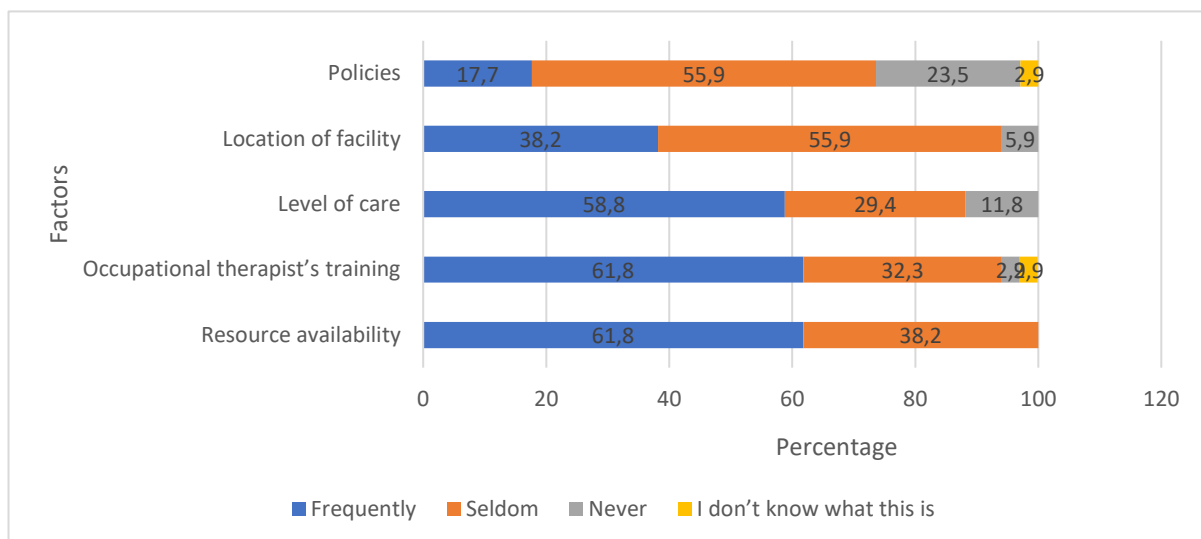


Figure 15 Frequency factors influenced service selection

### 4.5.1. Resource availability

While 33 participants responded to this question, five (15.2%) indicated that they have sufficient resources, and the remainder highlighted challenges with resource availability.

Physical resources and funding for therapeutic equipment and ADs was a limitation for half of the participants (n=16, 48.5%), with many concerned about lengthy waiting periods when resources were required. The inappropriate physical spaces available played a role in the type of treatments they provided (n=5, 15.2%). Participants expressed the following examples:

*“I work in a room that has no plinth, only basic table and chairs for kids. Treating a CP child in the restricted environment is extremely challenging. I often go find a separate spacious room to work in, usually the physio gym.” (Participant 0325)*

*“We can only see them on Fridays due to the department being too full on other days.”*

(Participant 0601)

Transport for both the therapist and families, also challenged the type and frequency of interventions (n=5, 15.2%). This impacted the caregiver’s ability to transport ADs, the therapist’s potential for home visits, and transporting equipment between facilities.

Human resources, with a direct impact on therapists’ caseloads and amount of time available, was raised (n=7, 21.2%).

*“Limited number of staff with limited caseload that can be managed. Priority often given to acute cases at clinics, leaving less time to follow-up on ongoing regular basis with CP children.”* (Participant 0309)

One additional participant (3%) noted that it was not specifically the lack of human resources, but that those present were not sufficiently trained to manage children with severe CP.

Nine participants (27.3%) conveyed matters regarding macro-level resource availability. Specifically highlighted were the lack of special schools, care centres or other community supports, as well as general poverty within families, which limited what they could implement at home.

Eight participants (24.2%) noted that resource availability was directly related to the level of care at which they worked, for example having access to equipment at the main facility that they serviced, but not at primary level clinics.

#### 4.5.2. Level of care

There were 28 responses relating to how level of care influenced services.

Physical factors, including space, equipment, budget and proximity to the community, were raised by 14 participants (50%). They communicated that resources required for specialist interventions were available at secondary and tertiary levels of care, but seldom at primary level. Benefits of working at primary level were, however, expressed in the following remark:

*“We are however closer to the patient’s living environment and crèche if visitations are indicated. The client has easier access to us for assistive device repairs.”*

(Participant 0601)

Human resources were highlighted by numerous participants (n=16, 57.1%). Quicker and more direct access to the multidisciplinary team was reported at higher levels of care, and referral to more specialised services was a challenge.

*“At higher levels of care, a variety of services are usually more easily available and thus more children can be referred. Referring children from a primary care level to a tertiary service level requires many resources and a long waiting time.”*

(Participant 0304)

*“The fact that we are a secondary institution allows us have a wide network of support, therefore we are able to refer our patients to the necessary disciplines as required.”* (Participant 0401)

Another consideration was Standard Operating Procedures, policies and service guidelines and quotas depicting what services could be provided at each level of care. This was discussed by two thirds of participants (n=19, 67.9%). Most highlighted concerns regarding equity and being unable to provide appropriate treatment when it was needed, especially at primary level. Three quotes outline these matters:

*“At Primary level it is not possible to provide intensive therapy. Focus is therefore on caregiver education and home programmes. In each session only the most pressing/urgent needs can be addressed.”* (Participant 0309)

*“There is a lot of pressure to refer to community workers, therefore therapy is less hands-on and more focused on functional activities and interventions that mid-level workers and parents will be able to conduct at home.”* (Participant 0701)

*“The focus of care at our facility is on adults, so priority for equipment goes to that.”*  
(Participant 0601)

#### 4.5.3. Location of facility

A third of the 27 respondents to this question discussed equipment and resources in terms of the location of their facilities. Facilities in urban areas were better resourced than those in rural areas (n=9, 33.3%), and in instances where facilities in urban areas were under-resourced, they were in closer proximity to secondary or tertiary level facilities to refer children to access what was needed.

Where therapists had responsibility for more than one facility, they often needed to make use of the same equipment at all of them, and minimal access to appropriate transport limited the intervention options they had at hand (n=4, 14.8%). This was demonstrated in the following quote:

*“Remote clinics often don't have appropriate therapy areas and very limited therapy equipment - I can only use equipment or objects that I can travel with.”* (Participant 0308)

Similarly, transport for families was a key challenge raised by nearly two thirds of participants (n=17, 63%). Large distances between homes and facilities, and transportation of mobility devices, both raised transport costs. This influenced the frequency of attendance, and thus the type of services prioritised. The following quotes highlight the scenarios faced, demonstrating that families in rural areas faced more challenges than those more central.

*“Transport challenges greatly affect how we structure the services offered. Families living near a clinic who have their own transport can easily come once a month for follow-up sessions. Others out on farms and outlying areas simply cannot afford this. Then services are structured differently and review only every 3 months or so, with great focus on caregiver training.”* (Participant 0309)

*“Seating clinic is based at the metropole hospital - taxi will charge patients double for the mobility device or sometimes refuse to transport.”* (Participant 0403)

Broad social matters were only raised by two participants (7.4%), with community stigma, perceptions of healthcare services and concerns for violence in the community negatively affecting how families approached healthcare services. Access to other community supports, such as schooling and home-based health workers in their catchment areas further influenced service selection (n=3, 11.1%). An example below demonstrates where access to occupational therapists was challenging, but home-based services was a promising option:

*“Families are not always close to the hospital and therefore needs to be followed up in the community by Healthcare Workers or Home-based Care Workers, whoever is serving in the particular community.”* (Participant 0320)

#### 4.5.4. Policies

Seven of the 22 respondents to this question (31.8%) did not think that policies impacted their services, leaving only 15 responses explaining more about the role of policy.

Participants described policies as being prescriptive of the services they provided and prioritised (n=12, 54.5%). This included policies on a national or provincial government level, as well as internal facility-level policies.

*“Healthcare 2030<sup>2</sup> (tertiary level should focus on inpatients).*

*Therefore, children should be referred to their nearest therapist (CHC [community health centre] level).” (Participant 0407)*

*“Inpatient treatment is priority at the district hospital I’m working at, therefore I’m limited in seeing any outpatient paed[iatric] cases.” (Participant 0323)*

*“We have a priority list which determines how often children can be seen (once a month maximum, ranging to 6 monthly).” (Participant 0316)*

Concern regarding service prescription that was highlighted by four of these 12 participants (33.3% of subset, 18.2% of total), related to the treatment of children of school-going age. Protocol stated that they should only access treatment through the Department of Education, rather than the DoH, as stated in this quote:

*“Policies prevent me from continuing therapy with children that are school-going age.”*  
(Participant 0305)

Policy relating to ADs was raised by nearly a quarter of participants (n=5, 22.7%). They noted that policies were supportive of children receiving required devices, but limitations were imposed regarding how and who they were provided to:

*“The National Rehabilitation Policy and the Western Cape position paper indicate that all children should receive rehabilitative services and ADs.” (Participant 0322)*

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<sup>2</sup> **Healthcare 2030** is the Western Cape DoH’s strategic planning document, outlining a whole society, participatory approach to sustainable healthcare and community wellness (Western Cape Government Health, 2014).

*“Issuing a mobility assistive device for a patient who does not have a Western Cape address - their province needs to.” (emphasis added, Participant 0403)*

One participant (4.5%) considered broader-scale socio-political factors, expressing concern for the basic conditions of communities in that they lacked support from other government sectors, in terms of water and electricity in homes.

#### 4.5.5. Occupational therapist’s training

Of the 31 responses, 23 (74.2%) felt that it would be ideal for therapists to have specialist or post-graduate training to better meet the needs of children with CP. Eleven (47.8% of subset, 35.5% of total) had attended additional courses, which benefitted their practice by broadening the interventions they could select. This is demonstrated below:

*“Additional postgraduate neurodevelopmental courses have expanded my OT ‘toolkit’ and improved my handling skills, resulting in me being more comfortable to treat and spend time observing and waiting for a response from the child.” (Participant 0321)*

*“Being trained in Bobath and Hambisela Pro<sup>3</sup>, these are at the core of therapy. These provide a nice balance between components and function.” (Participant 0317)*

Twelve of these participants (52.2% of subset, 38.7% of total) stated that they did not have additional relevant training, but most expressed how this would enhance service provision:

*“If I had more specialized training in neurology, I would be able to offer a better therapeutic service to these children and would be able to refer to other services more appropriately.”*

(Participant 0304)

On the other hand, the perceived requirement for therapists to have generalist roles and broader holistic approaches, particularly at primary level, was a further concept that emerged (n=7, 22.6%). One participant expressed that her role as a generalist limited her opportunities to access more specialised training:

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<sup>3</sup> **Hambisela Pro** is a local course offered to health professionals, focusing on treatment of children with CP in settings where resources are limited. A functional approach with strategies to involve and empower caregivers are core outcomes of the training (van Aswegen, Myezwa, Potterton, & Stewart, 2019).

*“Sometimes I'm not on par with the latest treatments available. My current skill set within the hospital requires me to be a general OT, therefore I'm not able to attend paed[iatric]-specific courses.” (Participant 0323)*

Two participants (6.5%) expressed the limited opportunities to access mentors in the field, in order to enhance skills and develop in their profession. Two participants (6.5%) concluded that they referred to other occupational therapists if more specialist interventions, beyond their own skills, were required.

#### 4.5.6. Models of practice

Amongst those that responded to this question (n=29), one was unsure of what this referred to, and other responses were greatly varied. Considering it was an open-ended question, a number of participants listed approaches and other structured guidelines not strictly viewed as models of practice or frameworks. However, these were included in the results, as they provided relevant insight into theoretical elements guiding services.

About a third of participants (n=10, 34.5%) listed the Person-Environment-Occupation model as a guiding model, and others frequently mentioned included the biopsychosocial approach (n=8, 27.6%), ICF (n=7, 24.1%), NDT approach (n=5, 17.2%) and Model of Human Occupation (n=5, 17.2%). The array of the remaining responses is listed in Appendix 15.

## 4.6. FULFILMENT OF OCCUPATIONAL THERAPY ROLE

To conclude the questionnaire, perceptions of the adequacy of participants' services were explored.

Figure 16 indicates the responses provided, with most participants believing that they were meeting a few or some of the children's needs (n=20, 58.8%). While 17.7% of participants (n=6) felt that they were meeting most of their needs, it was only together with other members of the multidisciplinary team that it was thought that all of their needs could be met (n=8, 23.5%).

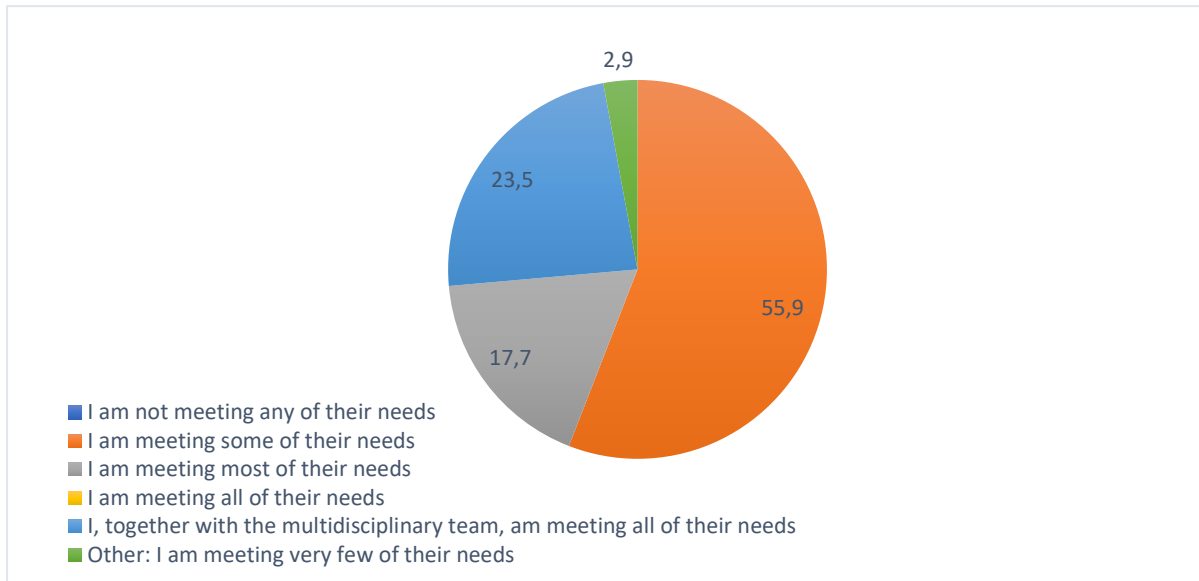


Figure 16 Perception of meeting the needs of the child

When exploring what participants felt that they were not sufficiently providing, most shared their concerns (n=30).

The provision of ADs, more thorough positioning programmes and orthotics were most commonly raised (n=12, 40%). Following this, the desire for more frequent treatment sessions was highlighted (n=9, 30%). These matters are illustrated below:

*“Waiting time for mobility assistive devices sometimes can increase disability.”*

(Participant 0320)

*“They can only be seen once a month which means that they need to follow their home programme. Intervention would of course be much more effective with more regular hands-on treatment... The more contact we have with carers and children, our service will be more effective and complications can be prevented.”* (Participant 0301)

Extending services to meet caregivers’ needs through training and support (n=8, 26.7%), was also expressed to be of importance, with some particularly feeling that more services in a group format could benefit both the children and their families (n=5, 16.7%).

*“Support to caregivers, especially group-based support. It is logistically and practically difficult, and time is limited.”* (Participant 0601)

Desires for more successful and efficient referrals to community services were also mentioned (n=5, 16.7%), as below:

*“Linking with the other facilities such as crèches or special schooling. There is just too much else to do. It requires dedicated, consistent services which I am not able to dedicate myself to.”* (Participant 0603)

Participants also wished to provide more appropriate services, particularly occupation-specific interventions (n=3, 10%), and services in their home languages (n=2, 6.67%) and home context (n=5, 16.7%). These were highlighted as opportunities to improve the quality of interventions:

*“Home visits will assist a great deal as these kids are mainly in their home environments, so assessing and treating them in those environments with the resources available to them will maximize occupational performance.”*

(Participant 0318)

Other areas felt to be insufficiently provided were ‘hands-on’ treatments (n=3, 10%) and opportunities to provide support to levels of care where they felt the need was greater (n=2, 6.7%). Lastly, participants desired to implement adequate re-assessments (n=1, 3.3%), improve continuity of care (n=1, 3.3%) and explore mechanisms to assist with patient transport (n=1, 3.3%).

#### **4.7. SUMMARY**

Occupational therapy services included assessments, goal-setting and interventions. Assessments were largely completed through interviews with the child’s caregiver and observations in play or self-care activities. Goals related to occupational performance components more than occupational performance outcomes, and largely aimed at maintaining the child’s condition or function, as opposed to promoting development or improvement. Caregivers were sometimes involved in goal-setting, but children seldom participated in this.

A range of interventions were provided, but were limited in terms of direct therapies. Many children needed ADs and orthotics, but faced lengthy waiting periods. Interventions occurred mainly in clinical settings and, since appointments were infrequent, home programmes and caregiver education were common indirect interventions.

Factors influencing the selection of services were mainly resource availability, therapists' training and the facility's level of care. Therapists felt they were meeting some of the children's needs, yet all of their needs could be met with the services of the multidisciplinary team.

## CHAPTER 5: DISCUSSION

### 5.1. INTRODUCTION

This research was initiated in response to the suspected challenges in occupational therapy service provision for children with lifelong disabilities and high therapeutic needs, within the under-resourced South African public healthcare system (Coetzee, 2018; Cullinan, 2006; Donald et al., 2015; Pretorius & Steadman, 2017).

This cross-sectional study aimed to describe the current services and contextual factors influencing service selection. This could prompt revision of resource allocation, policy guidelines and intervention strategies across healthcare levels. More efficient and meaningful service provision could facilitate improved QoL and participation of children and their families, and thereby reduce the burden on the healthcare system.

While not intending to appraise current services, the results will be discussed in relation to relevant policies and the notion of best practice for this population. Elements of best practice guiding this discussion are the family-centred approach, holistic evidence-based services, and intensive and early interventions (Darrah et al., 2010; Majnemer et al., 2013; Palisano et al., 2012; Saleh et al., 2008). This chapter concludes with a discussion about the representativeness and generalisability of the results.

### 5.2. THE FAMILY-CENTRED APPROACH

There were indicators of participants implementing elements of the family-centred approach, despite there only being a single mention of it amongst responses. Far more participants referred to efforts towards client- or person-centred approaches. While similar, family-centred services are depicted as an element of best practice for children with CP (Baker et al., 2012; Novak, 2010; Novak et al., 2009), and is recommended in the FSDR (Department of Health, 2015).

This approach involves partnerships with families as significant role players, where their knowledge of the child's needs is valued (Rosenbaum, King, Law, King, & Evans, 1998). Whether conscious or not, participants' service selection and responses to open-ended questions

showed evidence of collaboration occurring in assessments, goal-setting and interventions. Participants additionally expressed the desire to increase caregivers' active involvement.

The most frequently used assessments, namely interviews with the child's caregiver and observations, show collaboration and acknowledge the knowledge and roles that caregivers play in the child's life.

There were, however, challenges to the quality of implementation of the family-centred approach in assessments, such as language and cultural differences between involved parties. Additionally, the family-centred approach emphasises that the values lies in the family being the constant in the child's life (Rosenbaum et al., 1998). This, however, did not appear to be the reality of this study's context, where variable caregivers accompanied the child to appointments, often without sufficient knowledge of the child's condition or needs.

Participants were, however, not alone in experiencing challenges of fully assimilating the uniqueness of families required for true implementation of the family-centred approach (Rosenbaum et al., 1998; Saloojee et al., 2011; Shevell et al., 2019). While socio-political challenges may be navigated and overcome to an extent, the pressured South African public healthcare system may have limited resources required to do so effectively.

Novak (2010) recommends involving families in goal-setting, largely for considering interventions regarding contextual influences on the child's participation. While the local influences may be substantially different to those Novak encountered in Australia, the principle of family involvement remains the same. Involving families in goal-setting improves compliance (Chiarello et al., 2010); a matter of concern to many participants in this study.

Family-centred participation may be challenged by the apparent tension between wanting input from caregivers, and concerns that they tended to emphasise their own needs above those of the child. While participants mentioned that addressing caregiver needs required improvement, goals still typically related only to the child's occupational performance or performance components. It is, however, acknowledged that there may not have been sufficient scope in the questionnaire for participants to express other goals. In contrast to the findings of Saloojee et al. (2011), where parents in public hospitals in South Africa were rarely

consulted, participants reported frequent caregivers involvement in goal-setting; a commendable pursuit in light of their reported apprehension and context.

Many indirect interventions reflect the family-centred approach, although, once again, not without contextual challenges to meaningful implementation. An example of its, possibly inadvertent, application was addressing caregivers' stress and burden. Despite therapists' awareness of these family experiences, they reported minimal provision of psychosocial support, and few referrals to social workers or others who could fulfil this role. These are known needs of families, especially when the child is young, and as in the literature, this may be an area of family-centred service that is sub-optimally provided (Mohd Nordin, Hui Shan, & Zanudin, 2019; van Aswegen et al., 2019).

Similarly, an element discussed in the literature to require strengthening was the provision of information and education to parents (Jeglinsky, Autti-Rämö, & Brogren Carlberg, 2012; Molinaro et al., 2017; Myrhaug, Jahnsen, & Østensjø, 2016; Shevell et al., 2019). Participants in this study indicated education as an indirect intervention provided to most families. This practice should be encouraged as it facilitates parents making informed decisions and engaging appropriate community support (Myrhaug et al., 2016). In this regard, Shevell et al. (2019) recommend that caregiver education is designed to meet the unique needs of each family, by considering their context, and existing insight, understanding and needs. Unfortunately, the lack of time and human resources is a reality which may limit the practical implementation of this suggestion.

Caregiver involvement in home programmes would intuitively appear commendable. However, understanding whether home programmes were planned collaboratively or prescribed to the family, would indicate whether this may be viewed as effective family-centred practice. Novak et al. (2009) express that, while home programmes are recommended, families often tend to seek and prefer direct interventions from therapists. Contextual and institutional barriers in SA make this unrealistic and unsustainable, and the reliance on indirect interventions like home programmes, therefore appears to be necessary. These may be the primary mechanism of involving the family as team members, whilst direct therapy in clinical settings is typically more therapist-led (Kruijsen-Terpstra, Ellens, et al., 2016). Considering this imbalance of direct and indirect interventions and the intent to establish collaborative

partnerships, the role that therapists and families expect one another to play, may need to be addressed.

The family-centred approach improves caregiver satisfaction, attitudes and psychosocial wellbeing, as well as functional and participatory therapy outcomes (Baker et al., 2012; Dunst & Trivette, 2009; Shevell et al., 2019). With evidence of these benefits originating largely in the global north, it is recognised that positive outcomes may not be easily replicable in SA. Saloojee et al. (2011) note the current lack of an appropriate tool evaluating the implementation of family-centred services in resource-poor settings, which indicates the lack of evidence for these contexts. However, similarly, implementation in these research contexts tends to be fair to moderate, and also not yet fully adopted in contexts of PHC (Jeglinsky et al., 2012; Molinaro et al., 2017; Myrhaug et al., 2016; Shevell et al., 2019).

It appears that study participants would like to reap the benefits of a family-centred approach, yet face contextual challenges in doing so effectively. Interestingly, services that participants felt were lacking included home visits and sufficient frequency of opportunities for direct therapy, which usually took place in healthcare facilities. These two actions would support and contrast the family-centred approach respectively, which may clearly illustrate its current inconsistent application.

### **5.3. HOLISTIC EVIDENCE-BASED SERVICES**

Best practice is said to occur when modalities are evidence-based, contextually relevant and holistically address the child's needs (Raji, Hassani Mehraban, Aliabadi, Ahmadi, & Schiariti, 2018). With this said, evidence supporting practice should always be interrogated in terms of its context of origin, and thus its applicability and generalisability to the practice context.

Discussing holistic, evidence-based approaches begins with the foundational practice frameworks. While relatively varied, the models and frameworks participants mentioned, such as the Person-Environment-Occupation model, Model of Human Occupation and the biopsychosocial approach, are all prevalent in occupational therapy literature with various populations (Kielhofner, 2009; Law & Darrah, 2014). Additionally, these foundations align to varying degrees with the ICF, which is a recognised holistic framework for all health

professionals. Raji et al. (2018) and Palisano et al. (2004) noted challenges with implementing the ICF with children with CP, particularly since cause-and-effect relationships between impairments, environmental factors, and participation may be difficult to identify in the presence of complex contexts and diagnoses. Despite this, the ICF remains a valuable tool to guide holistic services (Raji et al., 2018) to effectively improve function, alter environments, adapt methods, prevent secondary concerns and create opportunities for participation (Dunn et al., 1994).

### 5.3.1. Assessments

It was unclear whether participants used a combination of assessments, but if used in isolation, none of the assessments included in the questionnaire would effectively address all elements of the ICF. Use of caregiver interviews and observations may provide insight into the elements of body functions and structure, and some information regarding activity participation. However, considering most assessments occurred in clinical settings, insight into the environmental factors influencing participation may be lacking. This was affirmed by participants' desire for more opportunities to assess in different environments, including the child's home.

While standardised assessments were seldom used, this is often an important element of occupational therapy education programmes and is emphasised when considering evidence-based practice (Peters, Chang, Morales, Barnes, & Allegretti, 2019). Participants' understandings of the potential value of standardised assessments aligned with literature, including the benefit of objective measures, the use of a common language and the guidance they provide towards treatment (Peters et al., 2019). However, the evidence for the utilisation of some standardised assessments with children with CP is lacking (Steultjens et al., 2004), especially in the global South, validating participants' concerns regarding their application.

When selected, standardised assessments varied greatly, and only the GMFCS, Gross Motor Function Measure and Manual Ability Classification Scale aligned with those most frequently used internationally (Ko & Kim, 2013; Peters et al., 2019). Other assessments used abroad, not mentioned by this study's participants, were the Assisting Hand Assessment, Paediatric Evaluation of Development Inventory, Canadian Occupational Performance Measure, Goal Attainment Scale, Paediatric Motor Activity Log and Quality of Upper Extremity Skills Test (Ko

& Kim, 2013; Peters et al., 2019). While some of these are freely available, many need to be purchased (Peters et al., 2019), calling for financial resources participants scarcely had available. Additionally, the controlled environment and average time of 30-40 minutes required (Peters et al., 2019) would be unrealistic for most therapists at government institutions.

Many standardised assessments relate to body functions and structure, rather than participation and environmental factors. This indicates a skewed approach to assessment, similar to the findings of Raji et al. (2018), where body functions had the highest importance and environmental factors were the biggest gap in assessment. This potentially challenges considering the child and their family holistically, and thus the formulation of appropriate goals.

### 5.3.2. Goal-setting

Goals expressed indicated a similar imbalance in the elements of the ICF. Participants tended to focus more on occupational performance components, which can be likened to the body functions and structure elements, than occupational performance, likened to functional participation. This aligned with the study by Palisano et al. (2012), where body functions and structure took precedence in therapists' approaches. Considering the profession's primary interest in everyday doing and participation, and implications on wellbeing (Law & Darrah, 2014), one would not expect this to be the case. The essence of the medical model being present in therapists' understandings of disability, may oppose prioritising occupational performance and participation, which would call for more holistic inclusion of other ICF elements in goal-setting (Albert, 2004; World Health Organization, 2011).

This said, when function and participation were considered in goal-setting, priority performance areas for participants were similar to that of American families (Chiarello et al., 2010). Basic self-care activities of eating and dressing took precedence for Chiarello's (2010) participants, and those in the current study. Socialisation appeared to be the most valued leisure pursuit for parents in the research of Chiarello et al. (2010), but was not mentioned by this study's participants.

Similar to the literature, goals related to body functions and structure emphasised physical components (specifically muscle strength, proprioception and range of movement), rather than cognitive or perceptual skills (Palisano et al., 2012; Raji et al., 2018). Papavasiliou (2009) discussed therapists' roles, suggesting that physiotherapists had greatest interest in gross motor skills and mobility and, while goals overlapped, occupational therapists additionally contributed to fine motor and upper limb skills, and perceptual and sensory processing skills. That is, occupational therapists considered body functions and structure more holistically, for the purpose of participation.

Raji et al. (2018) suggested reasons for prioritising physical components, in that these are the primary signifiers of CP, and pose risk for secondary conditions if not addressed. While this may be the case, approaches may also differ within this. The 'bottom-up' approach promotes focus on movement components and patterns, which in turn will affect function. Contrarily, the 'top-down' approach is recommended for occupational therapists as a more holistic approach, where the child's performance in context is prioritised, followed by activity analyses to identify underlying performance components needing attention (Majnemer & Mazer, 2004; Palisano et al., 2004; Raji et al., 2018). Considering the assessment methods discussed previously, while some participants displayed this 'top-down' approach, many alluded to having a 'bottom-up' method to their practice.

A possible additional explanation for the focus on physical components may lie in the environmental factors that participants described. In light of the limitations of human resources, many were expected to fulfil a generalist or transdisciplinary role. For example, opportunities for children to be treated by both occupational- and physiotherapists may be rare (Mahlathi & Dlamini, 2015), and occupational therapists may be expected to meet the child's priority challenges.

### 5.3.3. Intervention

Both direct and indirect treatments were selected; an illustration of efforts towards holistic practice. The literature relating to children with CP and other domains, however, mentions that many occupational therapists are not implementing treatment techniques that are proven to be effective (Novak et al., 2013; Saleh et al., 2008). There may be additional reasons for this in

this study's context, but Dodd et al. (2010b), Steultjens et al. (2004) and Novak et al. (2013) suggest conditions challenging therapists' commitment to evidence-based practice, including inadequate research availability, educational systems barriers and dispositions of therapists, patients and workplaces.

In the current study, it appeared that participants desired to implement more evidence-based practices. However, the influence of the workplace location, level of care, policies, and therapist factors echoed the above sentiments regarding contextual factors prompting their service selection. Specifically, participants discussed how additional training, or lack thereof, played a substantial role in selecting interventions, as many sensed that they did not have sufficient skills to address the needs of children and their families holistically. Confirming this, Bakuwa, Pilusa, and Saloojee (2020) discuss the benefits of practical post-graduate training, to broaden skills, shift attitudes and improve confidence. This, in turn, improves the outcomes for children and families.

Results relating to direct interventions highlight specific gaps between evidence and practice. Particularly notable is the contrast between the high frequency of NDT and stretching methods, and the low quality, minimal evidence for this (Novak et al., 2013; Papavasiliou, 2009). Raji et al. (2018) suggest that therapists choosing to implement NDT as their primary treatment modality may be acting on the assumption that restoring performance components will directly affect functional abilities. This again illustrates the 'bottom-up' approach and elements of the medical model at play.

CIMT and bimanual training are modalities with more evidence backing their use (Novak et al., 2013; Papavasiliou, 2009), yet were implemented very rarely, or not known about, by most participants in this study. Suggested reasons for this are the potential over-endorsement, or omission, of treatments in occupational therapy undergraduate programmes, and the influence of environmental limitations. These may include challenges with the required caregiver compliance, considering the consistency and additional behavioural interventions required for successful CIMT programmes (Milton & Roe, 2016).

Most direct interventions were implemented in healthcare facilities. While evidence is minimal regarding additional functional improvements when services were provided in community

settings, benefits related to compliance and satisfaction with services, and overall QoL (Dambi & Jelsma, 2015; Mohd Nordin et al., 2019; Steultjens et al., 2004). A shift towards community-based rehabilitation was recommended in recent policy documents (Department of Health, 2000, 2015), but appears to not yet be implemented. Unfortunately, this research did not elicit sufficient illustration of the service variances at each level of care, which would be valuable to consider relative to the guidelines in the FSDR (Department of Health, 2015).

While the use of splints and orthotics was commonly selected by participants, and is recommended in the literature, evidence remains mixed for their effectiveness (Novak et al., 2013; Papavasiliou, 2009; Steultjens et al., 2004). While the purpose of selection could not be understood from this study, literature mainly recommends splints and orthotics for the purpose of contracture management (Jackman et al., 2014; Ranjan et al., 2011), aligning with the emphasis placed on physical components in participants' goals rather than holistic function. Similarly, Novak et al. (2013) and Steultjens et al. (2004) explain how evidence for seating and positioning is mixed and lacking in rigour. These interventions, however, present few risks and remain recommended for their potential benefits for both performance component and functional participation outcomes. ADs are recommended to promote motor skills and function, but evidence is also somewhat varied (Novak et al., 2013; Papavasiliou, 2009). Thus, participants' concerns regarding limited access to appropriate positioning equipment and ADs may be warranted, and aligns with the requirement prescribed in the NRP (Department of Health, 2000).

Regarding indirect interventions, evidence promoting home programmes is comforting (Novak et al., 2009; Novak et al., 2013; Papavasiliou, 2009), as these were heavily relied upon by participants. While current literature appears to focus on caregiver compliance with home programmes, details lack regarding recommended content, formats and generalisability across populations or children with varying severity of conditions. It is, however asserted that function is improved through home programmes, as opposed to when home programmes are not implemented (Ngubane & Chetty, 2017; Novak et al., 2009).

The Hambisela programme was specifically mentioned by some participants, and is shown to be effective in increasing caregivers' understanding of their child's condition, resulting in improved acceptance and confidence in their role (van Aswegen et al., 2019). This may be

because the Hambisela programme has a transdisciplinary outlook (van Aswegen et al., 2019), and addresses elements of the ICF, matching recommendations for holistic frameworks for home programmes by Novak et al. (2009) and Palisano et al. (2012).

Other indirect interventions such as caregiver education and support appeared to be selected as a means to address caregiver stress and burden, which was a concern of participants in this study and other local literature (Dambi & Jelsma, 2015; van Aswegen et al., 2019; Zuurmond et al., 2018). The NRP (Department of Health, 2000) and Zuurmond et al. (2018) advocate for psychosocial support and family empowerment as a service provided by allied health professionals, holding sustainable benefits.

#### **5.4. EARLY INTERVENTION AND INTENSIVE APPROACHES**

Hadders-Algra (2017) acknowledges the lack of research regarding early intervention with children with CP specifically, since most studies look at high-risk babies in a general sense, who may later be diagnosed with CP. Similarly, research should be considered in terms of the variance in aetiology and presentation of CP in LMIC, relative to countries in the global North (Hadders-Algra, 2017). Despite these matters, therapy is considered most effective for functional development when implemented at as young an age as possible, and with a high intensity approach (Bailes et al., 2017; Herskind, Greisen, & Nielsen, 2015; Majnemer et al., 2013; Molteno et al., 1980; Palisano et al., 2012; Perat, 2012a; Venter, 2007).

In this study, the average age of first assessment varied greatly. This contrasts with the literature's recommendation for beginning intervention in the first six months of life (Gmmash & Effgen, 2019; Herskind et al., 2015). Questions thus arise regarding mechanisms for early detection and referral within government healthcare in SA. Reasons for later referral suggested by Gmmash and Effgen (2019) may be applicable, including the notion that recognition of developmental delays only arises later, as well as inconsistent standard referrals for high-risk babies. Concerns therefore remain, since children with *severe* CP usually display features prior to two years old, albeit unclear of the subtype (Novak et al., 2017), indicating potential for more prompt referrals, aligning with the FSDR guidelines (Department of Health, 2015).

Byrne, Noritz, and Maitre (2017) provide an example of a successful structured monitoring and intervention programme amongst a multidisciplinary team in North America, and acknowledged the contextual factors which facilitated this. These included effective early detection and diagnosis, clear and efficient referral processes and adequate funding, together with a uniquely positive institutional culture and support from management. These contextual matters foregrounded in their research contrast the expressed factors influencing participants' service selection in the current local research. It is thus not surprising that implementing early intervention programmes may be challenging. Whatever the reasons for later assessment by occupational therapists, there are concerning implications for not sufficiently providing early services (Novak et al., 2017).

Intensive therapy speaks to the frequency and length of sessions and the types of interventions selected (Law & Darrah, 2014). In an American study, therapists who provided services for seven to twelve hours over a three-month period expressed that children required more therapy, mostly for direct interventions, and sometimes parent support and education (Gmmash & Effgen, 2019). Participants in the current study, who commonly provided less than an hour session once monthly, therefore, remain well warranted in their concern for their lack of intensive and direct approaches.

Palisano et al. (2012) investigated the amount and focus of therapy amongst children with varying severities of CP, and noted that children on GMFCS Levels IV and V tended to have more therapy per month than those with less severe conditions. However, while an increased intensity of therapy may be assumed to be 'ideal,' they suggest that the frequency of therapy may be based more on convention than specific need. Considering the limited human resources in facilities in the local context, the researcher suggests that a combination of direct treatment at healthcare facilities and home programmes may be the appropriate approach to account for the low intensity of intervention, especially considering the literature's advocacy of home programmes (Hadders-Algra, 2017; Herskind et al., 2015; Palisano et al., 2004). However, for this combination approach to be sufficiently 'intensive' and effective, all aspects required to meet needs should be carried out regularly, with home programmes implemented in a consistently good quality manner (Dambi & Jelsma, 2015).

Progress of children with severe CP tends to be minimal and slow, even in cases of intensive early interventions (Palisano et al., 1997), and participants' goals relating to maintenance reflect this. In most cases, therapy appeared to involve positioning, basic sensory stimulation and socialisation. These may, therefore, meet the primary needs of the child (Novak, 2010), and may also have been selected by participants because they can indeed occur in indirect and less 'intensive' manners, in the daily routines of the family at home. It is thus likely that therapists in the Western Cape, where therapy is certainly not intensive or frequent, are using their time and efforts realistically within the challenging contexts in which they work, to meet the needs of the child.

## **5.5. PROFILES AND REPRESENTATIVENESS OF RESPONDENTS**

This study aimed to represent occupational therapy services provided by the Western Cape DoH to children with severe CP. A minimum of 55 participants of the population (N=63) would have been considered representative (95% CI, 0.05 precision). However, the participation of 34 therapists amounted to a 54% response rate. While not statistically representative, this was pleasing, given the circumstances of the COVID-19 pandemic, and when looking at studies with similar objectives and methodologies. For example, Jones et al. (2007) and Swinson et al. (2016) both had response rates below 50% for their descriptive survey research regarding other areas of practice.

### **5.5.1. Geographic representation**

While statistics are not available regarding the provincial distribution of children with CP, the variability of services across the province is important to consider. All health districts were adequately represented amongst participants. Of the total population in each district, the Overberg had the highest response rate (100%), followed by Eden and Central Karoo (70%), Cape Metropole (50%), Cape Winelands (42.9%) and West Coast (40%). Similarly, participants' physical locations were heterogenous, being located in urban (67.7%), rural (23.5%) and semi-urban (8.8%) areas. This allowed descriptions of services to be representative across locations and contexts.

### 5.5.2. Facility profile

Most participants were the only occupational therapist at their facility, and half were responsible for services in more than one facility. While the PHC approach and recent guidelines propose task-shifting and expanding roles of mid-level workers, especially at primary level (Barken, Denton, Plenderleith, Zeytinoglu, & Brookman, 2015; Denton, Brookman, Zeytinoglu, Plenderleith, & Barken, 2015), this does not appear to be occurring, as very few participants worked with mid-level workers. This illustrates the challenge of insufficient human resources, resulting in therapists' high caseloads and insufficient time (Mahlathi & Dlamini, 2015). These realities provide explanation of why occupational therapists are not managing to implement the elements of best practice described above, with potential unfortunate longer-term implications for children and families.

### 5.5.3. Occupational therapist profile

Only three participants (8.9%) had completed post-graduate studies at a Masters level. This may explain the dearth of local research and limited generation of evidence to support practice. Further investigation into relevant specialised training courses was omitted in the questionnaire, although this would have been beneficial in quantifying and describing relevant training accessed by therapists. However, when considering training as a factor influencing service selection in the open-ended questions, some participants highlighted CP-specific training they had completed or desired to complete. This showed the importance of considering training relative to services, and the possibility that many participants did not have knowledge of evidence or skills appropriate for meeting the needs of this population specifically.

Considering the varying length of time in the profession amongst participants, some practice models, policies and techniques taught many years ago may be out-of-date. It may be interesting to investigate correlations between approaches and years of experience, but at this level of study it may be speculated that those who graduated many years ago may not fully be embracing the holistic approach outlined in the ICF, biopsychosocial model, or other practice models. Thus, there may be an imbalance towards the medical model and more traditional clinical roles, rather than the holistic, family-centred and community-based approaches

described in policy and literature regarding best practice (Darrah et al., 2010; Department of Health, 2015; Law & Darrah, 2014; Palisano et al., 2012).

Participants were largely homogenous in the positions held, with the majority working in a full-time, permanent capacity, which relates to how positions and job descriptions are framed within the government healthcare sector. While literature expresses the concern for the high turnover of therapists (Mahlathi & Dlamini, 2015), this was not the case amongst the current participant group, where only a handful were in contract or community service positions. Having therapists employed on a permanent basis benefits the sustainability and consistency of services, departmental development and relationships with communities (Coetzee, 2018).

The seemingly low weekly caseload of children with CP, in relation to the high prevalence of the condition, is also notable. This may be indicative of the inaccessibility of services, therapists' need to prioritise services within their broader caseload, and the trend towards reliance on home programmes rather than regular direct treatments. Alternatively, this observation aligns with a limitation of this study, where services in other sectors were excluded.

## **5.6. STRENGTHS AND LIMITATIONS OF THE STUDY**

Valuable insights were gained into occupational therapy services for this population in this context, however some limitations were present.

Notably, services presented are only generalisable amongst occupational therapists in the public health sector at the time of the study, and are not representative of all occupational therapy services for children with severe CP in the province. For example, it excluded services provided by the private, education and non-governmental sectors at care homes, day-care centres or special schools, thus omitting a potentially sizeable portion of services in the province. It is thus likely that there was a greater variance in services, and conditions under which they were occurring, than what was presented in this study.

Pragmatic matters affecting response rate arose, due to recruitment occurring during the COVID-19 pandemic. It was agreed with the research supervisors that continuing data collection during the pandemic was appropriate, by maintaining an ethical approach towards the priorities of the healthcare sector. Overall, fair opportunity and adequate time was given to potential participants, and the reliability of responses was not compromised.

Because of the pandemic, the NHRD was unable to grant approval to approach participants in some facilities. Additionally, the researcher was not able to attend district meetings during recruitment. However, all correspondence could occur electronically, allowing data collection to continue. With a number of occupational therapists operating at a reduced service capacity, or in different roles during this period, they may have had more time to participate than when managing their usual busy caseloads.

Some occupational therapists in the population may have declined participation as a result of the title of the study, which may have reduced the sample size. They may not have specific interest in children with CP, or perceived that their low caseloads, lack of additional training or skills, or generalist role did not warrant participation. While the intention was for all occupational therapists servicing this population in any capacity to take part, this could have been made clearer during initial contact with potential participants.

Regarding the data collection instrument, the use of electronic questionnaires proved appropriate, as no one in the population declined participation because this was not a suitable means. Google Forms proved to be the preferred means of participation. Google Forms also facilitated efficient instrument development and allowed for all types of questions and responses required. Management of raw data from this platform was safe by exporting it to a Microsoft Excel spreadsheet.

The Microsoft Word format of the questionnaire allowed participation of those with unreliable internet access or unpredictable time availability, as they could save and complete and email back to the researcher on various occasions. It did, however, pose some obstacles. The researcher could not implement restrictions on types of responses provided, as was possible with Google Forms. For example, Google Forms had a function that allowed for only the input of integers for questions requiring this. Thus, those using the Microsoft Word format sometimes responded to questions regarding ages, waiting periods and so on with qualitative explanations or ranges, rather than a clear number, which could not be analysed with other numerical data. These invalid responses could have been avoided by clearer wording in the question, however evidence of participants needing to provide explanations does raise questions regarding the validity of the numerical responses received on the Google Form. This may indicate that participants entered an integer for completeness, rather than being a true reflection of more complex situations.

Effort was made to ensure the rigour of the instrument, by following respected principles to develop a valid and reliable questionnaire. After three stages of testing, no additional changes were recommended by expert pilot participants. However, upon reflecting on responses, it was evident that some participants wanted more opportunity to explain matters, while in other instances, some sub-questions were considered irrelevant and could have been omitted.

The self-report nature of the questionnaire was appropriate to ensure that responses related to participants' personal practice. However, there was no means of ensuring that what was reported related to their actual practice, and this could not be accounted for at this level of research. Although measures were taken to keep responses anonymous, it was recognised that therapists may have felt that their practice was being evaluated, eliciting social desirability in responses. Using unique response codes was effective in ensuring that participants only completed the questionnaire once and facilitating the lucky draw, whilst avoiding providing personal details on the questionnaire. An unforeseen occurrence was that, in two instances, two participants working together at a facility completed a single questionnaire, rather than each completing their own. Although participants assured the researcher that the response represented both of their opinions and services, the minor statistical impact is acknowledged, as they were reflected as non-responses rather than duplicating the weighting of those responses to account for their coverage.

Regarding questionnaire content, it is acknowledged that therapists' clinical reasoning and selection of modalities is complex, and is often unique and not generalisable or replicable across contexts and time (Kielhofner, 2009; Pendleton & Schultz-Krohn, 2017). With the purpose of gaining insight to prompt efficient, effective and meaningful service provision, the objective regarding factors influencing service selection was contained to a manageable level for the scope of this initial research. It was thus appropriate to focus on the broader environmental factors, rather than the intricacies of clinical reasoning. The manner in which these questions were asked was, however, broad, resulting in sometimes insufficient explanations in some cases.

## **5.7. SUMMARY**

While there were limitations in the generalisability and pragmatics of this research, the aims and objectives were realised. It became evident that the unique contextual factors in the local

setting were instrumental in determining the manner in which services provided related to best practice. While occupational therapists were employing holistic services in some instances, there was evidence on falling short on providing the intensity and more specialised direct interventions, in a truly family-centred and contextually-relevant manner, which may allow for more meaningful improvements in participation and QoL of this population.

## CHAPTER 6: RECOMMENDATIONS AND CONCLUSION

### 6.1. INTRODUCTION

This chapter provides recommendations for occupational therapy practice, further research and education, followed by a conclusion.

### 6.2. RECOMMENDATIONS

#### 6.2.1. Practice

- There is potential to enhance family-centred care, specifically regarding the implementation of home programmes. In light of participants' concerns for compliance, addressing caregivers' needs and roles that families play in therapy, mid-level workers' involvement at community level should be explored. Strategic task-shifting may improve the confidence with which indirect interventions and the family-centred approach may be applied. Through this, there may be merit in routines-based programmes being implemented within families (Chiarello et al., 2010), and overcome language differences, parents' low education levels, therapists' high caseloads and inability to conduct home visits themselves. Consideration of roles, training, policy development, and mechanisms for teamwork, referrals and supervision would be required (Barken et al., 2015; Hugo, 2004; Jesus et al., 2017).
- In this study, the ICF proved to be an effective framework to describe holistic services, and is advocated as a core model amongst health professionals. With its alignment with occupational therapy models in considering contextual factors, services may become more focused on function and participation. Similarly, occupation-focused assessments and interventions are encouraged, to ensure the emphasis remains on well-being through function and participation rather than body functions and structure. This may shift the popular discourse of disability models to a more holistic and integrated approach amongst health professionals and communities alike.
- Opportunities for early intervention could be facilitated by improving mechanisms for early detection of high-risk babies and efficient referral pathways amongst the multidisciplinary team. While therapy services may remain weighted towards home programmes, beginning

these at an early age may enhance the child's development, prevent secondary conditions and improve caregiver insight and compliance.

- Facility and departmental managers should consider the scope for records being kept regarding 'non-traditional' or 'non-clinical' work done by occupational therapists. The need to produce evidence for their services, in relation to policies and prescription of priorities, may motivate selection of some interventions above others, or mean that services are misrepresented or misinterpreted at higher level service analyses. Considering using the ICF to guide documentation of holistic services, may allow a needs-based service model to emerge through improved evaluation of practice. Considering the lack of local research, data collection through documentation may be used to develop 'practice-based evidence' or formal research. As suggested by Byrne et al. (2017), adequate record-keeping and reporting has the power to prompt attention at various levels of management and academics.
- Opportunities for occupational therapists to engage with stakeholders would be valuable, in order to open discussion regarding the broader environmental barriers to best practice services. This may entail direct consultations with facility management, or address matters at provincial level alongside disability organisations.

#### 6.2.2. Research

- This research could be viewed as a pilot to a national research project, in order to gain insight into the variances across provinces, public and private sector, different levels of healthcare and/or urban and rural services. The Western Cape is comprised of a fair balance of urban and rural settings, whereas some other provinces are more homogenous. Since the facility location and level of care were key factors influencing service provision, these should be investigated further to facilitate equitable services. This would, however, require changes to the current questionnaire, additional to those mentioned in 5.6.
- Since this research only touched on the factors influencing the selection of services, qualitative and participatory-action research should be conducted to further explore the perceived and experienced contextual elements at play. With results showing discrepancies in services relative to international literature, qualitative research would allow deeper insight into shifting barriers to services aligned with the elements of best practice.

- Occupation-focused assessments and interventions for this population should be investigated, to oppose the emphasis on body functions and structure and occupational performance components popular in the literature. This would benefit the profession in terms of its unique contribution, as well as the children in terms of prioritising meaningful participation.

### 6.2.3. Education and training

- Improvement of accessibility of specialised training courses is necessary for quality interventions to be implemented. These could be facilitated on online platforms for therapists in rural settings to access more affordably, and courses could be presented at various levels or specific topics, so that skills can be gained in relation to what is necessary and applicable.
- Despite the limited evidence available for various modalities in resource-constrained contexts such as South Africa, evidence-based practice should be encouraged amongst occupational therapists. Engagement in journal clubs or mentorship programmes are suggested to become part of the continuing professional development activities of therapists in the public health sector.

## 6.3. CONCLUSION

This study shows that the services provided by participating occupational therapists in government healthcare facilities in the Western Cape include assessments, goal-setting and interventions. While service provision held merits, there remains concern for current practice in this context, in relation to the notions of best practice described abroad. Although causal relationships cannot be assumed from descriptive research, there is an indication that, while occupational therapists attempt to base their service provision on recognised models and evidence for effective practice, contextual factors were instrumental in influencing the manner in which they are able to implement them.

Many limitations to implement holistic, early and intensive, evidence-based practice, relate to resource limitations and the roles that occupational therapists are required to fulfil, in accordance with the level of care and location at which they work. A resulting shortfall relates to the lack of opportunities for services to be provided in the child's home or other community contexts, challenging the implementation of true family-centred care. Additionally, the

generalist role and lack of human resources in government facilities influences the intensity and types of services. This was illustrated by substantial reliance on home programmes and tendencies to prioritise physical performance components, which may be perceived as most urgent. The elements of the ICF relating to personal factors and body functions and structure were thus prioritised in service provision, with neglect of environmental factors.

Overall, despite participants expressing desire and effort towards more holistic, family-centred practice, this imbalance reflects the ongoing dominance the medical model, rather than a truly biopsychosocial approach with the primary focus on occupation called for by the profession. Recommendations provided, in relation to practice, research and education of occupational therapists draw attention to these shortfalls and possible solutions. These solutions may create shifts towards services for children with severe CP becoming more efficient in meeting the child and family's needs, and thereby improving their overall participation and QoL, and reduce the burden on the healthcare system.

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## APPENDIX 1: DRAFT 1 OF QUESTIONNAIRE

Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape:  
An overview of current services

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE.

It consists of the following 6 sections:

SECTION 1: PROFILE OF PARTICIPATING OCCUPATIONAL THERAPIST	<ul style="list-style-type: none"><li>• Multiple choice or short answers relating to your basic work-related demographics and experience</li></ul>
SECTION 2: PROFILE OF FACILITY REPRESENTED	<ul style="list-style-type: none"><li>• Multiple choice or short answers relating to your work context and setting</li></ul>
SECTION 3: OT ASSESSMENTS	<ul style="list-style-type: none"><li>• Types of assessments, each requiring ratings of frequency used</li><li>• Brief open-ended questions</li></ul>
SECTION 4: GOAL-SETTING	<ul style="list-style-type: none"><li>• Ideas regarding goal-setting, each requiring ratings of frequency used</li><li>• Brief open-ended questions</li></ul>
SECTION 5: OT TREATMENT	<ul style="list-style-type: none"><li>• Types of interventions, each requiring ratings of frequency used</li><li>• Brief open-ended questions</li></ul>
SECTION 6: FACTORS INFLUENCING SELECTION OF SERVICES	<ul style="list-style-type: none"><li>• Brief open-ended questions</li></ul>

This questionnaire should take no longer than **15-20 minutes** to complete in total. This has been verified through pilot administration.

Please answer these questions **truthfully** in relation to your **current** practice within the government healthcare sector.

**Completion** of this questionnaire implies **consent**. The **anonymity** of your responses will be maintained.

If you have any **questions or concerns**, you are welcome to contact the researcher directly:

[laurenf004@gmail.com](mailto:laurenf004@gmail.com) or 072 9952790.

**Please note:**

1. If you work alongside a team of Occupational Therapy Technicians, Rehabilitation Care Workers or other similar assistants, answer the questions on behalf of this team's overall services, rather than only what you are implementing personally. Please ask your team members to also complete the questionnaire; your group's responses will be combined to represent your department/facility as a whole.
2. OTs working across a number of facilities (for example, based at a district hospital but providing outreach services at community health centres) should indicate this in the relevant section of the questionnaire, then answer the remainder of questions with all of their services in mind.

Please take note of **definitions of terms** as found in footnotes, as well as bearing the following in mind:

For the purpose of this study, the following definitions will be used:

**1. Child/children:**

Individuals 0 – 12 years old

**2. Severe cerebral palsy:**

Impairments resulting in classification on Level IV and V of the Gross Motor Function Classification Scale (GMFCS), requiring maximal assistance in aspects of daily life and functioning. See below outline of the GMFCS levels (Palisano, Rosenbaum, Bartlett & Livingston, 2007):

<b>GENERAL HEADINGS FOR EACH LEVEL</b>	
<b>LEVEL I</b>	- Walks without Limitations
<b>LEVEL II</b>	- Walks with Limitations
<b>LEVEL III</b>	- Walks Using a Hand-Held Mobility Device
<b>LEVEL IV</b>	- Self-Mobility with Limitations; May Use Powered Mobility
<b>LEVEL V</b>	- Transported in a Manual Wheelchair

<b>DISTINCTIONS BETWEEN LEVELS</b>	
<b>Distinctions Between Levels I and II</b> - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.	
<b>Distinctions Between Levels II and III</b> - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.	
<b>Distinctions Between Levels III and IV</b> - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.	
<b>Distinctions Between Levels IV and V</b> - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.	

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**SECTION 1: PROFILE OF PARTICIPATING OCCUPATIONAL THERAPIST**

*INSTRUCTION:*

*PLEASE MARK SELECTION WITH AN 'X'*

*OR WRITE IN YOUR RESPONSE''*

1.1. Sex	<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Prefer not to say	
1.2. What is your highest OT qualification?	<input type="checkbox"/> Bachelor's degree	<input type="checkbox"/> Honour's degree	<input type="checkbox"/> Master's degree	<input type="checkbox"/> Doctorate degree
1.3. In what year did you graduate as an OT?				
1.4. How many years of experience do you have with children with CP?				
1.5. What type of position do you hold within the Western Cape Department of Health?	<input type="checkbox"/> Full-time position	<input type="checkbox"/> Part-time position		
1.6. What is your employment status within the Western Cape Department of Health?	<input type="checkbox"/> Permanent employment		<input type="checkbox"/> Contract / locum employment	
1.7. What is your role of employment within your current position?	<input type="checkbox"/> Work at a single facility.		<input type="checkbox"/> Work across a number of facilities.	

## SECTION 2: PROFILE OF FACILITY REPRESENTED

### INSTRUCTION:

PLEASE MARK SELECTION WITH AN 'X'

OR WRITE IN YOUR RESPONSE

2.1. In which district(s) do you provide services? (select all that apply)	<input type="checkbox"/> Cape Metropole	<input type="checkbox"/> Cape Winelands	<input type="checkbox"/> Central Karoo	<input type="checkbox"/> Eden	<input type="checkbox"/> Overberg	<input type="checkbox"/> West Coast
2.2. What is the location of the facilities <sup>4</sup> in which you provide services? (select all that apply)	<input type="checkbox"/> Urban	<input type="checkbox"/> Semi-urban		<input type="checkbox"/> Rural		
2.3. At which levels of care do you provide services? (select all that apply)	<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary		<input type="checkbox"/> Tertiary		
2.4. How many OTs are in your department/facility?						
2.5. How many mid-level workers <sup>5</sup> provide services under your supervision?						
2.6. What is the nature of treatment spaces available?	<input type="checkbox"/> Shared space(s)			<input type="checkbox"/> Designated space(s) for OT services		
2.7. What is your approximate average weekly caseload of children with severe CP?	<input type="checkbox"/> 0 - 5	<input type="checkbox"/> 6 – 10	<input type="checkbox"/> 11 - 15	<input type="checkbox"/> 16 - 20	<input type="checkbox"/> 21 - 25	<input type="checkbox"/> >25

<sup>4</sup> **Location of facility** (Statistics South Africa, 1998; Statistics South Africa, 2003):

- **Urban:** A settlement which has been legally declared as being urban, irrespective of population density. This includes *formal* urban areas (cities/towns) as well as *informal* urban areas (found within a city/town, but consists of informal dwellings). Mining locations, factory and municipal hostels, hospitals, prisons and other institutions contained within a local authority boundary are also considered urban settlements.
- **Semi-urban:** An area that is not within a legally proclaimed urban areas boundaries, but borders it closely.
- **Rural:** Beyond the boundaries of urban and semi-urban areas, also referred to as non-urban areas. This includes villages, farms and small settlements.

<sup>5</sup> **Mid-level workers** may include OT assistants, technicians, rehabilitation careworkers and the likes

**SECTION 3: OT ASSESSMENTS**

**INSTRUCTION:**

PLEASE MARK SELECTION WITH AN 'X'

OR WRITE IN YOUR RESPONSE.

PLEASE NOTE, IF YOU SELECT 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUB-QUESTIONS RELATING TO THAT ASSESSMENT AS INSTRUCTED.

<p><b>3.1. How often do you conduct an <u>interview with the child</u> as a means of assessment?</b></p>	<p align="center"><input type="checkbox"/> Never</p>	<p align="center"><input type="checkbox"/> Rarely</p>	<p align="center"><input type="checkbox"/> Sometimes</p>	<p align="center"><input type="checkbox"/> Usually</p>	<p align="center"><input type="checkbox"/> Always</p>	<p align="center"><input type="checkbox"/> Not sure what this is (skip to 3.2.)</p>
<p>3.1.1. Are interviews with the <u>child</u> usually an effective means of assessment?</p>	<p align="center"><input type="checkbox"/> Yes</p>			<p align="center"><input type="checkbox"/> No</p>		
<p>3.1.2. What makes interviews with the <u>child</u> a challenging means of assessment?</p>						
<p>3.1.3. What makes interviews with the <u>child</u> an effective means of assessment?</p>						
<p><b>3.2. How often do you conduct an <u>interview with the child's caregiver</u> as a means of assessment?</b></p>	<p align="center"><input type="checkbox"/> Never</p>	<p align="center"><input type="checkbox"/> Rarely</p>	<p align="center"><input type="checkbox"/> Sometimes</p>	<p align="center"><input type="checkbox"/> Usually</p>	<p align="center"><input type="checkbox"/> Always</p>	<p align="center"><input type="checkbox"/> Not sure what this is (skip to 3.3.)</p>

3.2.1. Are interviews with the <u>caregiver</u> usually an effective means of assessment?	<input type="checkbox"/> Yes		<input type="checkbox"/> No			
3.2.2. What makes interviews with the <u>caregiver</u> a challenging means of assessment?						
3.2.3. What makes interviews with the <u>caregiver</u> an effective means of assessment?						
<b>3.3. How often do you use <u>standardized assessments/ checklists</u> as a means of assessment?</b>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 3.4.)
3.3.1. Are <u>standardized assessments/checklists</u> usually an effective means of assessment?	<input type="checkbox"/> Yes			<input type="checkbox"/> No		
3.3.2. What are the <u>standardized assessments or checklists</u> you frequently use?						
3.3.3. What <u>makes standardized assessments/checklists</u> challenging to use?						

3.3.4. What makes <u>standardized assessments/checklists</u> effective to use?						
3.4. How often do you use <u>observation in activities</u> as a means of assessment?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 3.5.)
3.4.1. What environments do these <u>observations</u> take place in most frequently?						
3.4.2. What <u>activities</u> are most frequently observed? (select all that apply)	<input type="checkbox"/> Self-care/Activities of Daily Living	<input type="checkbox"/> Play/leisure	<input type="checkbox"/> School/productivity	<input type="checkbox"/> Other. <i>Specify:</i>		
3.4.3. What makes <u>observations</u> in activities challenging to use?						
3.4.4. What makes <u>observations</u> in activities effective to use?						
3.5. What other assessment methods do you commonly use?						
3.6. What is the average age of first contact with OT for (estimate, age in years)?						
3.7. What is the average duration of initial assessment (estimate, time in minutes)?						

**SECTION 4: OT GOAL-SETTING**

*INSTRUCTION:*

*PLEASE MARK SELECTION WITH AN 'X'*

*OR WRITE IN YOUR RESPONSE.*

*PLEASE NOTE, IF YOU SELECT 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUBQUESTIONS AS INSTRUCTED.*

4.1. How often are the <u>children</u> actively involved in the goal-setting process?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
4.2. How often are the children's <u>caregivers</u> actively involved in the goal-setting process?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
4.3. How often do goals relate to <u>occupational performance</u> ?	<input type="checkbox"/> Never (skip to 4.4.)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 4.4.)
4.3.1. What self-care/ activities of daily living activities are focused on in goals (if any)?						
4.3.2. What play/leisure activities are focused on in goals (if any)?						
4.3.3. What school/productivity						

activities are focused on in goals (if any)?						
<b>4.4. How often do goals relate to underlying performance components?</b>	<input type="checkbox"/> Never (skip to 4.5.)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 4.5.)
4.4.1. What performance components are focused on in goals (if any)?						
<b>4.5. How often do goals set relate to <u>maintenance</u> and <u>prevention of further challenges</u> (as opposed to improvement/progress)?</b>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means
<b>4.6. How often do goals set relate to <u>improvement/development/progress</u> (as opposed to maintaining or preventing further challenges)?</b>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means

**SECTION 5: OT TREATMENT**

*INSTRUCTION:*

*PLEASE MARK SELECTION WITH AN 'X'*

*OR WRITE IN YOUR RESPONSE.*

*PLEASE NOTE, IF YOU SELECT 'NEVER,' 'REFER ELSEWHERE' OR 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUBQUESTIONS AS INSTRUCTED.*

**5.1. CONTACT TREATMENT METHODS**

5.1.1. How often do you conduct <u>Neuro-developmental Therapy</u> ( <u>Bobath Therapy</u> )?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.2. How often do you conduct <u>Constraint-Induced Movement Therapy</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.3. How often do you conduct <u>Bimanual Training</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.4. How often do you use <u>Electrical Stimulation</u> ?	<input type="checkbox"/> Never (skip to 5.1.5)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.1.5)	<input type="checkbox"/> Not sure what this is (skip to 5.1.5)
5.1.4.1. What specific type of Electrical Stimulation							

do you use?							
5.1.5. How often do you conduct <u>Proprioceptive Neuromuscular Facilitation</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.6. How often do you implement <u>Sensory Integration</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.7. How often do you do <u>Massage and Stretching</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.8. How often do you implement <u>Strength Training</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.9. How often do you use <u>functional tasks or activities as a means of treatment</u> ?	<input type="checkbox"/> Never (skip to 5.1.10)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.1.10)	<input type="checkbox"/> Not sure what this is (skip to 5.1.10)
5.1.9.1. What types of activities are frequently used as a means of treatment? (select all that apply)	<input type="checkbox"/> Self-care/ Activities of Daily Living		<input type="checkbox"/> Play/leisure		<input type="checkbox"/> School/productive activities		<input type="checkbox"/> Other. <i>Specify:</i>

5.1.10. How often do you implement <u>Cognitive Training Techniques</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.11. What other contact treatment methods do you commonly use?							
5.1.12. What setting does treatment usually occur in?							
5.1.13. What percentage of treatment takes place in a group format (estimate)?							
5.1.14. What is the average duration of treatment sessions (estimate, time in minutes)?							
5.1.15. What is the average frequency of treatment sessions (estimate, number per month)?							

## 5.2. ASSISTIVE DEVICES AND ORTHOTICS

<b>5.2. ASSISTIVE DEVICES AND ORTHOTICS</b>							
<b>5.2.1. At what level of care are assistive devices and orthotics <u>prescribed</u>?</b> (select all that apply)	<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary			<input type="checkbox"/> Tertiary		
<b>5.2.2. At what level of care are assistive devices and orthotics <u>issued</u>?</b> (select all that apply)	<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary			<input type="checkbox"/> Tertiary		
<b>5.2.3. At what level of care are assistive devices and orthotics <u>reviewed</u>?</b> (select all that apply)	<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary			<input type="checkbox"/> Tertiary		
<b>5.2.4. How often do you prescribe <u>mobility aids</u>?</b>	<input type="checkbox"/> Never <small>(skip to 5.2.5)</small>	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this <small>(skip to 5.2.5)</small>	<input type="checkbox"/> Not sure what this is <small>(skip to 5.2.5)</small>
<b>5.2.4.1. What mobility aids do you commonly prescribe?</b> (select all that apply)	<input type="checkbox"/> Wheelchair	<input type="checkbox"/> Buggy	<input type="checkbox"/> Walking frame	<input type="checkbox"/> Crutches	<input type="checkbox"/> Other. <i>Specify:</i>		
<b>5.2.4.2. What is the average waiting period for mobility aids (estimate, number of months)?</b>							
<b>5.2.4.3. What is the children's average age when mobility aids are first issued (estimate, age in years)?</b>							

5.2.4.4. What is the average frequency of review of mobility aids (number of months)?							
5.2.5. How often do you prescribe other <u>positioning devices</u> ?	<input type="checkbox"/> Never (skip to 5.2.6)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.2.6)	<input type="checkbox"/> Not sure what this is (skip to 5.2.6)
5.2.5.1. What other positioning devices do you commonly prescribe? (select all that apply)	<input type="checkbox"/> Side-lyer		<input type="checkbox"/> Standing frame		<input type="checkbox"/> Other. <i>Specify:</i>		
5.2.5.2. What is the average waiting period for these positioning devices (estimate, number of months)?							
5.2.5.3. What is the children's average age when these positioning devices are first issued (estimate, age in years)?							
5.2.6. How often do you prescribe <u>assistive devices for functional tasks</u> ?	<input type="checkbox"/> Never (skip to 5.2.7)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.2.7)	<input type="checkbox"/> Not sure what this is (skip to 5.2.7)

5.2.6.1. What are the assistive devices that you commonly issue for functional tasks?							
5.2.6.2. What is the average waiting period for these assistive devices (estimate, number of months)?							
5.2.7. How often do you prescribe <u>splints and orthotics</u> ?	<input type="checkbox"/> Never (skip to 5.3)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3)	<input type="checkbox"/> Not sure what this is (skip to 5.3)
5.2.7.1. What is the average waiting period for splints/orthotics (estimate, time in weeks)?							
5.2.7.2. What splints/orthotics do you commonly prescribe? (select all that apply)	<input type="checkbox"/> Upper limb rigid	<input type="checkbox"/> Upper limb soft	<input type="checkbox"/> Lower limb rigid	<input type="checkbox"/> Lower limb soft	<input type="checkbox"/> Other. <i>Specify:</i>		

**5.3. CAREGIVER EDUCATION, SUPPORT AND HOME PROGRAMMES**

<p><b>5.3.1. How often do you provide <u>caregiver education</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.3.2)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3.2)	<input type="checkbox"/> Not sure what this is (skip to 5.3.2)
<p><b>5.3.1.1. What is the common content of caregiver education? (select all that apply)</b></p>	<input type="checkbox"/> Diagnosis and prognosis	<input type="checkbox"/> Caregiver burnout	<input type="checkbox"/> Therapy processes	<input type="checkbox"/> Treatment goals and regimes	<input type="checkbox"/> Home programme content	<input type="checkbox"/> Other. <i>Specify:</i>	
<p><b>5.3.2. How often do you provide <u>home programmes</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.3.3)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3.3)	<input type="checkbox"/> Not sure what this is (skip to 5.3.3)
<p><b>5.3.2.1. What are typical contents and elements included in home programmes?</b></p>							
<p><b>5.3.3. How often do you provide <u>caregiver psychosocial support</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.3.4)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3.4)	<input type="checkbox"/> Not sure what this is (skip to 5.3.4)
<p><b>5.3.3.1. What is the more common format of caregiver psychosocial support?</b></p>	<input type="checkbox"/> Group				<input type="checkbox"/> Individual		

<p>5.3.4. What are the common relationships of caregiver to child that typically engage with these home programmes, education and support services?</p>	
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5.4. <u>CONTEXTUAL/ENVIRONMENTAL ACTIONS</u>							
5.4.1. How often do you  conduct <u>home visits</u> and  provide interventions at  home?	<input type="checkbox"/> Never  (skip to 5.4.2)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this  (skip to 5.4.2)	<input type="checkbox"/> Not sure what this is  (skip to 5.4.2)
5.4.1.1. What do these home visits/ interventions typically entail?							
5.4.2. How often do you visit  the children's <u>school or</u>  <u>day-care centre</u> ?	<input type="checkbox"/> Never  (skip to 5.4.3)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this  (skip to 5.4.3)	<input type="checkbox"/> Not sure what this is  (skip to 5.4.3)
5.4.2.1. What do these school/day-care centre visits typically entail?							
5.4.3. How often do you  implement <u>other</u>  <u>community actions</u>  (advocacy, awareness raising, public education etc.)?	<input type="checkbox"/> Never  (skip to 5.5)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this  (skip to 5.5)	<input type="checkbox"/> Not sure what this is  (skip to 5.5)
5.4.3.1. What do these 'other community actions' typically entail?							
5.4.3.2.							

**5.5. REFERRALS MADE TO OTHER PROFESSIONALS**

How often do you refer children to each of the following?

5.5.1. Physiotherapist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.2. Speech therapist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.3. Orthotist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.4. Orthopaedic surgeon	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.5. Dietician	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.6. Social worker	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.7. Special education system	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.8. Audiologist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.8. Other specialist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is

**SECTION 6: FACTORS INFLUENCING SERVICES SELECTED**

*INSTRUCTION:*

*PLEASE WRITE IN YOUR RESPONSE*

6.1. What are the main OT models or generic models of practice that influence your services and decisions?

6.2. How does **resource availability** influence your selection of services for children with severe CP?

6.3. How does working at your **level of care** influence your selection of services for children with severe CP?

6.4. How do **policies** influence your selection of services for children with severe CP?

6.5. How does **your training** influence your selection of services for children with severe CP?

6.6. How does **the location of the health facility** influence your selection of services for children with severe CP?

6.7. What **other factors** frequently influence your selection of services for children with severe CP? Explain each.

6.8. What interventions do you feel that you are **NOT sufficiently implementing and why?**

THANK YOU SO MUCH FOR YOUR TIME!

Before you submit your responses, a reminder:

By completing this questionnaire, consent will be assumed.

No separate informed consent form has been provided to you.

By submitting your questionnaire, you are showing that you understand what is presented on the information sheet and agree to participate in this research study.

## APPENDIX 2: INSTRUMENT TESTING FEEDBACK FORM

### Introduction

Thank you so much for agreeing to assist with piloting this research questionnaire.

I really appreciate your time and effort in helping to ensure that this tool is sufficiently rigorous and valid to roll out, so value your feedback greatly.

Following this introduction, you will find a one-page overview of the study, as well as the pilot Feedback Checklist to be completed and returned.

#### Instructions and tips for pilot process:

1. Please read through the Feedback Checklist on the following page before completing the questionnaire, so that you can be attentive to the type of feedback that will be asked of you.
2. Remember that I will require you to report on the time taken to complete the Questionnaire – so please complete it in one sitting and time yourself when doing so. That is, do not attempt to complete or make notes on the Feedback Checklist while still completing the Questionnaire – rather go to this afterwards.
3. Therefore, please answer the Questionnaire as if you would for any other survey in order for you to gauge its overall ease of use for any participant, and then engage your critical eye in order to provide more in-depth feedback.
4. Please be critical and honest. If there is anything you would like to draw my attention to, no matter how minor it may seem, please do so.

Thank you once again, and please feel free to contact me should you have further questions.

Your responses to both the Questionnaire as well as for the Feedback Checklist will be kept entirely confidential and anonymous.

Your responses to the questionnaire will not be included in the research and will be set aside before the official data collection commences.

I would appreciate if you could complete this within 14 days, submitting the complete Questionnaire online as well as email back the completed Feedback Checklist to me on [laurenf004@gmail.com](mailto:laurenf004@gmail.com)

# Overview of study

## Research question

What OT services are being provided to children with severe CP across the levels of government healthcare facilities in the Western Cape?

## Summary of research context, problem statement, purpose and rationale

Cerebral palsy (CP) is a leading childhood disorder, with local national estimates of 1/100 children with CP being up to five times higher than international prevalence (World Health Organisation, 2005; Donald, Samia, Kakooza-Mwesige, & Bearden, 2014). Individuals with severe CP require intensive continual care and multidisciplinary input, considering the significant impact on their daily quality of life and functioning (Dodd, Imms & Taylor, 2010; Colver, Fairhurst & Pharoah, 2014).

Occupational therapists (OTs) have a broad role with children with severe CP, including individual clinical work, and addressing issues of occupational justice, advocacy and social inclusion (Werner, 1987; Bantjes, Swartz, Conchar & Derman, 2015).

With most South Africans using the strained public health sector (Coetzee, 2018), it is concerning that the intensity and types of occupational therapy required is difficult to provide. This raises questions as to what services are being provided in healthcare facilities for this vulnerable population. There is concern that the priorities reflected in policies and individuals' presenting needs are not aligning with the resource allocation, therapy protocols and therapists' individual perspectives and practice. This calls for attention and investigation of OT service provision, in order to obtain a baseline description of the present realities of services at each level of healthcare and expose factors influencing the selection and implementation thereof. This will prompt the improvement of service availability, protocols, policies and OT training where necessary.

## Aim of the study

To describe the OT services being provided to children under the age of 12 with severe CP, across all levels of government healthcare facilities of the Western Cape.

## Research objectives

- To determine basic profiles (including number of OTs and assistants, years of experience, qualifications and so on) and distribution of OTs and OT departments within government healthcare facilities (geographically and across levels of care).
- To describe the types of OT services being provided to children with severe and the frequency with which they are available in government healthcare facilities
- To identify the perceived barriers influencing OTs' selection of services provided to children with severe CP in government healthcare facilities in the Western Cape.
- To identify additional services OTs in government healthcare facilities in the Western Cape feel they should be providing.

# Questionnaire pilot feedback checklist

## 1. ADMINISTRATION

A. Type of questionnaire piloted:

- Microsoft Word document
- Online (Google Form)
- Interview

B. How long did the questionnaire take to complete?

\_\_\_\_\_ (time in minutes)

C. Are the instructions for the questionnaire unambiguous and clear?

- YES
- NO
- SOME

Detail specific question numbers of concern/needing rewording or restructuring:

D. Is the wording of the questions unambiguous and clear?

- YES
- NO
- SOME

Detail specific question numbers of concern/needing rewording or restructuring:

## 2. ORGANISATION

A. Do the sections flow logically?

- YES
- NO
- PARTLY

Detail specific sections of concern/needing attention:

B. Do the questions within each section flow logically, and do they appear to fit into the sections they are in?

- YES
- NO
- SOME

Detail specific sections of concern/needing attention:

## 3. CONTENT

A. Are the questions clear and concise?

- YES
- NO
- SOME

Detail specific questions of concern/needing attention:

B. Do the questions meet the objectives of the study?

- YES
- NO
- SOME

Detail areas of objectives that you feel are not adequately met and need to be expanded on:

C. Do you think all the questions are necessary?

YES

NO

Detail specific questions that may be redundant/unnecessary:

D. Are the questions free of unnecessary jargon and complex terminology?

YES

NO

SOME

Detail specific words that need to be changed or added to the definitions of terms list:

E. Are questions unbiased, that is, not leading you to answer in a specific manner?

YES

NO

SOME

Detail specific questions that may be considered biased and need revision:

F. Are the response choices mutually exclusive and exhaustive, that is, was there always the answer that you would have chosen available as an option?

YES

NO

SOME

Detail questions where response choices may need revision:

4. **ANY ADDITIONAL FEEDBACK:**

### APPENDIX 3: COLLATED PILOT FEEDBACK

#### PILOT FEEDBACK: COLLATED FROM 4 PARTICIPANTS IN STAGE 1

QUESTION	PARTICIPANTS' RESPONSES			ACTION TAKEN / RESEARCHER COMMENT
<b>SECTION 1: ADMINISTRATION</b>				
<b>A. Type of questionnaire piloted</b>	Online		Microsoft Word	
	xxx		x	
<b>B. How long did the questionnaire take to complete?</b>	Online		Microsoft word	
	25 minutes		20 minutes	<i>Consider removing some questions in consultation with research supervisors; monitor in stage 2 of piloting.</i>
	25 minutes			
	30 minutes			
<b>C. Are the instructions for the questionnaire unambiguous and clear?</b>	Yes	No	Some	
	xxx		x	
Detail specific question numbers of concern/need rewording or restructuring	Informal query/request of clarification: Is population of interest all CP/severe CP only?			<i>Initial instruction and some questions revised to continually emphasise that their responses should be in relation to population of interest.</i>
<b>D. Is the wording of the questions unambiguous and clear?</b>	Yes	No	Some	
	Xx		xx	

<p>Detail specific question numbers of concern/needing rewording or restructuring</p>	<p>Q 5.3.4. Struggled to understand the question</p> <p>Q 5.3.4. Common relationships. Not sure what this means? Is it like mother-child?</p> <p>Q 5.3.4. Unclear – don't understand question</p> <p>Q 3.6. I found this difficult to answer personally. but my average age is 6 months so does that make my answer 0.6?</p> <p>Q 2.6. Shared treatment spaces: Shared with other MDT members or shared with other OT's?</p>	<p><i>Question 5.3.4. reworded and examples added for clarity.</i></p> <p><b>(‘What are the common relationships of caregiver to child that typically engage with these home programmes, education and support services?’ changed to ‘What are the common relationships between the child and caregiver who typically engages with these home programmes, education and support services (e.g. mother, aunt, sibling)?’)</b></p> <p><i>Purpose of question is to gain estimate of average. No change.</i></p> <p><i>Response options for Q 2.6. reworded. (‘Shared space(s)’ changed to ‘Shared space(s) with other health professions’)</i></p>		
<p><b>SECTION 2: ORGANISATION</b></p>				
<p>G. Do the sections flow logically?</p>	<p>Yes</p>	<p>No</p>	<p>Partly</p>	
<p>Detail specific sections of concern/ needing attention</p>	<p>xxxx</p>			

<b>H. Do the questions within each section flow logically, and do they appear to fit into the sections they are in?</b>	Yes	No	Some	
	xxxx			
Detail specific sections of concern/ needing attention				
<b>SECTION 3: CONTENT</b>				
<b>A. Are the questions clear and concise?</b>	Yes	No	Some	
	xxxx			
Detail specific questions of concern/ needing attention				
<b>B. Do the questions meet the objectives of the study?</b>	Yes	No	Some	
	xxxx			
Detail areas of objectives that you feel are not adequately met and need to be expanded on				
<b>C. Do you think all the questions are necessary?</b>	Yes	No	Some	
	xxxx			
Detail specific questions that may be redundant/unnecessary				

D. Are the questions free of unnecessary jargon and complex terminology?	Yes	No	Some	
	xxxx			
Detail specific words that need to be changed or added to the definitions of terms list	Q 4.3. I would have appreciated a definition of Occupational Performance (like you did with other questions) for this answer to ensure consistency with answers			<i>Definition of occupational performance added within question (online version) and as a footnote (Microsoft Word version).</i>
E. Are questions unbiased, that is, not leading you to answer in a specific manner?	Yes	No	Some	
	xxxx			
Detail specific questions that may be considered biased and need revision				
F. Are the response choices mutually exclusive and exhaustive, that is, was there always the answer that you would have chosen available as an option?	Yes	No	Some	
	xx	x	x	
Detail questions where response choices may need revision	Q 2.6. Would like an option to choose 'both'			<i>Addition made to question to 'select all applicable' and settings of online version changed to allow more than one selection.</i>
	Q 3.3. Would like an option of 'do not have access to st ass/checklists'			<i>This type of response speaks more to reasons for not occurring, which is covered in section 6, therefore no changes made.</i>

	<p>Q 5.2.5. Would like an option of 'do not have access to other'</p> <p>Q 3.2.1. Only yes/no but some aspects are effective while some not</p>	<p><i>This type of response speaks more to reasons for not occurring, which is covered in section 6, therefore no changes made.</i></p> <p><i>There is opportunity for explanation in following sub-questions. Addition of an option of 'partly' or 'sometimes' may lead to vague/poor quality responses.</i></p>
<p><b>SECTION 4: ANY ADDITIONAL FEEDBACK</b></p>	<p>Q 3.6. Varies too much in age to narrow down</p> <p>Q 5.5. Add Paediatrician</p> <p>Q 6.2-6.5. Was difficult to answer without a measurable scale (e.g. not at all --&gt; a lot)</p> <p>Q 6.2-6.4. Difficulty answering. Not sure what you were asking here? Perhaps it is my time away from this area that made it difficult but perhaps needs some examples or explanations</p>	<p><i>Purpose of question is to gain estimate of average. No change.</i></p> <p><i>Added as option 5.5.9.</i></p> <p><i>Revise and monitor quality of responses of Section 6 and consider change to closed-ended format with next stage of piloting.</i></p>

	<p>Section 6: The how questions do not elicit a detailed response, appears more closed-ended</p> <p>Questions on Splinting and Orthotics: you have grouped these together but at our hospital the upper limb hard splints are made by OT with less than a month waiting list while AFO's are done by O&amp;P with over a 6-month waiting period.</p> <p>Good format. Enough space to write on hard copy and kept as straightforward and simple as possible</p>	<p><i>Questions 2.2.4.2, 5.2.4.3., 5.2.4.4., 5.2.5.2., 5.2.5.3, 5.3.6.2 and 5.2.7.1. revised to allow opportunity for explanation if this is the case (added 'Note: If this varies greatly according to type/source of device/orthotic, please explain.')</i></p>
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**PILOT FEEDBACK: COLLATED FROM 2 PARTICIPANTS IN STAGE 2**

QUESTION	PARTICIPANTS' RESPONSES			ACTION TAKEN / RESEARCHER COMMENT
<b>SECTION 1: ADMINISTRATION</b>				
A. Type of questionnaire piloted	Online		Microsoft Word	
	xx			
B. How long did the questionnaire take to complete?	Online		Microsoft Word	
	25 minutes			<i>Information sheet changed to note realistic time taken to complete and consult with supervisors regarding incentive for participation.</i>
	30 minutes			
C. Are the instructions for the questionnaire unambiguous and clear?	Yes	No	Some	
	x	x		
Detail specific question numbers of concern/needing rewording or restructuring	I had to reread the questions to be sure of what you were asking			<i>Key words in questions changed to capital letters (underlined in Microsoft Word version) to emphasise key elements of the questions (this was only done in some questions in draft questionnaire).</i>
D. Is the wording of the questions unambiguous and clear?	Yes	No	Some	
	X		X	

Detail specific question numbers of concern/needing rewording or restructuring	You first ask about the interview and then the assessment. I see this as all part of the same process. I would give headings so that I know I am answering about interviews, then assessment, then therapy etc.			<i>Heading for sections considered clear according to the OT process – ‘interviews’ fall within the section of ‘assessments.’</i>
<b>SECTION 2: ORGANISATION</b>				
<b>A. Do the sections flow logically?</b>	Yes	No	Partly	
	xx			
Detail specific sections of concern/ needing attention	There is logic but there is some repetition. I think that the questions could be less and more stream lined. Usually I would not answer such a questionnaire especially with 26 minutes. I don't have this sort of time nor interest, so if it is longer than 10 minutes I don't bother.			<i>Questions 4.3.1. – 4.3.3., 5.1.4.1., 5.4.1.1. and 5.4.2.1 removed.  Supervisors consulted and all other questions considered necessary.  Offer incentive for participants as an alternative if length of questionnaire may jeopardise response rate and quality of responses.</i>
<b>B. Do the questions within each section flow logically, and do they appear to fit into the sections they are in?</b>	Yes	No	Some	
	xx			
Detail specific sections of concern/ needing  Attention				

SECTION 3: CONTENT				
<b>A. Are the questions clear and concise?</b>	Yes	No	Some	
	x	x		
Detail specific questions of concern/ needing attention				<i>No explanation available for response of 'no' and review of responses indicated they were understood as required. No changes.</i>
<b>B. Do the questions meet the objectives of the study?</b>	Yes	No	Some	
	x		x	
Detail areas of objectives that you feel are not adequately met and need to be expanded on	If you are focused on the services, I am not sure why there are questions about assessment etc. Keep to the topic of assessing the availability of services and the limitations within the service.			<i>Assessment is considered a valid and necessary service provided. Definition of terms in the research protocol outlines that services include steps of assessment, goal-setting and interventions/treatment. No change.</i>
<b>C. Do you think all the questions are necessary?</b>	Yes	No	Some	
	x	x		
Detail specific questions that may be redundant/unnecessary				<i>Questions 4.3.1. – 4.3.3., 5.1.4.1., 5.4.1.1. and 5.4.2.1 removed.</i>
<b>D. Are the questions free of unnecessary jargon and complex terminology?</b>	Yes	No	Some	
	x		x	

Detail specific words that need to be changed or added to the definitions of terms list	OT modules? Could be anything			<i>Appears that participant misread question pertaining to 'OT models' – which is considered an accepted and known term amongst the population.</i>
<b>E. Are questions unbiased, that is, not leading you to answer in a specific manner?</b>	Yes	No	Some	
	x		x	
Detail specific questions that may be considered biased and need revision	The question lead to an answer and there is assumptions in this.			<i>Specific question(s) not identified by participant. Not mentioned by other pilot participants. Monitor in stage 3 of testing.</i>
<b>F. Are the response choices mutually exclusive and exhaustive, that is, was there always the answer that you would have chosen available as an option?</b>	Yes	No	Some	
	x	x		
Detail questions where response choices may need revision	At times, I just chose an answer for the sake of having an answer.			<i>Specific question(s) not identified by participant. Questions considered to have sufficient options for responses to be truthful. Note that not all questions are compulsory to answer. Monitor in stage 3 of pilot.</i>
<b>SECTION 4: ANY ADDITIONAL FEEDBACK</b>	The tick lists really saved a lot of time...I liked that.			
	Q 5.1. MAES should be added as an additional treatment.			<i>Added as Q 5.1.11.</i>

	<p>Overall found it a positive experience to complete the questionnaire and was reminded of some modalities I could be using more or build more skill in.</p> <p>Please let me know if you will be expanding on your research at any stage. I am sure Northern Cape therapists would be happy to help.</p> <p>Q 4.3.3. Do not understand the question</p> <p>I like the idea of this study and think it is very necessary. We know that services in the WC are inadequate for the number of children with severe CP. This topic is very relevant and critical for many children. I would suggest that you stick to the services available rather than including interesting and broad questions. The system IDs the problem, not the child with CP nor the mother, so this study needs to look at the systems in place for services. If a few parents could answer this questionnaire it would be great, then it would have to be simpler.</p>	<p><i>Note as a potential indirect benefit of the research and participation</i></p> <p><i>Note as a potential recommendation for further research across other provinces</i></p> <p><i>Unnecessary open-ended questions removed in this section (Questions 4.3.1. – 4.3.3)</i></p> <p><i>Discussed comments with supervisors and agreed that the objectives of this level of research, and its quantitative descriptive nature, are adequately met through the sections and questions included. Responses from a single defined population is required for the nature of this research.</i></p> <p><i>All broad questions in section 6 changed to closed-ended format (with additional optional open-ended explanations), in response to the comments as well as the quality of responses in this and prior stage of piloting.</i></p>
--	--	---

**PILOT FEEDBACK: COLLATED FROM 2 PARTICIPANTS IN STAGE 3**

QUESTION	PARTICIPANTS' RESPONSES			ACTION TAKEN / RESEARCHER COMMENT
<b>SECTION 1: ADMINISTRATION</b>				
<b>A. Type of questionnaire piloted</b>	Online	Microsoft Word		
	xx			
<b>B. How long did the questionnaire take to complete?</b>	Online	Microsoft Word		
	60 (because the internet bombed so I had to start again)			
	29 min, 22 sec			
<b>C. Are the instructions for the questionnaire unambiguous and clear?</b>	Yes	No	Some	
	xx			
Detail specific question numbers of concern/need rewording or restructuring				
<b>D. Is the wording of the questions unambiguous and clear?</b>	Yes	No	Some	
	X		x	
Detail specific question numbers of concern/need rewording or	With the questions related to what assessments are used or what OTs assess, it may be helpful to specify whether you want			<i>Responses gained during all pilot stages have been appropriate to this question. During data</i>

restructuring	respondents to list specific assessments or generally the kinds of assessments they use.		<i>analysis, responses will be grouped according to similarities and themes. No changes made.</i>	
<b>SECTION 2: ORGANISATION</b>				
<b>A. Do the sections flow logically?</b>	Yes	No	Partly	
	xx			
Detail specific sections of concern/need attention				
<b>B. Do the questions within each section flow logically, and do they appear to fit into the sections they are in?</b>	Yes	No	Some	
	xx			
Detail specific sections of concern/need attention				
<b>SECTION 3: CONTENT</b>				
<b>A. Are the questions clear and concise?</b>	Yes	No	Some	
	xx			
Detail specific questions of concern/need attention				
	Yes	No	Some	

<b>B. Do the questions meet the objectives of the study?</b>	x		x	
Detail areas of objectives that you feel are not adequately met and need to be expanded on	All the questions do, but I wonder about whether for your last objective, there could be a question asking the therapist to speak to their perceptions of their practice – how good they think it is, what they think is missing, what they would do differently if their listed challenges weren't a problem			<p><i>Closed-ended question added for participants to indicate the extent to which they feel like they are meeting the children's needs, ahead of the last question which asks for what they feel they are not adequately providing.</i></p> <p>Q 6.8. added as 'To what extent do you feel like you are fulfilling your OT role in meeting the needs of the child with severe CP?'</p>
<b>C. Do you think all the questions are necessary?</b>	Yes	No	Some	
	xx			
Detail specific questions that may be redundant/unnecessary				
<b>D. Are the questions free of unnecessary jargon and complex terminology?</b>	Yes	No	Some	
	xx			
Detail specific words that need to be changed or added to the definitions of terms list				
	Yes	No	Some	

E. Are questions unbiased, that is, not leading you to answer in a specific manner?	xx			
Detail specific questions that may be considered biased and need revision				
F. Are the response choices mutually exclusive and exhaustive, that is, was there always the answer that you would have chosen available as an option?	Yes	No	Some	
	x		x	
Detail questions where response choices may need revision	For the question about at what age the child typically starts being seen, it would have been helpful for me to be able to answer with words and not just numbers – I would have said that if a problem is obvious at the birth, the child would be considered a ‘high risk’ infant and would start seeing OT every 2 months right away.			<i>Purpose of question is to gain estimate of average, not requiring an explanation for this level of quantitative analysis. No change.</i>
<b>SECTION 4: ANY ADDITIONAL FEEDBACK</b>	In the mobility aids section, it could help to have a why/why not option (not crucial) so that people can explain their response. In my case, it looks like we never issued wheelchairs which is true, but our clients did get wheelchairs from the physios because where I worked the physio adopted that as ‘her baby’.			<i>Q 5.2.5.4., Q 5.2.5.5., Q 5.2.5.6. and Q 5.2.5.7. have response options for ‘refer elsewhere for this,’ which would be an appropriate selection for this situation.</i>

	<p>The questionnaire was easy to complete and follow. I was very conscious of the time I took to complete it – questions that required additional explanations took me longer to answer as I wrote in full sentences.</p> <p>I struggled initially in the beginning as I am not working at the NGO anymore but as an academic, so I had to complete it based on my last memory of working as a clinician. So the timeframes for waiting periods of assistive devices and treatment intervention for example was a bit of a struggle for me to name a 'number' accurately.</p>	<p><i>Participants in the research will all be currently working in government facilities, so these challenges with recall will not be of concern.</i></p>
--	---	--

## APPENDIX 4: AUDIT TRAIL OF PILOT PROCESS

NAME	CONTACT MADE AND INFORMATION SHEET AND FEEDBACK CHECKLIST SENT	AGREED TO ASSIST	SENT LINK / SENT MICROSOFT WORD VERSION QUESTIONNAIRE	RETURNED
<b>STAGE 1</b>				
<b>Participant 1:</b> Currently working in government facilities at district and primary level care in another province. Home language and language of OT studies is Afrikaans. Languages of practice are Afrikaans and seSotho.	11-Dec-19	Yes: 12-Dec-19	12-Dec-19	17-Dec-19
<b>Participant 2:</b> Has vast experience with children with CP in government sector and private practice. Experience in research methodology.	11-Dec-19	Yes: 11-Dec-19	11-Dec-19	23-Dec-19
<b>Participant 3:</b> Has experience with children with CP in government sector. Experience in research methodology.	26-Dec-19	Yes: 27-Dec-19	30-Dec-19	01-Jan-20
<b>Participant 4:</b> Currently working at a tertiary government facility in another province.	26-Dec-19	Yes: 26-Dec-19	26-Dec-19	27-Dec-19
<b>STAGE 2</b>				
<b>Participant 5:</b> Has many years of experience with children with CP in government sector	17-Dec-19	On leave, so rather stage 2 in January	06-Jan-19	16-Jan-20

and private practice, with a special interest in early intervention. Has completed Masters research.				
<b>Participant 6:</b> Currently working in government facilities at district and primary level care in another province. Home language and language of practice is Afrikaans.	11-Dec-19	Yes: 12-Dec-19	12-Dec-19	11-Jan-20
<b>STAGE 3</b>				
<b>Participant 7:</b> Has experience with children with CP in government sector. Experience in research methodology.	29-Jan-20	Yes: 29-Jan-20	29-Jan-20	31-Jan-20
<b>Participant 8:</b> Considered an expert in the fields of paediatric neurology and research. Has worked with children with severe CP and currently a lecturer in this area. Has completed Masters and Doctoral research, and supervised numerous Postgraduate research students.	01-Feb-20	Yes: 01-Feb-20	01-Feb-20	02-Mar-20

## APPENDIX 5: FINAL QUESTIONNAIRE (GOOGLE FORMS FORMAT)

# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE. IT CONSISTS OF 6 SECTIONS.

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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## INTRODUCTION AND CONSENT

This questionnaire should 20-30 minutes to complete. This has been verified through pilot administration.

Please answer these questions truthfully in relation to your current practice within the government healthcare sector.

Completion of this questionnaire implies consent to use your responses in this research. If you have any questions or concerns, you are welcome to contact the researcher directly: [laurenf004@gmail.com](mailto:laurenf004@gmail.com) or 072 9952790.

Please only complete this questionnaire once.

Please note:

1. If you work alongside a team of Occupational Therapy Technicians, Rehabilitation Care Workers or other similar assistants, answer the questions on behalf of this team's overall services, rather than only what you are implementing personally - as long as these services are overseen by you, they are considered as OT services.
2. OTs working across a number of facilities (for example, based at a district hospital but providing outreach services at community health centres) should indicate this in the relevant section of the questionnaire, then answer the remainder of questions with all of their services in mind.

Please take note of definitions of terms as found within the questions.

Please bear in mind that all answers should refer to your services with CHILDREN WITH SEVERE CP. For the purpose of this study, the following definitions will be used:

1. Child/children:

Individuals 0 – 12 years old

2. Severe cerebral palsy:

Impairments resulting in classification on level IV and V of the Gross Motor Function Classification Scale (GMFCS), requiring maximal assistance in aspects of daily life and functioning. See below outline of the GMFCS levels (Palisano, Rosenbaum, Bartlett & Livingston, 2007):

LEVEL I: Walks without limitations

LEVEL II: Walks with limitations

LEVEL III: Walks with hand-held mobility device

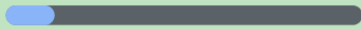
LEVEL IV: Self-mobility with limitations, may use powered mobility

LEVEL V: Transported in a manual wheelchair



Please enter your UNIQUE RESPONSE CODE found in your invitation email. This is needed to track responses, but will be removed from your answers to maintain anonymity. This code will also be used for the lucky draw you will be entered into :)

0



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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## SECTION 1: PROFILE OF PARTICIPATING OCCUPATIONAL THERAPIST

INSTRUCTION:  
PLEASE MARK SELECTION  
OR WRITE IN YOUR RESPONSE

1.1. Sex \*

- Female
- Male
- Prefer not to say

1.2. What is your highest OT qualification? \*

- Bachelors degree
- Honours degree
- Masters degree
- Doctoral degree



1.3. In what year did you graduate as an OT? \*

Your answer

1.4. How many YEARS OF EXPERIENCE do you have with children with CP? \*

Your answer

1.5. What type of position do you hold within the Western Cape Department of Health? \*

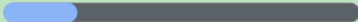
- Full-time employee
- Part-time employee

1.6. What is your employment status within the Western Cape Department of Health? \*

- Permanent employment
- Contract/locum employment
- Community service OT

1.7. What is your role of employment within your current position? \*

- Work at a single facility
- Work across a number of facilities

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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## SECTION 2: PROFILE OF FACILITY REPRESENTED

INSTRUCTION:  
PLEASE MARK SELECTION  
OR WRITE IN YOUR RESPONSE

2.1. In which DISTRICTS(S) do you provide services? (select all that apply) \*

- Cape Metropole
- Cape Winelands
- Central Karoo
- Eden
- Overberg
- West Coast



2.2. What is the LOCATION of the facilities in which you provide services? (select all that apply) Definitions below are according to Urban Statistics South Africa (1998), Statistics South Africa (2003). \*

- Urban (A settlement which has been legally declared as being urban, irrespective of population density. This includes formal urban areas (cities/towns) as well as informal urban areas (found within a city/town, but consists of informal dwellings). Mining locations, factory and municipal hostels, hospitals, prisons and other institutions contained within a local authority boundary are also considered urban settlements.)
- Semi-urban (An area that is not within a legally proclaimed urban areas boundaries, but borders it closely)
- Rural (Beyond the boundaries of urban and semi-urban areas, also referred to as non-urban areas. This includes villages, farms and small settlements)

2.3. At which LEVELS OF CARE do you provide services? (select all that apply) \*

- Primary
- Secondary
- Tertiary

2.4. How many OTs are in your department/facility? \*

Your answer \_\_\_\_\_

2.5. How many MID-LEVEL WORKERS provide services under your supervision? Mid-level workers may include OT assistants, technicians, rehabilitation careworkers and the likes. \*

Your answer \_\_\_\_\_



2.6. What is the nature of treatment spaces available? Select all applicable. \*

- Shared space(s) with other health professions
- Designated space(s) for OT services

2.7. What is your approximate average WEEKLY CASELOAD of children with severe CP? \*

- 0-5
- 6-10
- 11-15
- 16-20
- 21-25
- More than 25

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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## SECTION 3: OT ASSESSMENTS

INSTRUCTION:  
PLEASE MARK SELECTION  
OR WRITE IN YOUR RESPONSE.

PLEASE NOTE, IF YOU SELECT 'NEVER' OR 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUB-QUESTIONS RELATING TO THAT ASSESSMENT AS INSTRUCTED.

3.1. How often do you conduct an INTERVIEW WITH THE CHILD as a means of assessment? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is (skip to 3.2.)

3.1.1. Are interviews with the CHILD usually an effective means of assessment?

- Yes
- No



3.1.2. What makes interviews with the CHILD a challenging means of assessment?

Your answer

---

3.1.3. What makes interviews with the CHILD an effective means of assessment?

Your answer

---

3.2. How often do you conduct an INTERVIEW WITH THE CHILD'S CAREGIVER as a means of assessment? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is (skip to 3.3.)

3.2.1. Are interviews with the CAREGIVER usually an effective means of assessment?

- Yes
- No

3.2.2. What makes interviews with the CAREGIVER a challenging means of assessment?

Your answer

---



3.2.3. What makes interviews with the CAREGIVER an effective means of assessment?

Your answer

---

3.3. How often do you use STANDARDIZED ASSESSMENTS/CHECKLISTS as a means of assessment? \*

- Never (skip to 3.3.2.)
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is (skip to 3.4.)

3.3.1. What are the STANDARDIZED ASSESSMENTS/CHECKLISTS you frequently use?

Your answer

---

3.3.2. Are STANDARDIZED ASSESSMENTS/CHECKLISTS usually an effective means of assessment?

- Yes
- No



3.3.3. What makes STANDARDIZED ASSESSMENTS/CHECKLISTS challenging to use?

Your answer

---

3.3.4. What makes STANDARDIZED ASSESSMENTS/CHECKLISTS effective to use?

Your answer

---

3.4. How often do you use OBSERVATIONS IN ACTIVITIES as a means of assessment? \*

- Never (skip to 3.4.3.)
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is (skip to 3.5.)

3.4.1. What environments do these OBSERVATIONS take place in most frequently?

Your answer

---



3.4.2. What ACTIVITIES are most frequently observed? (select all that apply)

Self-care/Activities of Daily Living

Play/leisure

School/productivity

Other: \_\_\_\_\_

3.4.3. What makes OBSERVATIONS in activities challenging to use?

Your answer \_\_\_\_\_

3.4.4. What makes OBSERVATIONS in activities effective to use?

Your answer \_\_\_\_\_

3.5. What other assessment methods do you commonly use, if any?

Your answer \_\_\_\_\_

3.6. What is the average AGE OF FIRST CONTACT with OT for (estimate, age in years)? \*

Your answer \_\_\_\_\_

3.7. What is the average DURATION of initial assessment (estimate, time in minutes)? \*

Your answer \_\_\_\_\_





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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## SECTION 4: OT GOAL SETTING

INSTRUCTION:  
PLEASE MARK SELECTION  
OR WRITE IN YOUR RESPONSE.

PLEASE NOTE, IF YOU SELECT 'NEVER' OR 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUB-QUESTIONS AS INSTRUCTED.

4.1. How often are the CHILDREN actively involved in the goal-setting process? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



4.2. How often are the children's CAREGIVERS actively involved in the goal-setting process? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

4.3. How often do goals relate to OCCUPATIONAL PERFORMANCE?

'Occupational performance' refers to the experience of an individual engaging in purposeful activities and tasks within their environment (Law et al, 1996) \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



4.4. How often do goals relate to underlying PERFORMANCE COMPONENTS? 'Performance components' refers to the underlying attributes of a person, including physical, cognitive and others. \*

- Never (skip to 4.5.)
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is (skip to 4.5.)

4.4.1. What performance components are focused on in goals (if any)?

Your answer

---

4.5. How often do goals relate to MAINTENANCE AND PREVENTION of further challenges (as opposed to improvement/progress)? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



4.6. How often do goals relate to IMPROVEMENT/ DEVELOPMENT/ PROGRESS (as opposed to maintaining or preventing further challenges)? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

## SECTION 5: OT TREATMENT

INSTRUCTION:  
PLEASE MARK SELECTION  
OR WRITE IN YOUR RESPONSE.

PLEASE NOTE, IF YOU SELECT 'NEVER,' 'REFER ELSEWHERE' OR 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUBQUESTIONS AS INSTRUCTED.

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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## 5.1. CONTACT TREATMENT METHODS

5.1.1. How often do you conduct NEURODEVELOPMENTAL THERAPY (BOBATH THERAPY)? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is



5.1.2. How often do you conduct CONSTRAINT INDUCED MOVEMENT THERAPY?

\*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is

5.1.3. How often do you conduct BIMANUAL TRAINING? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is



5.1.4. How often do you use ELECTRICAL STIMULATION? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is

5.1.5. How often do you conduct PROPRIOCEPTIVE NEUROMUSCULAR FACILITATION? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is



5.1.6. How often do you implement SENSORY INTEGRATION? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is

5.1.7. How often do you do MASSAGE and STRETCHING? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is



5.1.8. How often do you implement STRENGTH TRAINING? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is

5.1.9. How often do you use FUNCTIONAL TASKS OR ACTIVITIES AS A MEANS of treatment? \*

- Never (skip to 5.1.10.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.1.10.)
- Not sure what this is (skip to 5.1.10.)

5.1.9.1. What types of functional activities are frequently used as a means of treatment? (select all that apply)

- Self-care/Activities of Daily Living
- Play/Leisure
- School/Productive activities
- Other: \_\_\_\_\_



5.1.10. How often do you implement COGNITIVE TRAINING TECHNIQUES? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is

5.1.11. How often do you implement Movement Analysis Education Strategies (MAES) Therapy? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is

5.1.12. What other contact treatment methods do you commonly use, if any?

Your answer

---



5.1.13. What SETTING/ENVIRONMENT does treatment usually occur in? \*

Your answer

---

5.1.14. What percentage of treatment takes place in a GROUP format (estimate)? \*

Your answer

---

5.1.15. What is the average DURATION of treatment sessions (estimate, time in minutes)? \*

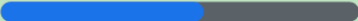
Your answer

---

5.1.16. What is the average FREQUENCY of treatment sessions (estimate, number per month)? \*

Your answer

---

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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## 5.1. ASSISTIVE DEVICES AND ORTHOTICS

5.2.1. At what level of care are assistive devices and orthotics PRESCRIBED?  
(select all that apply) \*

- Primary
- Secondary
- Tertiary

5.2.2. At what level of care are assistive devices and orthotics ISSUED? (select all that apply) \*

- Primary
- Secondary
- Tertiary



5.2.4. How often do you prescribe MOBILITY AIDS? \*

- Never (skip to 5.2.5.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.2.5.)
- Not sure what this is (skip to 5.2.5.)

5.2.4.1. What mobility aids do you commonly prescribe? (select all that apply)

- Wheelchair
- Buggy
- Walking frame
- Crutches
- Other: \_\_\_\_\_

5.2.4.2. What is the average WAITING PERIOD for mobility aids (estimate, number of MONTHS)? If this varies greatly according to type/source of aid, please explain.

Your answer \_\_\_\_\_



5.2.4.3. What is the children's average AGE when mobility aids are first issued (estimate, age in years)? If this varies greatly according to type of aid, please explain.

Your answer \_\_\_\_\_

5.2.4.4. How often do you REVIEW their mobility aids (average time between reviews, number of MONTHS)? If this varies greatly according to type of aid, please explain.

Your answer \_\_\_\_\_

5.2.5. How often do you prescribe OTHER POSITIONING DEVICES? \*

- Never (skip to 5.2.6.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.2.6.)
- Not sure what this is (skip to 5.2.6.)

5.2.5.1. What other positioning devices do you commonly prescribe? (select all that apply)

- Standing frame
- Side lyer
- Other: \_\_\_\_\_



5.2.5.2. What is the average WAITING PERIOD for these positioning devices (estimate, number of months)? If this varies greatly according to type/source of device, please explain.

Your answer

---

5.2.5.3. What is the children's average AGE when these positioning devices are first issued (estimate, age in YEARS)? If this varies greatly according to type of device, please explain.

Your answer

---

5.2.6. How often do you prescribe ASSISTIVE DEVICES FOR FUNCTIONAL TASKS?

\*

- Never (skip to 5.2.7.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.2.7.)
- Not sure what this is (skip to 5.2.7.)

5.2.6.1. What are the assistive devices that you commonly issue for functional tasks?

Your answer

---



5.2.6.2. What is the average WAITING PERIOD for these assistive devices (estimate, number of MONTHS)? If this varies greatly according to type/source of device, please explain.

Your answer \_\_\_\_\_

5.2.7. How often do you prescribe SPLINTS and ORTHOTICS? \*

- Never (skip to 5.3.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.3.)
- Not sure what this is (skip to 5.3.)

5.2.7.1. What is the average WAITING PERIOD for splints/orthotics (estimate, number of WEEKS)? If this varies greatly according to type/source of orthotic, please explain.

Your answer \_\_\_\_\_



5.2.7.2. What splints/orthotics do you commonly prescribe? (select all that apply)


Upper limb rigid

Upper limb soft

Lower limb rigid

Lower limb soft

Other: \_\_\_\_\_

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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## 5.3. CAREGIVER EDUCATION, SUPPORT AND HOME PROGRAMMES

5.3.1. How often do you provide caregiver EDUCATION? \*

- Never (skip to 5.3.2.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.3.2.)
- Not sure what this is (skip to 5.3.2.)

5.3.1.1. What is the common CONTENT of caregiver education? (select all that apply)

- Diagnosis and prognosis
- Caregiver burnout
- Therapy processes
- Treatment goals and regimes
- Home programme content
- Other: \_\_\_\_\_



5.3.2. How often do you provide HOME PROGRAMMES? \*

- Never (skip to 5.3.3.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.3.3.)
- Not sure what this is (skip to 5.3.3.)

5.3.2.1. What are typical CONTENTS and elements included in home programmes?

Your answer

---

5.3.3. How often do you provide caregiver PSYCHOSOCIAL SUPPORT? \*

- Never (skip to 5.3.4.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.3.4.)
- Not sure what this is (skip to 5.3.4.)



5.3.3.1. What is the more common FORMAT of caregiver psychosocial support?

- Group
- Individual

5.3.4. What are the common RELATIONSHIPS between the child and caregiver who typically engages with these home programmes, education and support services (e.g. mother, aunt, sibling)? \*

Your answer

---

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\* Required

## 5.4. CONTEXTUAL/ENVIRONMENTAL ACTIONS

5.4.1. How often do you conduct HOME VISITS and provide interventions at home? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is



5.4.2. How often do you visit the children's SCHOOL or DAY CARE CENTRE? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this
- Not sure what this is

5.4.3. How often do you implement OTHER COMMUNITY ACTIONS (advocacy, awareness raising, public education etc.)? \*

- Never (skip to 5.5.)
- Rarely
- Sometimes
- Usually
- Always
- Refer elsewhere for this (skip to 5.5.)
- Not sure what this is (skip to 5.5.)

5.4.3.1. What do these 'other community actions' typically entail?

Your answer

---

# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## 5.5. REFERRALS MADE TO OTHER PROFESSIONALS

How often do you refer children to each of the following?

### 5.5.1. Physiotherapist \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



5.5.2. Speech therapist \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

5.5.3. Orthotist \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

5.5.4. Orthopaedic surgeon \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



5.5.5. Dietician \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

5.5.6. Social worker \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

5.5.7. Special education system \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



5.5.8. Audiologist \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

5.5.9. Paediatrician \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

5.5.10. Other specialist \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



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# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

\* Required

## SECTION 6: FACTORS INFLUENCING SERVICES SELECTED

INTRSUCTION:  
PLEASE MARK SELECTION  
OR WRITE IN YOUR RESPONSE.

6.1. What are the main OT models or generic models of practice that influence your services and decisions? \*

Your answer

---

6.2. How often does RESOURCE AVAILABILITY influence your selection of services for children with severe CP? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



6.2.1. Briefly explain your response to 6.2.

Your answer

---

6.3. How often does WORKING AT YOUR LEVEL OF CARE influence your selection of services for children with severe CP? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

6.3.1. Briefly explain your response to 6.3.

Your answer

---

6.4. How often do POLICIES influence your selection of services for children with severe CP? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



6.4.1. Briefly explain your response to 6.4.

Your answer

---

6.5. How often does YOUR TRAINING influence your selection of services for children with severe CP? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is

6.5.1. Briefly explain your response to 6.5.

Your answer

---

6.6. How often does the LOCATION OF YOUR FACILITY influence your selection of services for children with severe CP? \*

- Never
- Rarely
- Sometimes
- Usually
- Always
- Not sure what this is



6.6.1. Briefly explain your response to 6.6.

Your answer

---

6.7. What other factors frequently influence your selection of services for children with severe CP, if any?

Your answer

---

6.8. To what extent do you feel like you are fulfilling your OT role in meeting the needs of the child with severe CP? \*

- I am not meeting any of their needs
- I am meeting some of their needs
- I am meeting most of their needs
- I am meeting all of their needs
- I, together with the multi-disciplinary team, am meeting all of their needs
- Not sure what this means
- Other: 

---

6.9. What needs or interventions do you feel that you are NOT sufficiently meeting or implementing and why (if any)? \*

Your answer

---



# Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services

THANK YOU SO MUCH FOR YOUR TIME!

Before you submit your responses, a reminder:

By completing this questionnaire, consent will be assumed. No separate informed consent form has been provided to you.

By submitting your questionnaire, you are showing that you understand what is presented on the information sheet and agree to participate in this research study.

You will be entered for a lucky draw, and winner will be contacted via email upon completion of the study.

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## APPENDIX 6: FINAL QUESTIONNAIRE (MICROSOFT WORD FORMAT)

Occupational Therapy for children with severe cerebral palsy in government healthcare facilities in  
the Western Cape:  
An overview of current services

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE.

It consists of the following 6 sections:

<b>SECTION 1: PROFILE OF PARTICIPATING OCCUPATIONAL THERAPIST</b>	<ul style="list-style-type: none"><li>• Multiple choice or short answers relating to your basic work-related demographics and experience</li></ul>
<b>SECTION 2: PROFILE OF FACILITY REPRESENTED</b>	<ul style="list-style-type: none"><li>• Multiple choice or short answers relating to your work context and setting</li></ul>
<b>SECTION 3: OT ASSESSMENTS</b>	<ul style="list-style-type: none"><li>• Types of assessments, each requiring ratings of frequency used</li><li>• Brief open-ended questions</li></ul>
<b>SECTION 4: GOAL-SETTING</b>	<ul style="list-style-type: none"><li>• Ideas regarding goal-setting, each requiring ratings of frequency used</li><li>• Brief open-ended questions</li></ul>
<b>SECTION 5: OT TREATMENT</b>	<ul style="list-style-type: none"><li>• Types of interventions, each requiring ratings of frequency used</li><li>• Brief open-ended questions</li></ul>
<b>SECTION 6: FACTORS INFLUENCING SELECTION OF SERVICES</b>	<ul style="list-style-type: none"><li>• Frequency ratings and brief open-ended questions</li></ul>

This questionnaire should take approximately **20 minutes** to complete. This has been verified through pilot administration.

Please answer these questions **truthfully** in relation to your **current** practice within the government healthcare sector.

**Completion** of this questionnaire implies **consent**. The **anonymity** of your responses will be maintained.

If you have any **questions or concerns**, you are welcome to contact the researcher directly:

[laurenf004@gmail.com](mailto:laurenf004@gmail.com) or 072 9952790.

**Please note:**

3. If you work alongside a team of Occupational Therapy Technicians, Rehabilitation Care Workers or other similar assistants, answer the questions on behalf of this team's overall services, rather than only what you are implementing personally - as long as these services are overseen by you, they are considered as OT services.
4. OTs working across a number of facilities (for example, based at a district hospital but providing outreach services at community health centres) should indicate this in the relevant section of the questionnaire, then answer the remainder of questions with all of their services in mind.

Please take note of **definitions of terms** as found in footnotes.

Please bear in mind that all answers should refer to your services with **CHILDREN WITH SEVERE CP**.

For the purpose of this study, the following definitions will be used:

**1. Child/children:**

Individuals 0 – 12 years old

**3. Severe cerebral palsy:**

Impairments resulting in classification on Level IV and V of the Gross Motor Function Classification Scale (GMFCS), requiring maximal assistance in aspects of daily life and functioning. See below outline of the GMFCS levels (Palisano, Rosenbaum, Bartlett & Livingston, 2007):

<b>GENERAL HEADINGS FOR EACH LEVEL</b>	
<b>LEVEL I</b>	- Walks without Limitations
<b>LEVEL II</b>	- Walks with Limitations
<b>LEVEL III</b>	- Walks Using a Hand-Held Mobility Device
<b>LEVEL IV</b>	- Self-Mobility with Limitations; May Use Powered Mobility
<b>LEVEL V</b>	- Transported in a Manual Wheelchair

<b>DISTINCTIONS BETWEEN LEVELS</b>	
<b>Distinctions Between Levels I and II</b> - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.	
<b>Distinctions Between Levels II and III</b> - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.	
<b>Distinctions Between Levels III and IV</b> - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.	
<b>Distinctions Between Levels IV and V</b> - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.	

© Palisano, Rosenbaum, Bartlett & Livingston, 2007 Page 2 of 4

## SECTION 1: PROFILE OF PARTICIPATING OCCUPATIONAL THERAPIST

### INSTRUCTION:

*PLEASE MARK SELECTION WITH AN 'X'*

*OR WRITE IN YOUR RESPONSE''*

1.1 Sex	<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Prefer not to say
1.2. What is your highest OT qualification?	<input type="checkbox"/> Bachelors degree	<input type="checkbox"/> Honours degree	<input type="checkbox"/> Masters degree
1.3. In what year did you graduate as an OT?			
1.4. How many <u>years of experience</u> do you have with children with CP?			
1.5. What type of position do you hold within the Western Cape Department of Health?	<input type="checkbox"/> Full-time position	<input type="checkbox"/> Part-time position	
1.6. What is your employment status within the Western Cape Department of Health?	<input type="checkbox"/> Permanent employment	<input type="checkbox"/> Contract / locum employment	<input type="checkbox"/> Community service OT
1.7. What is your role of employment within your current position?	<input type="checkbox"/> Work at a single facility.	<input type="checkbox"/> Work across a number of facilities.	

## SECTION 2: PROFILE OF FACILITY REPRESENTED

### INSTRUCTION:

PLEASE MARK SELECTION WITH AN 'X'

OR WRITE IN YOUR RESPONSE

2.1. In which <u>district(s)</u> do you provide services? (select all that apply)	<input type="checkbox"/> Cape Metropole	<input type="checkbox"/> Cape Winelands	<input type="checkbox"/> Central Karoo	<input type="checkbox"/> Eden	<input type="checkbox"/> Overberg	<input type="checkbox"/> West Coast
2.2. What is the <u>location</u> of the facilities <sup>6</sup> in which you provide services? (select all that apply)	<input type="checkbox"/> Urban		<input type="checkbox"/> Semi-urban		<input type="checkbox"/> Rural	
2.3. At which <u>levels of care</u> do you provide services? (select all that apply)	<input type="checkbox"/> Primary		<input type="checkbox"/> Secondary		<input type="checkbox"/> Tertiary	
2.4. How many OTs are in your department/facility?						
2.5. How many <u>mid-level workers</u> <sup>7</sup> provide services under your supervision?						
2.6. What is the nature of treatment spaces available? Select all applicable	<input type="checkbox"/> Shared space(s) with other health professions			<input type="checkbox"/> Designated space(s) for OT services		
2.7. What is your approximate average <u>weekly caseload</u> of children with severe CP?	<input type="checkbox"/> 0 - 5	<input type="checkbox"/> 6 - 10	<input type="checkbox"/> 11 - 15	<input type="checkbox"/> 16 - 20	<input type="checkbox"/> 21 - 25	<input type="checkbox"/> >25

<sup>6</sup> **Location of facility** (Statistics South Africa, 1998; Statistics South Africa, 2003):

- **Urban:** A settlement which has been legally declared as being urban, irrespective of population density. This includes *formal* urban areas (cities/towns) as well as *informal* urban areas (found within a city/town, but consists of informal dwellings). Mining locations, factory and municipal hostels, hospitals, prisons and other institutions contained within a local authority boundary are also considered urban settlements.
- **Semi-urban:** An area that is not within a legally proclaimed urban areas boundaries, but borders it closely.
- **Rural:** Beyond the boundaries of urban and semi-urban areas, also referred to as non-urban areas. This includes villages, farms and small settlements.

<sup>7</sup> **Mid-level workers** may include OT assistants, technicians, rehabilitation careworkers and the likes

**SECTION 3: OT ASSESSMENTS**

**INSTRUCTION:**

PLEASE MARK SELECTION WITH AN 'X'

OR WRITE IN YOUR RESPONSE.

PLEASE NOTE, IF YOU SELECT 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUB-QUESTIONS  
RELATING TO THAT ASSESSMENT AS INSTRUCTED.

<b>3.1. How often do you conduct an <u>interview with the child</u> as a means of assessment?</b>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 3.2.)
3.1.1. Are interviews with the <u>child</u> usually an effective means of assessment?	<input type="checkbox"/> Yes			<input type="checkbox"/> No		
3.1.2. What makes interviews with the <u>child</u> a challenging means of assessment?						
3.1.3. What makes interviews with the <u>child</u> an effective means of assessment?						
<b>3.2. How often do you conduct an <u>interview with the child's caregiver</u> as a means of assessment?</b>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 3.3.)
3.2.1. Are interviews with the <u>caregiver</u> usually an effective means of assessment?	<input type="checkbox"/> Yes			<input type="checkbox"/> No		
3.2.2. What makes interviews with the <u>caregiver</u> a challenging means of assessment?						
3.2.3. What makes interviews with the <u>caregiver</u> an effective means of assessment?						
<b>3.3. How often do you use <u>standardized assessments/ checklists</u> as a means of</b>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is

assessment?	(skip to 3.3.2)					(skip to 3.4.)
3.3.1. What are the <u>standardized assessments or checklists</u> you frequently use?						
3.3.2. Are <u>standardized assessments/checklists</u> usually an effective means of assessment?	<input type="checkbox"/> Yes			<input type="checkbox"/> No		
3.3.3. What <u>makes standardized assessments/checklists</u> challenging to use?						
3.3.4. What makes <u>standardized assessments/checklists</u> effective to use?						
3.4. How often do you use <u>observation in activities as a means of assessment?</u>	<input type="checkbox"/> Never (skip to 3.4.3.)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 3.5)
3.4.1. What environments do these <u>observations</u> take place in most frequently?						
3.4.2. What <u>activities</u> are most frequently observed? (select all that apply)	<input type="checkbox"/> Self-care/Activities of Daily Living	<input type="checkbox"/> Play/leisure	<input type="checkbox"/> School/ productivity	<input type="checkbox"/> Other. <i>Specify:</i>		
3.4.3. What makes <u>observations</u> in activities challenging to use?						
3.4.4. What makes <u>observations</u> in activities effective to use?						
3.5. What other assessment methods do you commonly use, if any?						
3.6. What is the average <u>age of first contact with OT</u> for (estimate, age in years)?						
3.7. What is the average <u>duration of initial assessment</u> (estimate, time in minutes)?						

**SECTION 4: OT GOAL-SETTING**

*INSTRUCTION:*

PLEASE MARK SELECTION WITH AN 'X'

OR WRITE IN YOUR RESPONSE.

PLEASE NOTE, IF YOU SELECT 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUBQUESTIONS AS INSTRUCTED.

4.1. How often are the <u>children</u> actively involved in the goal-setting process?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
4.2. How often are the children's <u>caregivers</u> actively involved in the goal-setting process?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
4.3. How often do goals relate to <u>occupational performance</u> <sup>8</sup> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
4.4. How often do goals relate to <u>underlying performance components</u> <sup>9</sup> ?	<input type="checkbox"/> Never (skip to 4.5.)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is (skip to 4.5.)
4.4.1. What performance components are focused on in goals (if any)?						
4.5. How often do goals relate to <u>maintenance and prevention of further challenges</u> (as opposed to improvement/progress)?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means
4.6. How often do goals relate to <u>improvement/development/progress</u> (as opposed to maintaining or preventing further challenges)?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means

<sup>8</sup> **Occupational performance** refers to the experience of an individual engaging in purposeful activities and tasks within their environment (Law et al, 1996)

<sup>9</sup> **Performance components** refers to the underlying attributes of a person, including physical, cognitive and others.

## SECTION 5: OT TREATMENT

### INSTRUCTION:

*PLEASE MARK SELECTION WITH AN 'X'*

*OR WRITE IN YOUR RESPONSE.*

*PLEASE NOTE, IF YOU SELECT 'NEVER,' 'REFER ELSEWHERE' OR 'NOT SURE WHAT THIS IS', LEAVE OUT THE SUBQUESTIONS AS INSTRUCTED.*

### 5.1. CONTACT TREATMENT METHODS

5.1.1. How often do you conduct <u>Neuro-developmental Therapy (Bobath Therapy)?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.2. How often do you conduct <u>Constraint-Induced Movement Therapy?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.3. How often do you conduct <u>Bimanual Training?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.4. How often do you use <u>Electrical Stimulation?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.5. How often do you conduct <u>Proprioceptive Neuromuscular Facilitation?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.6. How often do you implement <u>Sensory Integration?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.7. How often do you do <u>Massage and Stretching?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.8. How often do you implement <u>Strength Training?</u>	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.9. How often do you use <u>functional tasks or activities as a means of treatment?</u>	<input type="checkbox"/> Never (skip to 5.1.10)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.1.10)	<input type="checkbox"/> Not sure what this is

							(skip to 5.1.10)
5.1.9.1. What types of activities are frequently used as a means of treatment? (select all that apply)	<input type="checkbox"/> Self-care/ Activities of Daily Living		<input type="checkbox"/> Play/leisure		<input type="checkbox"/> School/productive activities		<input type="checkbox"/> Other. <i>Specify:</i>
5.1.10. How often do you implement <u>Cognitive Training Techniques</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.11. How often do you implement <u>Movement Analysis Education Strategies (MAES) Therapy</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.1.12. What other contact treatment methods do you commonly use, if any?							
5.1.13. What <u>setting/ environment</u> does treatment usually occur in?							
5.1.14. What percentage of treatment takes place in a <u>group</u> format (estimate)?							
5.1.15. What is the average <u>duration</u> of treatment sessions (estimate, time in minutes)?							
5.1.16. What is the average <u>frequency</u> of treatment sessions (estimate, number per month)?							

**5.2. ASSISTIVE DEVICES AND ORTHOTICS**

<p><b>5.2.1. At what level of care are assistive devices and orthotics <u>prescribed</u>? (select all that apply)</b></p>	<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary	<input type="checkbox"/> Tertiary				
<p><b>5.2.2. At what level of care are assistive devices and orthotics <u>issued</u>? (select all that apply)</b></p>	<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary	<input type="checkbox"/> Tertiary				
<p><b>5.2.3. How often do you prescribe <u>mobility aids</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.2.5)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.2.5)	<input type="checkbox"/> Not sure what this is (skip to 5.2.5)
<p><b>5.2.3.1. What mobility aids do you commonly prescribe? (select all that apply)</b></p>	<input type="checkbox"/> Wheelchair	<input type="checkbox"/> Buggy	<input type="checkbox"/> Walking frame	<input type="checkbox"/> Crutches	<input type="checkbox"/> Other. <i>Specify:</i>		
<p><b>5.2.3.2. What is the average <u>waiting period</u> for mobility aids (estimate, number of months)?</b></p>	(Note: If this varies greatly according to type/source of aid, please explain)						
<p><b>5.2.3.3. What is the children's average <u>age</u> when mobility aids are first issued (estimate, age in <u>years</u>)?</b></p>	(Note: If this varies greatly according to type of aid, please explain)						
<p><b>5.2.3.4. How often do you <u>review</u> their mobility aids (average time between reviews, number of <u>months</u>)?</b></p>	(Note: If this varies greatly according to type of aid, please explain)						
<p><b>5.2.4. How often do you prescribe other <u>positioning devices</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.2.6)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.2.6)	<input type="checkbox"/> Not sure what this is (skip to 5.2.6)
<p><b>5.2.4.1. What other positioning devices do you</b></p>	<input type="checkbox"/> Side-lyer		<input type="checkbox"/> Standing frame		<input type="checkbox"/> Other. <i>Specify:</i>		

commonly prescribe? (select all that apply)							
5.2.4.2. What is the average <u>waiting period</u> for these positioning devices (estimate, number of <u>months</u> )?	(Note: If this varies greatly according to type/source of device, please explain)						
5.2.4.3. What is the children's average <u>age</u> when these positioning devices are first issued (estimate, age in <u>years</u> )?	(Note: If this varies greatly according to type of device, please explain)						
5.2.5. How often do you prescribe <u>assistive devices for functional tasks</u> ?	<input type="checkbox"/> Never (skip to 5.2.7)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.2.7)	<input type="checkbox"/> Not sure what this is (skip to 5.2.7)
5.2.5.1. What are the assistive devices that you commonly issue for functional tasks?							
5.2.5.2. What is the average <u>waiting period</u> for these assistive devices (estimate, number of <u>months</u> )?	(Note: If this varies greatly according to type/source of device, please explain)						
5.2.6. How often do you prescribe <u>splints and orthotics</u> ?	<input type="checkbox"/> Never (skip to 5.3)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3)	<input type="checkbox"/> Not sure what this is (skip to 5.3)
5.2.6.1. What is the average <u>waiting period</u> for splints/orthotics (estimate, time in <u>weeks</u> )?	(Note: If this varies greatly according to type/source of orthotic, please explain)						
5.2.6.2. What splints/orthotics do you commonly prescribe? (select all that apply)	<input type="checkbox"/> Upper limb rigid	<input type="checkbox"/> Upper limb soft	<input type="checkbox"/> Lower limb rigid	<input type="checkbox"/> Lower limb soft	<input type="checkbox"/> Other. <i>Specify:</i>		

**5.3. CAREGIVER EDUCATION, SUPPORT AND HOME PROGRAMMES**

<p><b>5.3.1. How often do you provide <u>caregiver education</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.3.2)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3.2)	<input type="checkbox"/> Not sure what this is (skip to 5.3.2)
<p><b>5.3.1.1. What is the common <u>content</u> of caregiver education? (select all that apply)</b></p>	<input type="checkbox"/> Diagnosis and prognosis	<input type="checkbox"/> Caregiver burnout	<input type="checkbox"/> Therapy processes	<input type="checkbox"/> Treatment goals and regimes	<input type="checkbox"/> Home programme content	<input type="checkbox"/> Other. <i>Specify:</i>	
<p><b>5.3.2. How often do you provide <u>home programmes</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.3.3)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3.3)	<input type="checkbox"/> Not sure what this is (skip to 5.3.3)
<p><b>5.3.2.1. What are typical <u>contents</u> and elements included in home programmes?</b></p>							
<p><b>5.3.3. How often do you provide <u>caregiver psychosocial support</u>?</b></p>	<input type="checkbox"/> Never (skip to 5.3.4)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.3.4)	<input type="checkbox"/> Not sure what this is (skip to 5.3.4)
<p><b>5.3.3.1. What is the more common <u>format</u> of caregiver psychosocial support?</b></p>	<input type="checkbox"/> Group				<input type="checkbox"/> Individual		
<p><b>5.5.4. What are the common <u>relationships</u> between the child and caregiver who typically engages with these home programmes, education and support services (e.g. mother, aunt. sibling)?</b></p>							

5.4. <u>CONTEXTUAL/ENVIRONMENTAL ACTIONS</u>							
5.4.1. How often do you conduct <u>home visits</u> and provide interventions at home?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.4.2. How often do you visit the children's <u>school or day care centre</u> ?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this	<input type="checkbox"/> Not sure what this is
5.4.3. How often do you implement <u>other community actions</u> (advocacy, awareness raising, public education etc.)?	<input type="checkbox"/> Never (skip to 5.5)	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Refer elsewhere for this (skip to 5.5)	<input type="checkbox"/> Not sure what this is (skip to 5.5)
5.4.3.1. What do these 'other community actions' typically entail?							

**5.5. REFERRALS MADE TO OTHER PROFESSIONALS**

**How often do you refer children to each of the following?**

5.5.1. Physiotherapist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.2. Speech therapist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.3. Orthotist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.4. Orthopaedic surgeon	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.5. Dietician	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.6. Social worker	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.7. Special education system	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.8. Audiologist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.9. Paediatrician	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is
5.5.10. Other specialist	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this is

**SECTION 6: FACTORS INFLUENCING SERVICES SELECTED**

*PLEASE MARK SELECTION WITH AN 'X'*

*OR WRITE IN YOUR RESPONSE.*

6.1. What are the main OT models or generic models of practice that influence your services and decisions?						
6.2. How often does <b>resource availability</b> influence your selection of services for children with severe CP?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means
6.2.1. Briefly explain your response to 6.2.						
6.3. How often does <b>working at your level of care</b> influence your selection of services for children with severe CP?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means
6.3.1. Briefly explain your response to 6.3.						
6.4. How often do <b>policies</b> influence your selection of services for children with severe CP?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means
6.4.1. Briefly explain your response to 6.4.						
6.5. How often does <b>your training</b> influence your selection of services for children with severe CP?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means
6.5.1. Briefly explain your response to 6.5.						

6.6. How often does <b>the location of your healthcare facility</b> influence your selection of services for children with severe CP?	<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Usually	<input type="checkbox"/> Always	<input type="checkbox"/> Not sure what this means	
6.6.1. Briefly explain your response to 6.6.							
6.7. What <b>other factors</b> frequently influence your selection of services for children with severe CP? Explain each.							
6.8. To what extent do you feel like you are fulfilling your OT role in meeting the needs of the child with severe CP?	<input type="checkbox"/> I am not meeting any of their needs	<input type="checkbox"/> I am meeting some of their needs	<input type="checkbox"/> I am meeting most of their needs	<input type="checkbox"/> I am meeting all of their needs	<input type="checkbox"/> I, together with the multi-disciplinary team, am meeting all of their needs	<input type="checkbox"/> Not sure what this means	<input type="checkbox"/> Other. <i>Please explain:</i>
6.8. What interventions do you feel that you are <b>NOT sufficiently implementing and why, if any?</b>							

**THANK YOU SO MUCH FOR YOUR TIME!**

**Before you submit your responses, a reminder:**

**By completing this questionnaire, consent will be assumed.**

**No separate informed consent form has been provided to you.**

**By submitting your questionnaire, you are showing that you understand what is presented on the information sheet and agree to participate in this research study.**

## APPENDIX 7: SUMMARY OF VARIABLES AND TYPES OF DATA

CATEGORICAL DATA	ORDINAL DATA					
	Frequency various services occur, referrals made and factors impacting service selection (Sections 3, 4, 5 & 6)			Perception of quality of service (Section 6)		
	<u>Response options:</u> Never Rarely Sometimes Usually Always I don't know what this is Refer elsewhere for this			<u>Response options:</u> I am not meeting any of their needs I am meeting some of their needs I am meeting most of their needs I am meeting all of their needs I, together with the multidisciplinary team, am meeting all of their needs Not sure what this means		
	NOMINAL DATA					
	Participant sex (Section 1)	Highest OT qualification (Section 1)	Type of position held (Section 1)	Employment status (Section 1)	Role of employment (Section 1)	Year graduated as an OT (Section 1)
	<u>Response options:</u> Male Female	<u>Response options:</u> Bachelor degree Honours degree Masters degree Doctoral degree	<u>Response options:</u> Full-time Part-time	<u>Response options:</u> Permanent Community service Locum/contract	<u>Response options:</u> Work at a single facility Work across a number of facilities	<u>Data elicited:</u> Year
	Districts serviced (Section 2)	Location of facility (Section 2)	Nature of treatment spaces (Section 2)	Level of care services occur (Section 2&5)	Effectivity of assessment methods (Section 3)	Activities observed and treated (Sections 3&5)
	<u>Response options:</u>	<u>Response options:</u>	<u>Response options:</u>	<u>Response options:</u>	<u>Response options:</u>	<u>Response options:</u>

	<i>Cape Metropole</i> <i>Eden</i> <i>Central Karoo</i> <i>Overberg</i> <i>Cape Winelands</i> <i>West Coast</i>	<i>Urban</i> <i>Semi-urban</i> <i>Rural</i>	<i>Designated space(s) for OT</i>  <i>Shared space(s) with other health professions</i>	<i>Primary</i> <i>Secondary</i>  <i>Tertiary</i>	<i>Yes</i>  <i>No</i>	<i>Self-care/ Activities of daily living</i>  <i>Play/Leisure</i>  <i>School/ Productivity</i>  <i>Other</i>
	<b>Mobility aids prescribed (Section 5)</b>  <u>Response options:</u> <i>Wheelchair</i> <i>Buggy</i> <i>Walking frame</i> <i>Crutches</i> <i>Other</i>	<b>Positioning devices prescribed (Section 5)</b>  <u>Response options:</u> <i>Side-lyer</i> <i>Standing frame</i> <i>Other</i>	<b>Splints / orthotics prescribed (Section 5)</b>  <u>Response options:</u> <i>Lower limb rigid</i> <i>Lower limb soft</i> <i>Upper limb rigid</i> <i>Upper limb soft</i>	<b>Content of caregiver education (Section 5)</b>  <u>Response options:</u> <i>Caregiver burnout</i> <i>Diagnosis/ prognosis</i> <i>Therapy processes</i> <i>Treatment goals and regimes</i> <i>Home programme content</i> <i>Other</i>	<b>Format of caregiver support (Section 5)</b>  <u>Response options:</u> <i>Group</i> <i>Individual</i>	
<b>NUMERICAL DATA</b>	<b>INTERVAL DATA</b>					
	<b>Weekly caseload of children with CP (Section 2)</b>  <u>Response options:</u> <i>0 – 5</i> <i>6 – 10</i> <i>11 – 15</i> <i>16 – 20</i> <i>21 – 25</i> <i>More than 25</i>					
	<b>RATIO / CONTINUOUS DATA</b>					

	<p><b>Number of years of experience with children with CP</b> (Section 1)</p> <p><u>Data elicited:</u> <i>Number of years</i></p>	<p><b>Number of OTs in department</b> (Section 2)</p> <p><u>Data elicited:</u> <i>Number of people</i></p>	<p><b>Number of mid-level workers under OT supervision</b> (Section 2)</p> <p><u>Data elicited:</u> <i>Number of people</i></p>	<p><b>Child's age at first contact and issue of devices</b> (Section 3 &amp; 4)</p> <p><u>Data elicited:</u> <i>Age in years</i></p>
	<p><b>Duration of sessions</b> (Section 4 &amp; 5)</p> <p><u>Data elicited:</u> <i>Time in minutes</i></p>	<p><b>Percentage of treatment in group setting</b> (Section 5)</p> <p><u>Data elicited:</u> <i>Percentage (/100)</i></p>	<p><b>Frequency of treatment and review of devices</b> (Section 5)</p> <p><u>Data elicited:</u> <i>Number per month</i></p>	<p><b>Waiting period for mobility and positioning devices</b> (Section 5)</p> <p><u>Data elicited:</u> <i>Time in months</i></p>

## APPENDIX 8: INFORMATION SHEET



UNIVERSITY OF CAPE TOWN  
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Information sheet for research entitled:

**OCCUPATIONAL THERAPY FOR CHILDREN WITH SEVERE CEREBRAL PALSY IN  
GOVERNMENT HEALTHCARE FACILITIES IN THE WESTERN CAPE:  
AN OVERVIEW OF CURRENT SERVICES**

This **research** is being conducted as part of the completion of a Masters in Occupational Therapy at the University of Cape Town. The primary researcher is Lauren Fuller, under supervision of Dr Amshuda Sonday and Associate Professor Helen Buchanan. **Ethical approval** for this study has been obtained from the Human Research Ethics Committee of the University of Cape Town (HREC 702/2019 as well as permission from the Western Cape Department of Health via the National Health Research Database (WC\_201910\_023). The Human Research Ethics Committee can be contacted on 021 406 6338 if participants have any questions regarding their rights and welfare as participants on the study.

Since there is minimal local literature available regarding the current provision of services for children with severe cerebral palsy, the **aim** of this study is to provide a descriptive overview of the current services occurring in all government healthcare facilities in the Western Cape for this population group. The purpose is not to evaluate or 'audit' services, but rather gain insight into overall current practice. As an OT working in this sector with contact with this population group, you are requested to take part in the study in order to contribute to this body of knowledge. The aim is to receive responses from OTs working across all districts and levels of service within the province, thus your participation is valuable in completing the data received.

Your **participation** and **honest** responses will provide valuable contributions in order to make recommendations regarding service protocols, policy development and undergraduate education programmes – overall advocating for improved service availability for children with severe cerebral palsy within South Africa’s primary healthcare systems.

Participation in this study will involve completing a **questionnaire**. While there will be **no compensation** provided, you may, however, **benefit** from the opportunity and process of self-reflection while answering the questionnaire. Should you complete the questionnaire, you will be entered into a **lucky draw** to be a winner of one of two R250 Takealot vouchers.

The researcher understands that clinicians have high-pressured caseloads and busy lives, so the questionnaire will take no longer than **15-20 minutes** to complete in your own space and time. You may select any of the following formats:

1. ONLINE QUESTIONNAIRE  
(which can be completed in your own time on any electronic device and submitted directly)
2. MICROSOFT WORD QUESTIONNAIRE  
(which can be completed using a black pen, and then either returned via email (scanned), arrange to be collected, faxed or posted back to the researcher)
3. TELEPHONIC / VERBAL INTERVIEW  
(using the same questionnaire format, the researcher will ask questions and answers will be recorded directly as spoken – *may take slightly longer than the 15-20 minutes in this format*)

The questionnaire is made up of **6 sections**, in order to achieve the study objectives. A definition of terms will be provided to supplement the questionnaire. The sections have the following content, loosely following the main steps in the OT process:

<b>SECTION 1: PROFILE OF PARTICIPATING OCCUPATIONAL THERAPIST</b>	<ul style="list-style-type: none"> <li>•Quick, multiple choice answers relating to your basic work-related demographics and experience</li> </ul>
<b>SECTION 2: PROFILE OF FACILITY REPRESENTED</b>	<ul style="list-style-type: none"> <li>•Quick, multiple choice answers relating to your work context and setting</li> </ul>
<b>SECTION 3: TYPES OF ASSESSMENTS USED</b>	<ul style="list-style-type: none"> <li>•List of assessment options requiring ratings of frequency used.</li> <li>•Brief open-ended questions optional</li> </ul>
<b>SECTION 4: GOAL-SETTING PROCESSES</b>	<ul style="list-style-type: none"> <li>•List of ideas relating to goal-setting processes requiring ratings of frequency used.</li> <li>•Brief open-ended questions optional</li> </ul>
<b>SECTION 5: TYPES OF INTERVENTIONS IMPLEMENTED</b>	<ul style="list-style-type: none"> <li>•List of intervention options requiring ratings of frequency used.</li> <li>•Brief open-ended questions optional</li> </ul>
<b>SECTION 6: FACTORS INFLUENCING SELECTION OF SERVICES</b>	<ul style="list-style-type: none"> <li>•Brief open-ended questions</li> </ul>

**Remember**, the purpose is not to critique your personal OT practice and service provision, but rather to determine what services are occurring provincially with this population. There are thus **no risks** associated with participating in this study and anonymity and confidentiality of responses is guaranteed through appropriate data management and storage. Raw responses will only be accessed by the researcher and her supervisors. **Results** will be summarised in report format and presented holistically through statistical means, so nobody may link the results with you as a participant or the facility at which you work.

A summary of the study findings will be sent to all participants after completion of the research. Participation is entirely **voluntary** and you may choose to **withdraw** from the study or remove your responses at any point in time by contacting the researcher directly, with no consequences for you or the facility at which you work. The researcher commits to **respecting** this decision.

**Thank you for taking the time to consider participating in this research.**

Should you have any **questions** or need **further information**, the researcher or her supervisors are available on the contact details below.

LAUREN FULLER

DR SONDAY

ASSOC PROF BUCHANAN

Primary researcher

Research supervisor

Research supervisor

EMAIL ###

EMAIL ###

EMAIL ###

CELL ###

The chairperson of the Human Research Ethics Committee (Prof. M. Blockman) can be contacted on 021 406 6338 / EMAIL ### for further queries.

**Consent:**

**By completing this questionnaire, consent will be assumed. No separate informed consent form will be provided to you.**

**By this, you are showing that you understand what is presented on the information sheet and agree to participate in this research study.**

**The aim, procedures to be used, as well as the potential risks and benefits of your participation have been provided to you in detail. Refusal to participate in or withdrawal from this study at any time will have no effect on you in any way. You are free to contact me, to ask questions or request further information, at any time during this research.**

## APPENDIX 9: PARTICIPANT INVENTORY AND DATA COLLECTION AUDIT TRAIL

Participant code allocated	Date of initial contact	Date responded	Response	Date questionnaire sent out	Date of first follow up (if necessary)	Date of second follow up (if necessary)	Date of third follow up (if necessary)	Date of completion	Format of questionnaire completed
0306	08/03/2020	10/03/2020	Agreed to participate	10/03/2020	2020/03/26	29/04/2020	18/05/2020	08/06/2020	Google Form
0301	08/03/2020	09/03/2020	Agreed to participate	09/03/2020	2020/03/26			30/03/2020	Google Form
0308	08/03/2020	16/03/2020	Agreed to participate	16/03/2020				16/03/2020	Google Form
0307	12/03/2020	12/03/2020	Agreed to participate	12/03/2020	2020/03/26			01/04/2020	Google Form
0502	12/03/2020	18/05/2020	Agreed to participate	18/05/2020	2020/03/20	18/05/2020	22/06/2020	24/06/2020	Google Form
D01	14/03/2020	16/03/2020	Declined: Not servicing children with CP						
0402	14/03/2020	06/04/2020	Agreed to participate	06/04/2020	2020/03/30			06/04/2020	Google Form

0406	31/03/2020	17/04/2020	Agreed to participate	17/04/2020	2020/04/16	18/05/2020	22/06/2020	Not returned	Not returned
0322	31/03/2020	31/03/2020	Agreed to participate	31/03/2020				15/04/2020	Google Form
0404	06/04/2020	16/04/2020	Agreed to participate	16/04/2020	2020/04/16			16/04/2020	Google Form
0602	18/05/2020	17/06/2020	Agreed to participate	17/06/2020	2020/06/15			17/06/2020	Microsoft Word document
D02	18/05/2020	None	None		2020/06/15	22/06/2020	24/06/2020		
0604	18/05/2020	22/06/2020	Agreed to participate	22/06/2020	15/06/2020			2020/06/30	Microsoft Word document
0321	08/03/2020	(05/03/2020)	Agreed to participate	31/03/2020				01/04/2020	Google Form
0302	08/03/2020	09/03/2020	Agreed to participate	09/03/2020				10/03/2020	Google Form
D03	10/03/2020	20/03/2020	Declined: HOD, not doing clinical work		20/03/2020				
0403	20/03/2020	06/04/2020	Agreed to participate	06/04/2020	31/03/2020			06/04/2020	Google Form

0407	20/03/2020	17/04/2020	Agreed to participate	17/04/2020	08/04/2020			28/04/2020	Google Form
0315	20/03/2020	21/03/2020	Agreed to participate	21/03/2020	08/04/2020	18/05/2020	03/06/2020	Not returned	Not returned
0316	20/03/2020	21/03/2020	Agreed to participate	21/03/2020	08/04/2020			08/04/2020	Google Form
0313	18/03/2020	19/03/2020	Agreed to participate	19/03/2020	03/04/2020			Not returned. Completed with colleague	Not returned. Completed with colleague
0401	18/03/2020	03/04/2020	Agreed to participate	03/04/2020	30/03/2020			21/04/2020	Google Form
0320	12/03/2020	31/03/2020	Agreed to participate	31/03/2020	20/03/2020	18/05/2020		19/05/2020	Google Form
0501	15/05/2020	15/05/2020	Agreed to participate	15/05/2020	03/06/2020	15/06/2020	29/06/2020	Not returned	Not returned
0303	08/03/2020	09/03/2020	Agreed to participate	09/03/2020				11/03/2020	Google Form
0318	08/03/2020	30/03/2020	Agreed to participate	30/03/2020	18/03/2020			04/04/2020	Google Form
D04	08/03/2020	11/03/2020	Declined: Not servicing		2020/03/30				

			children with CP						
0305	08/03/2020	10/03/2020	Agreed to participate	10/03/2020				26/03/2020	Google Form
D05	11/03/2020	None	Maternity leave		20/03/2020	18/05/2020			
D06	10/03/2020	10/03/2020	Declined: Not servicing children with CP						
D07	17/06/2020	None	None		22/06/2020	25/06/2020			
D08	17/06/2020	None	None		22/06/2020	25/06/2020			
0503	08/03/2020	19/05/2020	Agreed to participate	19/05/2020	18/03/2020	18/04/2020	03/06/2020	Not returned	Not returned
D09	08/03/2020	None	None		18/03/2020	18/05/2020	22/06/2020		
0504	10/03/2020	21/05/2020	Agreed to participate	22/05/2020	18/03/2020	18/05/2020	03/06/2020	04/06/2020	Google Form
D10	10/03/2020	None	None		18/03/2020	22/06/2020	22/06/2020		
0601	15/06/2020	15/06/2020	Agreed to participate	17/06/2020				25/06/2020	Microsoft Word document

0603	17/06/2020	17/06/2020	Agreed to participate					17/06/2020	Google Form
0701	17/06/2020	17/06/2020	Maternity leave until 16/07 then agreed to participate	16/07/2020				17/07/2020	Microsoft Word document
0314	18/03/2020	20/03/2020	Agreed to participate	20/03/2020				02/04/2020	Google Form
D12	18/03/2020	None	None		30/03/2020	18/05/2020	22/06/2020		
0319	30/03/2020	30/03/2020	Agreed to participate	30/03/2020	16/04/2020			17/04/2020	Google Form
0325	30/03/2020	02/04/2020	Agreed to participate	02/04/2020	16/04/2020	29/04/2020		30/04/2020	Google Form
0405	31/03/2020	17/04/2020	Agreed to participate	17/04/2020	08/04/2020	23/04/2020		29/04/2020	Microsoft Word document
0323	31/03/2020	31/03/2020	Agreed to participate	31/03/2020				31/03/2020	Google Form
D13	02/04/2020	None	None		16/04/2020	18/05/2020	22/06/2020		
D14	31/03/2020	None	None		08/04/2020	18/05/2020	22/06/2020		

0304	08/03/2020	09/03/2020	Agreed to participate	09/03/2020	26/03/2020			30/03/2020	Google Form
D15	09/03/2020	19/03/2020	Declined: No capacity/time		18/03/2020	2020/04/16			
0311	09/03/2020	18/03/2020	Agreed to participate	18/03/2020	18/03/2020			30/03/2020	Google Form
0309	18/03/2020	18/03/2020	Agreed to participate	18/03/2020	02/04/2020			03/04/2020	Google Form
0310	18/03/2020	18/03/2020	Agreed to participate	18/03/2020	02/04/2020			Not returned. Completed with colleague	Not returned. Completed with colleague
0317	27/03/2020	27/03/2020	Agreed to participate	27/03/2020				30/03/2020	Google Form
0324	31/03/2020	31/03/2020	Agreed to participate	31/03/2020	31/03/2020	29/04/2020		30/03/2020	Microsoft Word document

# APPENDIX 10: UNIVERSITY OF CAPE TOWN HUMAN RESEARCH ETHICS COMMITTEE APPROVAL



**UNIVERSITY OF CAPE TOWN**  
**Faculty of Health Sciences**  
**Human Research Ethics Committee**



**Room E53-46 Old Main Building**  
**Groote Schuur Hospital**  
**Observatory 7925**

**Telephone [021] 406 6626**

**Email: [Olivia.Jangenhoven@uct.ac.za](mailto:Olivia.Jangenhoven@uct.ac.za)**

**Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)**

16 October 2019

**HREC REF:702/2019**

**Prof A. Sunday**

Division of Occupational Therapy  
F56 Room 76  
OMB GSH

Dear Prof Sunday

**PROJECT TITLE: OCCUPATIONAL THERAPY FOR CHILDREN WITH SEVERE CEREBRAL PALSY IN GOVERNMENT HEALTHCARE FACILITIES IN THE WESTERN CAPE: AN OVERVIEW OF CURRENT SERVICES (MASTER DEGREE - MISS LAUREN FULLER)**

Thank you for submitting your new study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has formally **approved** the above-mentioned study subject to the following conditions:

1. Kindly separate the HREC contact details from the Investigator contact details
2. Kindly add Prof M. Blockman as the HREC contact person.

**Approval is granted for one year until the 30 October 2020.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms))

***We acknowledge that the student: Miss Lauren Fuller will also be involved in this study.***

**Please note that no research may occur without formal written HREC approval.**

**Please quote the HREC reference number in all your correspondence.**

Yours sincerely

Signature Removed

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

NHREC-registration number: REC-210208-007

HREC REF 702/2019

# APPENDIX 11: NATIONAL HEALTH RESEARCH DATABASE PERMISSION

(example: one received per facility)



## STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za  
tel: +27 21 483 0866; fax: +27 21 483 6058  
5<sup>th</sup> Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001  
[www.capegateway.gov.za](http://www.capegateway.gov.za)

REFERENCE: WC\_201910\_023

ENQUIRIES: Dr Sabela Petros

**University of Cape Town**  
**Anzio Road**  
**Observatory**  
**Cape Town**  
**7925**

For attention: DR Amshuda Sondag, MS Lauren Fuller, PROF Helen Buchanan

**Re: Occupational therapy for children with severe cerebral palsy in government healthcare facilities in the Western Cape: An overview of current services**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

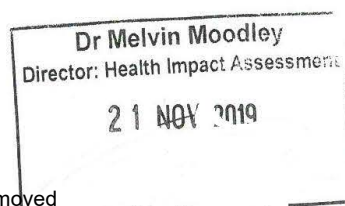


Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator ([Health.Research@westerncape.gov.za](mailto:Health.Research@westerncape.gov.za)).
3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator ([Health.Research@westerncape.gov.za](mailto:Health.Research@westerncape.gov.za)).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

**DRM MOODLEY**  
**DIRECTOR: HEALTH IMPACT ASSESSMENT**  
**DATE:**



Signature Removed

## APPENDIX 12: OPTIONAL OPEN-ENDED QUESTIONS RESPONSES

The following table displays the number of responses to the optional open-ended questions.

Question number	Question	Number of responses (n)	Section of Results Chapter
3.1.2.	What makes interviews with the child a challenging means of assessment?	33	4.3.1.2.
3.1.3.	What makes interviews with the child an effective means of assessment?	30	4.3.1.2.
3.2.2.	What makes interviews with the caregiver a challenging means of assessment?	32	4.3.1.1.
3.3.1.	What are the standardized assessments/checklists you frequently use?	24	4.3.1.4.
3.3.3.	What makes standardized assessments/checklists challenging to use?	30	4.3.1.4.
3.3.4.	What makes standardized assessments/checklists effective to use?	31	4.3.1.4.
3.4.1.	What environments do these observations take place in most frequently?	33	4.3.1.3.
3.4.3.	What makes observations in activities challenging to use?	33	4.3.1.3.
3.5.	What other assessment methods do you commonly use, if any?	19	4.3.1.3.
4.4.1.	What performance components are focused on in goals, if any?	30	4.3.2.

5.1.12.	What other contact treatment methods do you commonly use, if any?	14	4.3.3.1.1.
5.2.4.2.	What is the average waiting period for mobility aids (estimate, number of months)?	14	4.3.3.1.2.
5.2.4.3.	What is the children's average age when mobility aids are first issued (estimate, age in years)?	24	4.3.3.1.2.
5.2.4.4.	How often do you review their mobility aids (average time between reviews, number of months)?	22	4.3.3.1.2.
5.2.5.1.	What other positioning devices do you commonly prescribe?	24	4.3.3.1.2.
5.2.5.2.	What is the average waiting period for these positioning devices (estimate, number of months)?	14	4.3.3.1.2.
5.2.5.3.	What is the children's average age when these positioning devices are first issued (estimate, age in years)?	15	4.3.3.1.2.
5.2.6.1.	What are the assistive devices that you commonly issue for functional tasks?	26	4.3.3.1.2.
5.2.6.2.	What is the average waiting period for these assistive devices (estimate, number of months)?	19	4.3.3.1.2.
5.2.7.1.	What splints/orthotics do you commonly prescribe?	31	4.3.3.1.2.
5.2.7.2.	What is the average waiting period for splints/orthotics (estimate, number of weeks)?	11	4.3.3.1.2.
5.3.2.1.	What are typical contents and elements included in home programmes?	33	4.3.3.2.
5.4.3.1.	What do these 'other community actions' typically entail?	17	4.3.3.2.

6.1.	What are the main OT models or generic models of practice that influence your services and decisions?	29	4.4.8.
6.2.1.	Briefly explain your response to 6.2 (regarding resource availability influencing selection of services).	33	4.4.3.
6.3.1.	Briefly explain your response to 6.3 (regarding level of care influencing selection of services).	28	4.4.4.
6.4.1.	Briefly explain your response to 6.4 (regarding policies influencing selection of services).	22	4.4.6.
6.5.1.	Briefly explain your response to 6.5 (regarding OT training influencing selection of services).	31	4.4.7.
6.6.1.	Briefly explain your response to 6.6 (regarding location of facility influencing selection of services).	27	4.4.5.
6.7.	What other factors frequently influence your selection of services for children with severe CP, if any?	14	n/a
6.9.	What needs or interventions do you feel that you are not sufficiently meeting or implementing and why, if any?	30	4.5.

## APPENDIX 13: FULL LIST OF PERFORMANCE COMPONENTS IN GOALS

Below, a full list of responses to Question 4.4.1. of the questionnaire, as summarised in Section 4.3.2. of results.

Physical and sensory performance components	Cognitive performance components	Other responses
Range of movement	Awareness and level of arousal	Reaching
Muscle tone	Motivation	Self-soothing
Endurance	Concentration and attention	Sensory stimulation and activity
Balance	Choice-making	Seating and positioning
Co-ordination	Perceptual skills	Transfers, transitional movements and bed mobility/rolling
Eye movement and visual tracking	Cognition (unspecified)	Basic concepts
Head control	Psychosocial skills (unspecified)	Social interaction and communication
Trunk control	Sequencing	Developmental milestones
Postural alignment and control		Initiation and termination of activities
Fine motor skills		Independence (unspecified)
Gross motor skills		
Reflex responses		
Bilateral integration		
Grips and grasps		
Sensation and sensory processing		
Muscle strength		

Hand function (unspecified)		
Sensorimotor (unspecified)		
Neuromuscular (unspecified)		
Physical components (unspecified)		

## APPENDIX 14: FULL LIST OF CONTENTS OF HOME PROGRAMMES

Below, a full list of responses to Question 5.3.2.1. of the questionnaire, as summarised in Section 4.3.3.2. of results.

	NO. (%)
<u>Addressing body functions and structure</u>	
<i>Positioning</i>	17 (50)
<i>General handling</i>	3 (8.8)
<i>Massage</i>	2 (5.9)
<i>Passive mobilisation</i>	9 (26.5)
<i>Exercises (unspecified)</i>	4 (11.8)
<i>Methods to influence tone</i>	1 (2.9)
<i>Maintenance of range of movement</i>	5 (14.7)
<i>Perceptual skills</i>	1 (2.9)
<i>Gross and fine motor skills</i>	2 (5.9)
<u>Addressing activity limitations and participation restrictions</u>	
<i>Daily routine and structure</i>	1 (2.9)
<i>Facilitating active engagement</i>	4 (11.8)
<i>Functional activities and occupation-based goals (unspecified)</i>	2 (5.9)
<i>Activities of daily living / Self-care activities</i>	8 (23.5)
<i>Play and stimulation activities</i>	17 (50)
<i>Social interaction and behaviour management</i>	3 (8.8)
<i>Facilitating towards developmental milestones</i>	4 (11.8)
<i>Transfers</i>	2 (5.9)
<u>Assistive devices and orthotics</u>	
<i>Use and care for assistive devices</i>	3 (8.8)
<i>Use and care for splints and orthotics</i>	1 (2.9)
<u>Specific generic programmes provided</u>	
<i>START Activity Sheets*</i>	1 (2.9)
<i>Hambisela Programme**</i>	2 (5.9)

\* The START (Striving Towards Achieving Results Together) Programme was developed by a local organisation, with aims for the development of children with physical and intellectual disabilities (Solarsh, Katz, & Goodman, 1990).

\*\* The Hambisela programme is a locally-developed training programme which focuses on providing skills to caregivers of children with CP, specifically regarding their understanding of the condition and practical skills to facilitate daily activities with their child (van Aswegen et al., 2019).

## APPENDIX 15: FULL LIST OF PRACTICE MODELS, FRAMES OF REFERENCE AND APPROACHES

Below, a full list of responses to Question 6.1. of the questionnaire, as summarised in Section 4.5.6. of results.

	<b>NO. (%)*</b>
<b><u>Model of practice, frame of reference or approach to intervention</u></b>	
Person-Environment-Occupation model	10 (34.5)
Biopsychosocial approach	8 (27.6)
International Classification of Functioning, Disability & Health	7 (24.1)
Neurodevelopmental Therapy approach	5 (17.2)
Model of Human Occupation	5 (17.2)
Biomechanical frame of reference	2 (6.9)
Developmental frame of reference	2 (6.9)
Client-centred approach	2 (6.9)
Family-centred approach	1 (3.4)
Model of Creative Ability	1 (3.4)
Early Childhood development	1 (3.4)
Person-Environment-Occupation-Performance Model	1 (3.4)
The F Words in Cerebral Palsy	1 (3.4)
Treatment guidelines issued via the MOTH communication tree and developed by Neuro work group	1 (3.4)
Community models (not specified)	1 (3.4)
Bio-Psycho-Social-Spiritual approach	1 (3.4)
Bio-Socio-Mechanical Model	1 (3.4)
Gross Motor Function Classification Scale	1 (3.4)
Communication Function Classification Scale	1 (3.4)
Canadian Model of Occupational Performance	1 (3.4)
First 1000 Days	1 (3.4)

\*Many participants listed more than one response