

**Investigating the Perceptions of Speech-Language Therapists working
in the Public Health and Education Sectors, about the Services they
provide to Children with Cerebral Palsy in the Greater Johannesburg
Region, from Birth to Six Years.**

by
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Declaration

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Abstract

Background

Prior to entering the basic education system at six years of age, speech and language assessment, diagnosis, and treatment of children with cerebral palsy (CP), take place in hospitals and primary healthcare settings in the South African public sector. This is informed by governmental guidelines. Paediatric patients are directed through a referral pathway, ideally from a hospital setting to a primary healthcare facility for rehabilitation and issuing of appropriate assistive devices. Once children are of school-going age, they are referred to the education sector for schooling. Nearly twenty years since the establishment of the National Rehabilitation Policy, strides have been made to improve accessibility to rehabilitation services as well as the quality of life of children with CP in the health and education sectors. Shortfalls however still exist in implementing this policy. It is therefore important to explore the referral pathway that bridges these two sectors, to identify possible gaps that may occur and affect the continuity of therapy for children with CP.

Aims and Objective

The main objective of this study was to investigate the perceptions of Speech-Language Therapists (SLTs) working in the Gauteng Department of Health (GDH) and Gauteng Department of Education (GDE), in Johannesburg region A, about the services they provide to children with cerebral palsy, from birth to six years of age.

Participants and Methodology

A qualitative research design was followed, specifically the approach of phenomenology. A semi-structured interview protocol was employed, which consisted of open-ended questions and probes. This protocol was used to guide eight focus groups and one individual interview. A total of 31 SLTs working in public hospitals, clinics and Learners with Special Educational Needs (LSEN) schools participated. Interviews were audio-recorded for transcription and subsequent thematic analysis.

Findings

The most prominent theme was that there was a perceived chasm between the GDH and the GDE in the referral process of young children with CP. Participants working in the health sector

and participants in the education sector expressed frustration that highlighted the need to address the perceived lack of communication between these two sectors in the region. A recurring perception of the participants was that the GDE failed to address the specific needs of the child during school placement. Failure to place children into schools where the existing resources and infrastructure are aligned with the specific needs of the child, placed enormous strain on the rehabilitation systems, with outcomes such as increased caseloads in the health sector; strains on the curriculum; ineffective deployment of resources; and a breakdown in trust between the community and the education system.

Conclusion

The results suggest that a cohesive plan should be formulated and executed in order to bridge the perceived chasm between the GDH and the GDE in the referral process of children with CP from the hospital or clinic setting, into the school environment. This may facilitate communication, collaboration, education, as well as resource sharing between the departments.

Uittreksel

Agtergrond

Voordat kinders op die ouderdom van ses jaar in die basiese onderwysstelsel opgeneem word, vind spraak- en taalassessering, diagnosering en behandeling van kinders met serebrale gestremdheid in hospitale en primêre gesondheidsorginstansies in die Suid-Afrikaanse openbare sektor plaas. Dit word deur regeringsriglyne bepaal. Pediatriese pasiënte word deur 'n verwysingsroete begelei, ideaalgesproke vanaf 'n hospitaalomgewing tot 'n primêre gesondheidsorgfasiliteit vir rehabilitasie en die uitreik van toepaslike hulptoestelle. Wanneer kinders skoolgaande ouderdom bereik, word hulle vir onderrig na die onderwyssektor verwys. Amper twintig jaar na die ontstaan van die Nasionale Rehabilitasiebeleid is daar al vordering in die gesondheids- en onderwyssektore gemaak om die toeganklikheid tot rehabilitasiedienste, asook die lewenskwaliteit van serebraalgestremde kinders, te verbeter. Daar is egter steeds tekortkominge in die implementering van hierdie beleid. Dit is dus belangrik om die verwysingsroete wat hierdie twee sektore verbind, te verken met die doel om moontlike gapings wat 'n impak op die kontinuïteit van terapie vir serebraalgestremde kinders kan hê, te identifiseer.

Doelwitte en Oogmerk

Die hoofdoel van hierdie studie was om spraak-taalterapeute wat vir die Gautengse Departement van Gesondheid (GDG) en die Gautengse Departement van Onderwys (GDO) in Streek A van Johannesburg werk se persepsies aangaande die diens wat hulle aan serebraalgestremde kinders van geboorte tot sesjarige ouderdom lewer, te ondersoek.

Deelnemers en Metodologie

'n Kwalitatiewe navorsingsontwerp, spesifiek die fenomenologie-benadering, is gevolg. 'n Semigestruktureerde onderhoudprotokol wat uit oop en indringende vrae saamgestel is, is aangewend. Hierdie protokol is as riglyn vir die ag fokusgroepe en een individuele onderhoud gebruik. 'n Totaal van 31 spraak-taalterapeute wat in hospitale, klinieke en skole vir leerders met spesiale opvoedkundige behoeftes (LSOB-skole) werk, het deelgeneem. Klankopnames is van onderhoude gemaak vir transkribering en die daaropvolgende ontleding van temas.

Bevindinge

Die prominentste tema was die persepsie dat daar 'n gaping tussen die GDG en die GDO bestaan ten opsigte van die verwysingsproses van jong serebraalgestremde kinders. Die gevolglike frustrasie van deelnemers wat in die gesondheidssektor en die onderwyssektor werk beklemtoon die noodsaaklikheid daarvan om hierdie persepsie van gebrekkige kommunikasie tussen die twee sektore in die streek, aan te spreek. 'n Herhalende persepsie onder deelnemers was dat die GDO daarin gefaal het om die spesifieke behoeftes van kinders tydens skoolplasings aan te spreek. Wanneer daarin misluk word om kinders in ooreenstemming met hul spesifieke behoeftes in skole met bestaande hulpbronne en infrastruktuur te plaas, plaas dit geweldige stremming op die rehabilitasiesistels en lei dit tot 'n verhoogde gevalle-lading in die gesondheidssektor; stremming op die kurrikulum; ondoeltreffende aanwending van hulpbronne; en die afbreek van vertroue tussen die gemeenskap en die onderwysstelsel.

Gevolgtrekking

Die resultate suggereer dat 'n samehangende plan geformuleer en uitgevoer moet word ten einde die waargenome gaping tussen die GDG en die GDO ten opsigte van die verwysingsproses van serebraalgestremde kinders vanaf die hospitaal- of kliniekopset tot in die skoolomgewing, te oorbrug. Dit kan kommunikasie, samewerking, onderrig, asook die deel van hulpbronne tussen departemente fasiliteer.

*Αυτή η διατριβή είναι αφιερωμένη στη μνήμη των γονιών μου, του Ιωάννη Προδρόμου
Μεσσιαν (1946-2016) και της Γαρουφαλίας Μεσσιαν (1962-2019)*

*This thesis is dedicated in memory of my parents, Iannis Prodromos Messian (1946-2016)
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List of Abbreviations

AAC:	Augmentative Alternative Communication
ACPF:	African Child Policy Forum
CHC:	Community Health Clinic
CP:	Cerebral Palsy
CT:	Clinic Therapist
DoE:	Department of Education
DoH:	Department of Health
ECI:	Early Childhood Intervention
GDE:	Gauteng Department of Education
GDH:	Gauteng Department of Health
HPCSA:	Health Professions Council of South Africa
HREC:	Health Research Ethics Committee
HT:	Hospital Therapist
ICF:	International Classification of Functioning, Disability and Health
ICF-CY:	International Classification of Functioning, Disability and Health – Child and Youth
INDS:	Integrated Disability Strategy
LMIC:	Low- to Middle-income Country
LSEN:	Learners with Special Educational Needs
LTSM:	Learner-Teacher Support Material
MDT:	Multidisciplinary Team

MID:	Mild/Moderate Intellectual Disability
NHRD:	National Health Research Department
NRP:	National Rehabilitation Policy
PHC:	Primary Healthcare
PID:	Profound Intellectual Disability
R2ECWD:	Rights to Education of Children with Disabilities Campaign
SCPE:	Surveillance of Cerebral Palsy in Europe
SGB:	School Governing Body
SIAS:	Screening, Identification and Support
SID:	Severe Intellectual Disability
SLT:	Speech-Language Therapist
ST:	School Therapist
WHO:	World Health Organisation

Chapter 1: Introduction

Cerebral palsy (CP), a condition that has affected mankind since antiquity, is a motor disability affecting people and starts in childhood. Our knowledge of the aetiology of the condition allows us to assume that the condition existed prior to formal research that provided concrete examples and definitions of CP (Panteliadis et al., 2013). Despite a lack of detailed medical descriptions from before the 19th century, mentions of the condition can be found in representational art, literary sources and paleopathology from the past. Works by Hippocrates, the ancient Greek Physician of the Age of Pericles, provided the first medical description of CP (Panteliadis et al., 2013). In the 19th century, the first concrete definition of CP emerged through the research and works of William John Little, which were expanded upon in the 20th century by William Osler and Sigmund Freud (Panteliadis et al., 2013). The contributions of these three scientists have led to the latest significant developments in the field of CP.

CP is a neurodevelopmental disorder that affects movement and posture due to non-progressive damage to the immature brain, ultimately affecting the child throughout their life (Bax et al., 2005, as cited in Kim et al., 2019). As a child develops into an adult, the severity of the disability and functional level of the individual changes. Ultimately, the functional level achieved as an adult is entirely dependent on the levels of function that the individual was able to reach as a child. Achieving the best possible outcomes is facilitated through continuous rehabilitation in order to achieve maximum potential and prevent functional deterioration from occurring (Vos et al., 2013, as cited in Kim et al., 2019).

For a long time in South Africa, continuous intervention had not been provided to the population with CP and the development of a strategy that addresses the neglect of rehabilitative services to children with disabilities, was required. This gave rise to the *Integrated Disability Strategy* (INDS) that was established in 1997 by the Office of the Deputy President of South Africa (Office of the Deputy President, 1997, as cited in de Wet, 2013). This strategy was developed as there was no policy on the rehabilitation services provided to people with disabilities. These services were traditionally disjointed and uncoordinated. In order for optimal functional levels to be reached and maintained within this population by means of rehabilitation, the INDS proposed a *National Rehabilitation Policy* (NRP) (Department of Health, 2000, as cited in de Wet, 2013). The *National Rehabilitation Policy* was finalised and published in 2001.

Simultaneously, in 2001, the Department of Education (DoE) issued a framework policy document called White Paper 6: *Special Needs Education, Building an Inclusive Education and Training System* (Department of Education, 2001). This policy document, produced by the government, set out their proposal for future legislation regarding special needs education. The policy acknowledged that all children and youth can learn and those that needed remediation to cope with educational demands should be provided with the support they needed. Furthermore, the policy aimed to acknowledge the education structures, systems and learning methodologies needed to meet the needs of all learners (Department of Education, 2001).

Whilst the South African government was attempting to lay down foundational policy and a legislative framework regarding the rehabilitation and education of children with disabilities, similar challenges were being experienced across the African continent. As a result, in 2003, the African Child Policy Forum (ACPF) was founded by Dr. Assefa Bequele. He is a Pan-Africanist of Ethiopian origin, an economist by training and an authority on child rights and well-being. The ACPF is a non-profit, Pan-African institute of policy research and dialogue on the African child. The forum's convictions are based on placing the rights and well-being of children first on the public agenda, in order to bring about social and economic progress in Africa (African Child Policy Forum [ACPF], 2011). The ACPF's work is based on relevant regional and international human rights instruments and its aim is to develop and implement effective pro-child policies and programmes, as well as to promote a common voice for children in Africa (ACPF, 2011). They believe that sufficient attention in this regard has not been afforded in research, policy or legislation in order to protect the rights of children living with disabilities. The forum states that limited political commitment, a genuine lack of resources, as well as a lack of current policy and legislative programming options are to blame for the current situation regarding this population (ACPF, 2011).

In 2013, the South African Department of Health recognised that in order to address the health inequalities experienced by persons with disabilities in our society, a transformation of the current South African health system had to occur. Hence, the *Framework and Strategy for Disability and Rehabilitation Services in South Africa* (National Department of Health, 2016) was compiled. This framework aims to reconfigure rehabilitation as an integral part of health services across all programmes, within all levels of care. It aims to increase access, equitability, inclusivity and participation for the population living with disabilities within their communities (National Department of Health, 2016). The framework recognises that rehabilitation services

are a crucial link between medical treatment and the adaptation of a person's restored functionality into a health-promoting social and productive economic life (National Department of Health, 2016). This is specifically relevant for children living with CP. Furthermore, the framework states that appropriate referral pathways create access to suitable care of this population and must be aligned to departmental policy on referrals, clinical guidelines and protocols.

Nearly twenty years on from the establishment of the National Rehabilitation Policy developed by the INDS, the White Paper 6, as well as the ACPF, strides have been made to implement policy in order to improve accessibility to all rehabilitation services and thereby improve the quality of life of children with disabilities in both the health and education sectors (Department of Basic Education, 2015). It has however become evident that limited collaboration exists between the health and education sectors, resulting in continued fragmented and uncoordinated service delivery. As a speech-language therapist (SLT) working in the public education sector for eleven years, I regard these deficiencies in the system as incontestable.

SLTs working in the public sector interact daily with the systems and procedures in place with regard to the management of children with CP. They are therefore well positioned to provide valuable insight into the effectiveness of these policies that they are required to carry out. An in-depth investigation into the perceptions of these professionals could lead to effective policy implementation. This may in turn lead to improved service delivery with increased cohesion, and further collaboration between sectors.

1.1 Background, rationale and personal motivation for the research study

The South African Department of Social Development (2009) states that there remain fragmented and unequal services for children with disabilities in the country. Government departments are uncoordinated and act in isolation. Early identification of disabilities and tracking of progress through early childhood to school-going age, remain systematically deficient (Department of Social Development, 2009, as cited in ACPF, 2011). This is despite progress made in legislative and policy reform. Furthermore, as noted by Rule et al. (2006, as cited in ACPF, 2011), many children receive formal rehabilitation for the first time when they enter the formal schooling system. Given the socio-economic environment of the country, despite policy dictating that a child's formal education begins at six years of age, this can often be later (Munnik & Smith, 2019). This observation strongly correlates with feedback received

at a recent meeting held between SLTs working in the health sector and SLTs working in education within the greater Johannesburg region. The meeting was held on August 15, 2018 in Johannesburg, between six therapists working in central and tertiary hospitals and therapists working at four special needs schools, including the researcher. The purpose of the meeting was to discuss the carryover of speech- and language services, for children with CP, between the two sectors. A common frustration experienced by SLTs working in the education sector was that children with CP entering the education system at five and six years of age do so with no assistive devices or communication aids. Furthermore, they reported a general lack of referral documentation, with no open lines of communication between referring SLTs in the health and education sectors. Therefore, speech-language therapy in the education system may begin under the premise that no or limited prior therapy has been administered. The therapists working in central and tertiary hospitals reported that they provide services to children from birth to three years of age, including provision of assistive devices and communication aids. The children are then referred to community health centres and clinics in the surrounding areas. The problems identified with this process are that clinics and community health centres are generally under-resourced and consist predominately of community service SLTs that change every year. These factors may contribute to a lack in continuity in service delivery to the paediatric population with CP and their caregivers, as they move between the health and education sectors. As an SLT working in a school for learners with special educational needs (LSEN), it appears that a more in-depth study into the procedures and practices of SLTs working with the paediatric population with CP in the public sector, would be beneficial in identifying and understanding weaknesses and shortfalls of the rehabilitation process.

1.2 Research question

What are the perceptions of SLTs working in the public health and education sectors, about the continuity of services they provide to children with CP, from birth to six years of age?

1.3 Main aim and objectives

Understanding the perceptions and experiences of SLTs working in governmental institutions with children with CP, will provide valuable information as to how policy is currently being implemented in the day-to-day functioning of the health and education sectors.

Main Aim

To investigate the perceptions of SLTs working in the public health or education sectors in the greater Johannesburg region, about the speech-language therapy services that children with CP receive from birth to six years of age.

Objectives

- To determine the SLTs' perceptions about the procedures implemented in their institutions with regard to the communication rehabilitation of children with CP;
- To determine the carryover procedures regarding the management of children with CP from one institution and sector of government to the next;
- To explore the strengths and weaknesses of the policy with regard to the speech-language therapy services children with CP receive in government institutions;
- To investigate the relationship and carryover procedures between therapists working in hospital and clinic contexts;
- To investigate the relationship and carryover procedures between therapists working in the health sector and therapists working in the education sector.

1.4 Outline of the thesis

The research will be documented in detail in the following chapters:

- Chapter 2 provides a literature review focusing on the definition of CP; the management and rehabilitation of this condition; as well as the structure of the referral pathway in order to establish a picture of how the child with CP moves from the public health sector into the public education sector in Region A, Gauteng.
- Chapter 3 describes the methodology of the study, including a description of the participants; sampling strategy; data collection material and procedure; the data analysis; as well as the ethical considerations taken in this study.
- Chapter 4 comprises the manuscript of the journal article.
- Chapter 5 documents the findings and includes a discussion of each theme.
- Lastly, Chapter 6 contains the conclusions, limitations and implications of the study.

Chapter 2: Literature Review

2.1 Introduction

This research project investigates the (dis)continuity of speech-language therapy services provided to children with CP from birth to school-going age in the public health and education sectors, from the perspective of SLTs. SLTs assess and treat children with CP, specifically in the areas of feeding, oral-motor control, communication, and articulation. Prior to children entering the education system at six years of age, assessment, diagnosis and treatment of children with CP take place in hospital and primary healthcare settings in the South African public sector. This is informed by governmental guidelines. Patients are directed through a referral pathway, ideally from a hospital (central, tertiary or district) setting to a primary healthcare facility (clinics or community health clinics [CHCs]), for rehabilitation and issuing of appropriate assistive devices. Once children are of school-going age (six years), they are referred to the education sector for schooling. It is important to explore this referral pathway between the health and education sectors in order to identify possible gaps and challenges, affecting the continuity of therapy for children with CP, that may occur. The researcher will discuss the literature relating to these aspects in order to situate the study within the bigger conceptual framework.

2.2 Cerebral palsy

Definition and Classification

An international workshop on the definition and classification of CP was held in the United States in July 2004, from which the following definition was compiled and has since been internationally accepted and recognised:

“Cerebral palsy describes a group of disorders of the development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder, and by secondary musculoskeletal problems.” (Bax et al., 2005, p. 572)

The motor abnormalities seen in CP dominate the clinical picture and form the basis for the definition of CP. Thus, according to this definition, abnormal motor control is the core feature of CP. It results in various abnormal patterns of movement and posture, which are related to impairments in the coordination of movements and/or regulation of muscle tone (Rosenbaum et al., 2006).

With regard to the classification of CP subtypes, significant geographical variations exist. These are based on the type and topographical pattern¹ of the movement disorder. This affects the way in which the various types of CP are labelled (Goldsmith et al., 2016). With spastic CP, European programmes use the terms ‘unilateral’ and ‘bilateral’ to classify topography. In Australia, the terms monoplegia, hemiplegia, diplegia, triplegia, and quadriplegia are used instead. Most North American programmes use both systems (Goldsmith et al., 2016).

The international clinical classification schemes for CP are based on the type of movement disorder and/or the distribution pattern of the trunk and limbs affected. The movement disorder can either be spastic, ataxic or dyskinetic (Eyong et al., 2018). This is reiterated by the Surveillance of Cerebral Palsy in Europe (SCPE) which states that CP can be classified into three main groups, namely spastic, dyskinetic and ataxic CP (see Figure 2.1). A combination of two or more types of CP can occur, known as mixed CP (Cans et al., 2007; Levitt & Addison, 2019).

Spastic CP presents with increased tone and pathological reflexes (Cans et al., 2007). Affected limbs may demonstrate increased reflexes, tremors, muscular hypertonicity, weakness and scissored gait with toe walking. Muscle tone is increased, with velocity-dependent resistance to passive movement. Selective motor control is reduced, and abnormal and limited movement patterns are evident. There is excessive co-activation of muscular activity, with limited range of motion (Kriger, 2006).

Dyskinetic CP presents with involuntary, uncontrolled, recurring, and occasionally stereotyped movements (Cans et al., 2007). Movements appear uncontrolled with abnormally slow writhing movements of the hands, feet, arms, or legs that are exasperated during periods of stress and absent during sleep (Kriger, 2006). Movements are abnormal in timing, direction and spatial characteristics. Impaired postural stability and fluctuating muscle tone are evident (Kriger,

¹ Topographical pattern describes the body parts affected by cerebral palsy; describing how and where the body is affected by the disorder.

2006). Two subtypes of this CP are known as Choreo-Athetotic CP and Dystonic CP (Cans et al., 2007).

Ataxic CP presents with loss of orderly muscular coordination, which results in movements being performed with abnormal force, rhythm and accuracy (Cans et al., 2007). Impaired postural control is evident, with impairment in balance and timing of coordinated movements. Walking is with a wide-based gait and intention tremors are present. These movements mostly affect fine motor function. There is also decreased force during active movement (Kriger, 2006). If a child presents with a combination of two or more types of CP, a diagnosis of mixed CP will be made.

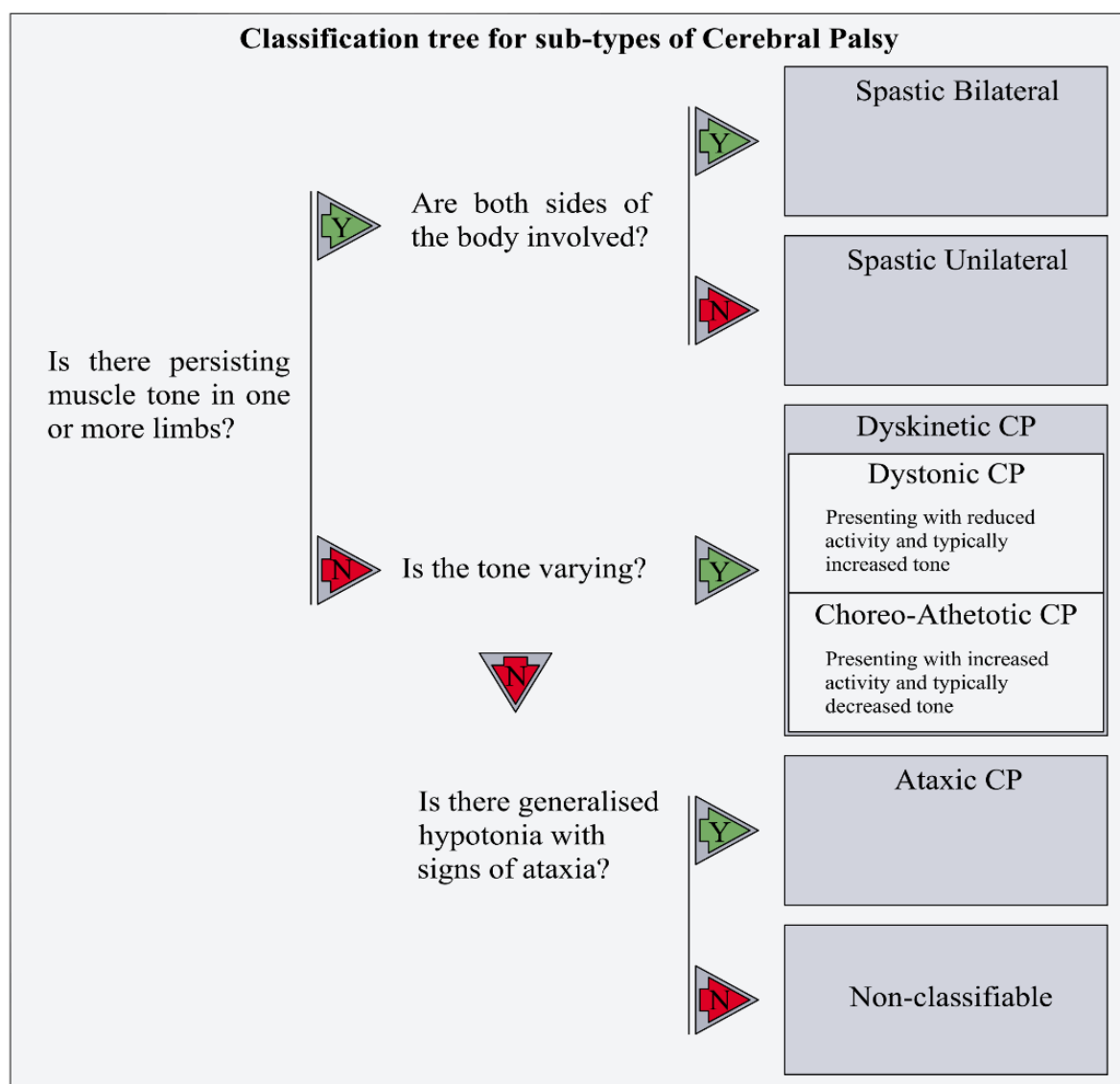


Figure 2.1 A diagram of the subtypes of cerebral palsy. This figure illustrates the classification of cerebral palsy and has been adapted from the *Surveillance of Cerebral Palsy in Europe Scientific report 1998–2018* (Surveillance of Cerebral Palsy in Europe, 2018).

Prevalence, Aetiology and Comorbidities

Population-based studies globally show that prevalence of CP ranges from 1.5 to more than 4 per 1 000 live births or children of a defined age range (Mandal, 2019; Stavsky et al., 2017). It is the most common motor disorder of childhood according to the Centres for Disease Prevention and Control (CDC) (Mandal, 2019). The mean or average prevalence rate for CP is reported to be 3.3 children per 1 000 live births in the United States of America and 2 per 1 000 live births in Europe, according to the SCPE (Mandal, 2019; Stavsky et al., 2017). The overall prevalence in Australia is 2.1 per 1 000 live births (Stavsky et al., 2017). Despite concerns of underreporting, the prevalence of CP in developing countries throughout Africa has been suggested to be higher (Donald et al, 2014, as cited in Malek et al., 2020). With regard to the South African context, the prevalence of CP according to governmental reports is very high (Levin, 2006). However, accurate CP registers are unavailable since South Africa lacks the resources, such as finances and manpower, as well as a central service provision structure to establish any formal registration of children with CP (Levin, 2006). A study done by Eyong et al. (2018) stated that the prevalence information of CP in Africa is less precise, due to limited information. It depicts a wide range of figures ranging from 2–10/1 000 live births. The prevalence of this condition has increased over the last two decades which can largely be ascribed to the increased survival rates of premature infants as a result of the success of new technology (Korzeniewski et al., 2018).

Whilst knowledge of prevalence rates is significant, it is equally important to recognise and appreciate that South Africa, as an upper middle-income country (The World Bank, 2020), experiences a variety of factors that contribute towards the aetiology of CP as well. These include poverty; HIV/Aids; TB meningitis; premature birth, malaria; as well as low birth weight (Levin, 2006; Kakooza-Mwesige et al., 2017). These aetiologies can result in either acquired or congenital CP. Children who sustain damage to the brain during the first two years of life, before anatomical or physiological development of the brain is complete, are considered to have acquired CP (Miller & Bachrach, 2017). In addition, road accidents, near-drownings or accidental choking can also lead to a diagnosis of CP (Levin, 2006). With regard to congenital CP, the damage to the brain occurs in the pre-, peri-, or immediate postnatal periods of pregnancy (Miller & Bachrach, 2017). Birth trauma used to be considered as the primary cause of CP, however, due to improved diagnostic approaches, prenatal care and improved care for at-risk newborn infants, birth trauma is no longer the main cause (Miller & Bachrach, 2017). Low birth weight, survival of premature birth, and birth asphyxia are the risk factors most

closely associated with a diagnosis of CP (Miller & Bachrach, 2017). As mentioned before, in South Africa, large sectors of the population are poor. Due to this, prenatal care may be inaccessible, people live in unsanitary conditions, have inadequate nutrition, and do not have access to specialised medical care and intervention (Levin, 2006; Korzeniewski et al., 2018). These factors may explain the higher prevalence of CP in South Africa as opposed to high-income countries (Levin, 2006).

The World Health Organisation (WHO) progress report 2014–15 completed by the Department of Maternal, Newborn, Child and Adolescent Health indicated that 10% of the then 18 million children in South Africa were neurologically impaired (World Health Organisation [WHO], 2016). Korzeniewski et al. (2018) stated that CP is the most common severe motor disability in children. The condition was quantified by reporting that 40% of children with CP cannot walk independently, up to one third are non-verbal, one third have epilepsy and about half the population have cognitive impairment (Kirby et al., 2011; Christensen et al., 2014; Zang, Oskoui & Shevell, 2015; Mei et al., 2016; Levy et al., 2010; Delobel-Ayoub et al., 2017, as cited in Korzeniewski et al., 2018). Eyong et al. (2018) found a number of comorbidities existed with CP. The most dominant of these comorbidities being epilepsy, microcephaly and speech impairment. These comorbidities were found to be common in children with spastic quadriplegia, as compared to those presenting with athetoid and diplegia CP types. This is likely due to the global cerebral involvement and malformations that occur with spastic quadriplegia. Children presenting with athetosis and diplegia were less likely to present with these comorbidities due to cortical sparing of the pathological events resulting in these types of CP (Eyong et al., 2018).

An editorial written by Du Toit (2019) stated that comorbidities, including depression; anxiety; intellectual disability; visual impairment; eating and swallowing disorders; language and speech disorders; dysarthria; gastrointestinal disorders; urinary disorders; auditory limitations, as well as cardiovascular problems, may all affect this population more than the motor disorders do. He further stated that up to 70% of this population struggle to perform activities associated with daily living and experience a slow and progressive decline in their functional reserve and overall strength (Du Toit, 2019). As a result of these comorbidities, it is clear that children living with this condition rate their overall quality of life lower than that of the general population (Du Toit, 2019).

In order to improve the quality of life experienced by individuals living with disabilities, implementing interventions as early as possible, is important.

2.3 Early childhood intervention

Early childhood intervention (ECI) is characterised by multidisciplinary services provided to children from birth to five years of age (Shonkoff & Meisels, 2000). By providing individualised developmental, educational, and therapeutic services to these children, child health and well-being are promoted, developmental delays are minimised, and emerging competencies are enhanced. Furthermore, emerging disabilities and functional deterioration can be identified and remediated. Lastly, with the promotion of adaptive parenting, overall family functioning benefits from these services (Shonkoff & Meisels, 2000).

The earliest years of a child's life are the most important as they lay the foundation of their learning development. It is during these early years that children develop the physical, emotional, social, and cognitive skills they require to succeed in life (Singh & Anekar, 2018). If children with disabilities and their families are not afforded early intervention at an appropriate age, the lifelong consequences can be severe (Singh & Anekar, 2018). For children to reach their developmental potential, evidence implies that parents, caregivers and families ought to be supported in providing nurturing care and safety for their children.

A study conducted by Fox et al. (2010) supported previous findings that stated that intervention and investment in a child's development at an early stage, before neural circuits become well established and thus difficult to modify, can result in improved overall function that would otherwise not be achievable later on in their lives. Therefore, intellectual and cognitive potential is influenced by how the brain develops during the early years of life (Singh & Anekar, 2018).

When formulating an effective therapeutic intervention in the early years, it is essential that young children living with disabilities are viewed in a holistic manner.

2.4 The Framework of International Classification of Functioning, Disability and Health (ICF) and its Children and Youth version (ICF-CY)

This ICF framework was derived from the WHO and adopts a biopsychosocial model when organising and documenting information on function and disability (WHO, 2007). The

biopsychosocial model is based on an integration of the social and medical models of disability. The medical model of disability focuses on the individual and the impairment by providing intervention and assistive devices to enable the individual to adapt to society. In contrast, the social model of disability focuses on disabling and discriminatory elements within the environment, and advocates for societal changes that will reduce barriers to social inclusion.

The framework conceptualises functioning as a dynamic interaction between an individual's health condition, environmental factors, and personal factors. In 2007 the WHO derived the ICF-CY, which was developed to be considerate to changes associated with a child's growth and development, by recording characteristics of the developing child and the influence of environments surrounding the child (WHO, 2007). The ICF-CY builds on the ICF conceptual framework and shares the same classification properties (see Figure 2.2).

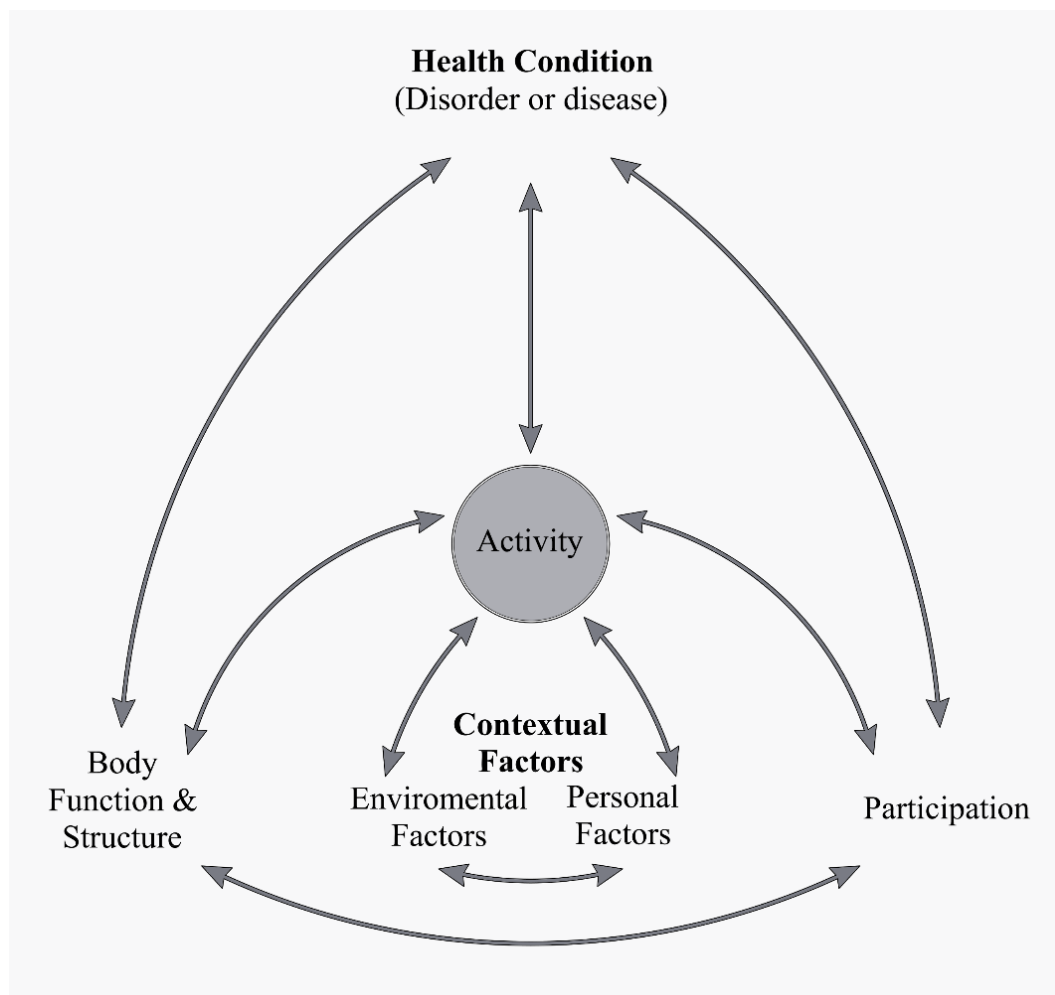


Figure 2.2 Figure adapted from The Framework of International Classification of Functioning (ICF) (Adapted from WHO, 2001).

By providing a common language and terminology, the ICF-CY framework enables the recording of limitations involving functions and structures of the body, activity limitations and participation constraints. These manifest in infancy, childhood, and adolescence, as well as appropriate environmental factors (WHO, 2007). The ICF-CY belongs to the ‘family’ of international classifications developed by the WHO for application to various aspects of health (WHO, 2007).

In classifying function and disability, ICF is aetiology-neutral as it states that it cannot infer a person’s participation level in everyday life by the medical diagnosis alone, thereby stating that there is no explicit or implicit distinction between various health conditions (WHO, 2013). By moving the emphasis from diagnoses to level of functioning, the ICF describes all health conditions as being on an equal footing, acknowledging them to be compared through a common framework in terms of how an individual is able to function. The ICF conceptualises a person’s level of functioning as a dynamic interaction between their health conditions, environmental factors, and personal factors (WHO, 2013).

The underlying biopsychosocial model of ICF does not refute the impact of impairments on functioning, rather, it recognises functioning as an interaction between a person’s health condition(s) and their contextual factors (environmental and personal factors) (WHO, 2013). Therefore, ‘functioning’ is a broad term for body function, body structures, activity and participation. These terms are defined as follows:

- Body function: The physiological functions of body systems (including psychological functions);
- Body structures: Anatomical parts of the body such as organs, limbs and their components;
- Activity: The execution of a task or action by an individual; and
- Participation: Involvement in a life situation (WHO, 2013).

In the education setting, the ICF provides a framework to link disability-based and curriculum-based knowledge, as well as clinical and educational information. Furthermore, the framework can help connect assessment results from both viewpoints (health and competence) to provide a thorough representation of the functioning of a child in a particular educational environment (WHO, 2013). It is not always apparent to which extent challenges in learning might be due to a health condition, social disadvantage, or inadequate teaching. It is therefore important to

consider that it is not enough simply to measure the academic performance of the child in carrying out predefined tasks in a predefined environment, but rather to attempt to describe each child's level of participation in their education setting (WHO, 2013).

2.5 Management of cerebral palsy

According to Milner et al. (1996, as cited in Saloojee et al., 2011), CP is a lifelong condition which requires rehabilitation services to assist the child and family function in the most successful way possible. Due to the limitations in physical activity in a child with CP, the child would require rehabilitation throughout life (Levitt & Addison, 2019). The goal of management of CP is not a curative one, but rather one of increased functionality and improved capabilities of cognition, social interaction and independence (Levitt & Addison, 2019). Treating the child within a multidisciplinary rehabilitation team is essential for a successful habilitation process to occur. The team approach requires combining the knowledge and skills of professionals from many disciplines in order to ensure that complicated challenges receive the thorough attention they require (Levitt & Addison, 2019). Early intervention, ideally from the child's initial diagnosis, results in the best clinical outcomes, within a multidisciplinary team (MDT) approach. The team may consist of doctors (neurologists, paediatricians, physicians and orthopaedists), nurses, physiotherapists, SLTs, audiologists, occupational therapists, social workers, psychologists and educators (Levitt & Addison, 2019). Each professional has a different role in the team, however, each professional needs to collaborate with the other team members in order to achieve optimal and well-integrated care for the child with CP. The roles of these professionals extend from early detection to acute care, physical and cognitive rehabilitation, and prompt referral and psychosocial support. This is done with the purpose of integrating children into their communities (Ngubane & Chetty, 2017).

The MDT in the South African public healthcare field manages children with CP from primary care settings through to tertiary settings. There is a shift from healthcare delivery in centrally located institutions of healthcare toward the primary healthcare model. This constitutes clinics within the community, which are vital settings for South African healthcare to become reachable to the larger population (Ngubane & Chetty, 2017). Whilst the shift of healthcare to the clinic settings is still in its development and implementation stages, principles of practice for the MDT requires that the issues of access in resource-limited settings be addressed (Ngubane & Chetty, 2017). Within the management of children with CP it is important also to consider the caregiver's role in the rehabilitation process. The participation of the caregivers

and their degree of satisfaction is valuable as their involvement has an influence on the rehabilitation outcomes. Ngubane and Chetty (2017) investigated the perceptions of South African caregivers of children with CP, living in KwaZulu Natal, about the rehabilitation and healthcare services they received in the public sector. They found that the caregivers experienced untimely referrals, shortage of information from healthcare staff, inadequate consultation with the rehabilitation professionals and a lack of communication.

The role of the SLT in the management of CP is an important one. Associated complications of CP may include difficulties in the production of speech, reception and expression of language; gesture for communication; hearing impairment, and feeding difficulties (American Speech-Language-Hearing Association, 2016). Communication difficulties associated with CP can be due to numerous factors resulting from motor, intellectual and sensory impairments. Children with this diagnosis can experience mild to severe difficulties in expressing themselves (American Speech-Language-Hearing Association, 2016). They are often referred to an SLT to improve their communication skills and to assist them in taking as independent a role as possible during communication activities (American Speech-Language-Hearing Association, 2016). Speech-language therapy can include the assessment and/or treatment of the following: verbal forms of communication; augmentative and alternative communication (AAC) systems, such as symbol charts or communication supports with artificial speech; swallowing disorders; receptive and expressive language skills; and cognitive and executive functioning (Department of Health, 2017).

The public healthcare sector plays an integral role in the provision of healthcare services in South Africa (ACPF, 2011). Based on a report by the Council of Medical Schemes 2015–16, only 16% of South Africans are members of a medical aid scheme; implying that approximately 84% of the population is reliant on the network of public hospitals and community health centres (Council for Medical Schemes, 2016). Similarly, the rehabilitation of children with CP in South Africa is largely facilitated through this network.

2.6 Rehabilitation of cerebral palsy in the public sector

The aim of rehabilitation is to enable people with disabilities to achieve and preserve optimal levels of functioning by offering them with the tools they need to achieve autonomy and self-determination (WHO 1994, as cited in Mji et al., 2017). The physical, mental, cognitive and social rehabilitation of persons with CP in South Africa is outlined by the National Department

of Health's *Framework and Strategy for Disability and Rehabilitation Services in South Africa* (2016). According to this document rehabilitation should be decentralised and begin as early as possible and should extend from community level to tertiary and specialised rehabilitation levels. The framework states that access should be provided to the most appropriate and best qualified service providers through a referral pathway for persons with disabilities. It is critical that departmental referral pathways, clinical guidelines and protocols are in line with this policy framework. The framework alludes to the fact that there is limited recent data on the overall prevalence of childhood disability in South Africa. Various studies have been undertaken over the last 30 years, however, there is limited recent data. Additionally, the use of different definitions of disability and methods of data collection renders the available research studies not directly comparable. Nevertheless, with improved medical technology and a higher survival rate for children with disabilities, there are an increasing number of children presenting with developmental delays and CP in South Africa (National Department of Health, 2016).

According to the Framework (National Department of Health, 2016), there are a number of challenges that complicate the effectiveness of rehabilitation services within the population of children with CP in South Africa. These include *inter alia*:

- Poor collaboration between sectors;
- Poor knowledge in the rehabilitation chain regarding the specific needs and challenges of persons with disabilities, which may result in a delay in early identification and intervention;
- Inadequate follow-up and a ambiguity on referral pathways;
- Poor accessibility of services from central hospitals to district, regional and community-based rehabilitation centres. This is compounded by inadequate rehabilitation units down the referral chain;
- In most cases, the ideal core rehabilitation team is unavailable to the population with disabilities, due to high vacancy rates of service providers at the various levels of care, especially, rehabilitation staff at a primary healthcare level (that is clinics and community health centres); and
- Inadequate provision of appropriate assistive devices.

Louw et al. (2018) stated that access to effective rehabilitation is a basic human right and that rehabilitation has the ability to economically optimise health outcomes and overall quality of life. However, the twenty rehabilitation professionals (physiotherapists, occupational

therapists, SLTs, podiatrists, rehabilitation managers or directors) who participated in Louw et al.'s (2018) study stated that, despite the government's efforts to re-engineer public healthcare, rehabilitation services at primary healthcare level have not improved (Louw et al., 2018).

According to Mji et al. (2017), the primary aim of the adjustments of the health policies in South Africa was to improve access to health services, especially to the poor. The constitution gives all South Africans living with disabilities the right to comprehensive rehabilitation services. These services, medical and rehabilitative, are important in creating equal opportunity and full participation for this population (Mji et al., 2017).

2.7 The effects of low socio-economic status on rehabilitation

A scoping review conducted by Adugna et al. (2020) stated that poverty was the most reported obstacle limiting children with disabilities and their caregivers from accessing healthcare services. According to Graham et al. (2014), there is a circular connection between poverty and disability whereby poverty may lead to disability, and disability in turn exacerbates poverty. This creates multiple layers of marginalisation for those affected by both. Understanding and recognising this is important in creating policy to address this marginalisation and produce outcomes which benefit the population who are poor and live with a disability (Graham et al., 2014). In South Africa, a number of challenges are faced by people who live in poverty when attempting to access healthcare services. In developing countries, numerous barriers to healthcare are experienced by persons living with disabilities in low socio-economic conditions (Graham et al., 2014). Transport costs and distance to healthcare facilities are examples of such barriers. People with disabilities need good access to healthcare for both their disability-related and general healthcare needs. Understanding the healthcare needs of people with disabilities as well as the challenges they may face in accessing both general as well as specialised healthcare services, is essential (Graham et al., 2014).

Research conducted about the perceptions and satisfaction of caregivers regarding rehabilitation services in the Western Cape of South Africa, indicated that the majority of caregivers interviewed expressed transport to rehabilitation facilities constituted a substantial portion of their expenses, given the great distances (Mlenzana et al., 2018). Caring for a child with a disability can be an costly undertaking as they often need special food, assistive devices, and transportation fees for medical appointments (Nota et al., 2015, as cited in Adugna et al., 2020). Without financial support, children with disabilities and their caregivers experience

difficulty accessing healthcare services, paying transportation fees, accessing assistive devices, and more (Adugna et al., 2020). This was reiterated by Visagie et al. (2017) who stated that the natural environment, the cost of transportation, and accessing healthcare services were the most difficult and most common environmental barriers to activities of daily living. A number of reasons make transport challenging in Africa, including rough terrain, poor road infrastructure, large distances, and poor or unavailable public transport. The natural environment and a lack of transportation, in combination with distances and general poverty, affects access to healthcare in poorer contexts (Visagie et al., 2017). Reduced socio-economic status and greater activity limitations, perpetuated the magnitude of environmental barriers (Visagie et al., 2017).

Additionally, Pickard and Ingersoll (2016) found that lower socio-economic status families access fewer services as they were uninformed about the specialty services needed for their children or the service options available to them. They were less inclined to reveal that their child needed specialised services and were not likely to advocate for their children as parents of higher socio-economic status may do (Pickard & Ingersoll, 2016).

Furthermore, it is important to recognise that people living with disabilities are a vulnerable portion of the population, and that providing particular interventions such as access to special needs schools, is key in closing the education inequality gap (Graham et al., 2014). Groce et al. (2011, as cited in Graham et al., 2014) stated that the lack of education is a contributing factor to poverty amongst the population living with disabilities. Similarly, poverty has an unfavourable impact on education. Children with disabilities require supportive and assistive devices for everyday activities in order to increase participation and access the curriculum, however, when these needs are not met due to poverty-related reasons, their participation in the education setting is limited (WHO, 2011, as cited in Graham et al., 2014). Unequal access to education opportunities often increases this population's vulnerability to poverty. As such, it is important to recognise and address the access to education amongst children living with disabilities (Graham et al., 2014).

Disability exacerbates the experience of environmental barriers. The reduction of these barriers and measures to deliver necessary support and adaptation to this population is required to achieve full inclusion in society (Visagie et al., 2017). The socio-political movement of disability has developed over the last several decades with regard to redefining the word 'disability' (Malek et al., 2020). This movement aims to reduce limitations to participation and to challenge the way in which society views the condition. The environmental factors at home,

school and in the community, play an important role in the participation and inclusion of the population living with CP (Malek et al., 2020). It is thus important to research the participation of these people in various cultural settings, especially in resource-limited African countries (Malek et al., 2020).

2.8 Structure of the referral pathway

The South African hospital network is administered through its various provincial metropolitan regions, with hospitals structured to provide services in a categorised service level system.

Figure 2.3 illustrates the referral pathway system specific to Johannesburg Region A.

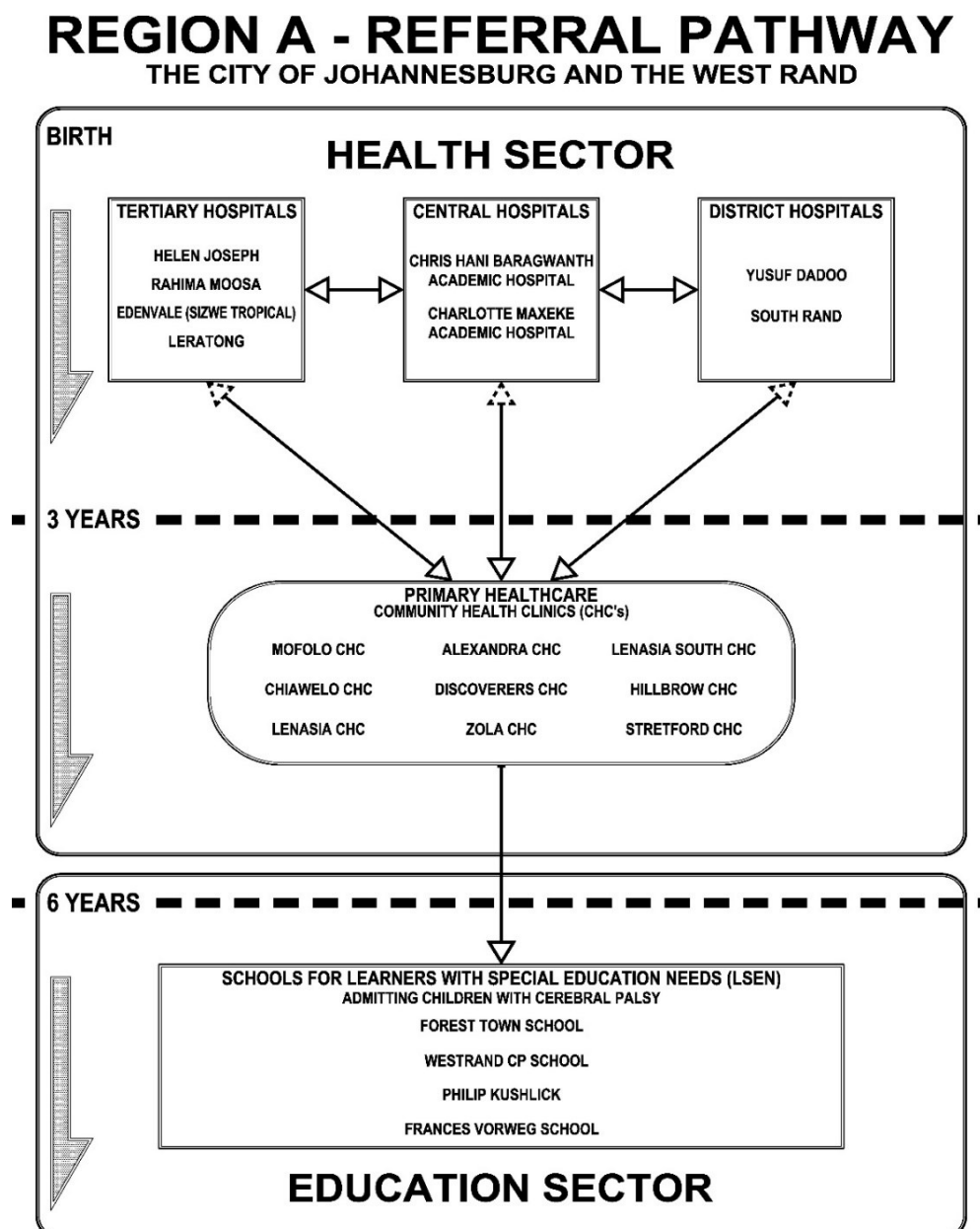


Figure 2.3 A diagram of the referral pathway. This figure illustrates the referral pathway for children with cerebral palsy from birth to six in the public health and education sectors of Gauteng Region A.

A central hospital needs to provide tertiary hospital services as well as training for healthcare providers (National Department of Health, 2016). Central hospitals are also centres of research and academic instruction. These hospitals are a key link in the referral chain, receiving patients referred from outside of the province (National Department of Health, 2016). The two central hospitals in the greater Johannesburg region are the Chris Hani Baragwanath Academic Hospital and Charlotte Maxeke Johannesburg Academic Hospital. Central hospitals provide highly specialised units with scarce skills personnel. For rehabilitation, patients are treated for a short period of time within central hospitals (National Department of Health, 2016). The rehabilitation team needs a broad base of specialist skills to ensure appropriate referrals to lower level healthcare facilities.

A tertiary hospital must provide specialist level services, with intensive care services and training for healthcare service providers (National Department of Health, 2016). These hospitals receive referrals from regional hospitals within the provincial boundary. Rehabilitation teams need to be able to prescribe and issue assistive devices (National Department of Health, 2016). Regional hospitals provide 24-hour services with limited specialities. Their role is to provide trauma and emergency services, and to receive patients from a defined regional area, as well as referrals from district hospitals (National Department of Health, 2016). The rehabilitation team needs to provide specialist services to major disabling conditions in assessment, prescription and issuing of assistive devices (National Department of Health, 2016).

A district hospital acts to support primary healthcare (PHC) in a localised area on a 24-hour basis. It provides PHC services and training for healthcare service providers, where practical (National Department of Health, 2016). District hospitals receive rehabilitation outreach support from specialists based at regional hospitals. An MDT should be available to provide general rehabilitation, including assessment and clinical interventions. They also need to recommend and issue a broad range of assistive devices (National Department of Health, 2016).

The role of PHC is to provide screening and assessment at a community level for a range of disabilities to enable appropriate referral onto hospital-based services (National Department of Health, 2016). Anecdotal evidence suggests that typically, children under the age of three years receive diagnostic and rehabilitation services at hospitals in order to obtain acute specialised care. Once the appropriate management of the child's condition has been established, the child is referred to PHC for continued rehabilitation services. This typically happens from

approximately the age of three years. Whilst acute care and diagnosis happen at hospital level, it remains important that healthcare workers in PHC facilities, who may be the first point of contact for caregivers, receive training to enable early detection of disability through screening. This in turn facilitates appropriate referrals back to hospital level for specialised services to be received. PHC staff needs to be able to provide counselling, support and education for the integration of individuals with disabilities into the community, including home visits and outreaches. PHC facilities provide early assessment and intervention for general childhood health conditions, as well as wheelchair repair services and issuing of minor assistive devices (National Department of Health, 2016).

Once the child with CP is of school-going age, they leave the rehabilitation team in the public health sector and enter rehabilitation in the education sector. According to the National Department of Education (2009, as cited in ACPF, 2011), the role of special needs schools is to develop a special education programme for each learner, based on the child's learning capabilities. The rehabilitation team working in these special schools assess and treat each child's barrier to learning, which may include physical limitations (gross and fine motor difficulties), hearing impairments, speech and language difficulties, visual impairments and challenges with sensory integration (National Department of Health, 2016).

2.9 The quality of rehabilitation in the public healthcare system

The literature on the effectiveness of rehabilitation in the public healthcare sector in South Africa presents some recurring themes over several years. Factors affecting rehabilitation of children with CP in Africa were raised in a study conducted in 2014 where doctors from 22 countries in Africa participated in discussions regarding the identification and management of children with CP (Donald et al., 2015). Additionally, findings of a study by Saloojee et al. (2011), investigating caregivers' perceptions of rehabilitation services in public sector hospitals for children with CP, specifically in the Gauteng and Limpopo provinces of South Africa, suggested similar themes. These themes included: ratios of medical professionals to children with CP fall short of the recommendations of the WHO; a lack of resources in rural South Africa to provide basic diagnostic and intervention services; guidelines from high resource settings, that are often inappropriate to patients that live in remote and widely scattered settlements; lack of support services, schools and treatment choices, which are aspects that are difficult to change as they necessitate shifts in policies and procedures beyond the scope of which therapists currently have much authority; over-burdened medical systems; and poor

infrastructure. These are all factors that influence therapists' intervention approach in the public sector, as rehabilitation specialists need to do more than purely deliver their services in a clinical setting. The therapists are required to have a broader perspective when providing a service for children with CP, which includes the social needs of their patients, such as, food, transport, access to schools, and support for the whole family. According to Donaldson et al. (2017), a social model to intervention that seeks to identify ways to break down social barriers to communication could enable individuals to overcome challenges using their own individual strengths.

The guidelines as set out by the *Integrated National Disability Strategy* propose that community-based rehabilitation enables social integration and encourages the promotion of comprehensive rehabilitation in health, education and social sectors (Office of the Deputy President, 1997). Furthermore, early childhood development guidelines emphasise that parents of children with disabilities need to receive information on community services and treatment options. To facilitate this, healthcare practitioners must also be trained in early childhood development and management, including skills to accommodate children with disabilities (ACPF, 2011). The South African Department of Social Development (2009, as cited in ACPF, 2011) stated that there remain fragmented and unequal services for children with disabilities. Government departments are uncoordinated and act in isolation. Early identification of disabilities and tracking of progress through early childhood to school-going age remain systematically deficient (Department of Social Development, 2009, as cited in ACPF, 2011). This is despite progress made in legislative and policy reform.

A study on the experiences and challenges faced by rehabilitation community service therapists within the South African PHC system (Ned et al., 2017) revealed that the conditions at community healthcare level are difficult as there is a scarcity of professionals, failures in resource allocations, as well as overcrowding. A study conducted by Khoza-Shangase and Mophosho (2018) supported this finding, specifically stating that there is a shortage of SLTs working in the public health sector. When referral happens, in some instances, there are no human resources available to receive these referrals at the community level (Hussey et al., 2017). Premature discharge from tertiary and secondary levels of care, with referral into the primary level of care, creates problems with carryover of care due to a lack of follow-up between institutions. Collaboration between the various levels of care would result in

comprehensive insight into contextual issues of disability and further promote investigations into health systems (Ned et al., 2017).

Healthcare professionals who were interviewed by Louw et al. (2018) stressed the importance of communication across all levels of care in the public health sector. These included improved communication between provinces, educational and governmental institutions, professional associations and team members (Louw et al., 2018). Communication and collaboration between the different stakeholders in the rehabilitation process are crucial to encourage the use of rehabilitation clinical practice guidelines and could ensure continuity of care between the various sectors at all levels of care (Louw et al., 2018). Improved collaboration is also essential to facilitate increased interprofessional healthcare delivery at all rehabilitation levels (Louw et al., 2018).

In summary, for children with CP, a lifelong condition that requires continuous intervention, the healthcare professionals working for the Department of Health (DoH) remain integral in providing ECI. They provide the foundation for further interventions to occur by means of referral into the education system. The referral to allied health professionals working in the education sector should lead to focused and specialised treatment that is specific to the needs of an individual. A failure in the appropriate referral and carryover from one sector into the other, can potentially result in a deficiency in rehabilitation for those who need it most.

2.10 The implementation of policy in public schools for learners with special educational needs (LSEN)

In 2001, the DoE issued a framework policy document called White Paper 6: *Special Needs Education, Building an Inclusive Education and Training System*. This document was drawn up as a response to the post-apartheid state of special needs schooling (Department of Education, 2001). Children with special educational needs did not receive specialised education and support, based on a racial basis. This meant that most learners with special educational needs were placed into mainstream schools with educators who could not address these needs specifically, or they failed to attend school altogether. The number of children with disabilities not attending school at the time was estimated to be 280 000 (Department of Education, 2001).

According to the position statement, *Promoting the Right to Education of Children with Disabilities*, written by the Right to Education of Children with Disabilities Campaign (R2E CWD) (2016), the progress on inclusive education fourteen years post the publication of White

Paper 6, has been exceedingly slow. This report highlighted a number of concerns regarding the effective implementation of the policy, and how the failure to do so violates the rights of many children. This has been reiterated by Engelbrecht et al. (2016) who stated that in the South African context that statements made in policy do not equate to the delivery of educational rights in practice. Even though policy guidelines aim to bridge the gap between idealistic conceptualisation and implementation, learners with special educational needs in South Africa still experience substantial educational inequalities (Engelbrecht et al., 2016). The right to ‘substantive equality’ means that the DoE is urged to improve its attempts to guarantee that poor children with disabilities living in the rural areas enjoy drastically improved learning conditions (Right to Education for Children with Disabilities (R2E CWD), 2016).

Another human rights violation that cannot be ignored, is that failures in the system result in children with disabilities being kept out of school. The R2E CWD (2016) urged the DoE to address this by establishing a communication platform between government and civil society stakeholders who work with children with disabilities, in order to encourage collaboration and consultation. Furthermore, the number of children remaining out of school for extended periods whilst on waiting lists remains a violation of the Schools Act (Right to Education for Children with Disabilities (R2E CWD), 2016).

In addition to the number of children with disabilities not attending schools, there are many school-going children who do not receive the support they require as they are in the wrong learning programmes (Right to Education for Children with Disabilities (R2E CWD), 2016). According to the R2E CWD (2016), the increase of learners enrolled in special needs schools does not result in an improvement in the quality of education that they receive, but rather has a negative effect on the quality of education for all children in the school. Most special schools have a specific focus on a particular disability. This means that children with more than one disability may not be accommodated for by a specific school that addresses all these needs. Rather, they are accommodated at a school that addresses only their greatest barrier to learning (Right to Education for Children with Disabilities (R2E CWD), 2016). Furthermore, the report stated that in both special and mainstream schools, effective curriculum adaptation needs to be done in order for children with disabilities to access the curriculum. Educators however, expressed the need for more training in this area. Educators ability to teach children with disabilities has been significantly impacted by a failure to prepare educators to tailor the curriculum (Right to Education for Children with Disabilities (R2E CWD), 2016). It is

important that the same basic curriculum is made available to all children with disabilities. It is essential that the necessary adaptations and differentiations are made to the classroom environment, the learning materials, curriculum and assessment (Right to Education for Children with Disabilities (R2E CWD), 2016). Nel et al. (2016) recommended that additional funding is required for Learner-Teacher Support Materials (LTSM) in order to provide educators and learners alternative ways to manage educational tasks on varied levels.

Children with disabilities have a right to skilled educators and specialist support staff. In order for educators to provide the education curricular for children with disabilities, the weighting of educator and support staff to learner ratios needs to be complied with. When this is not done, children at special needs schools are placed in a class that is twice or three times the size of the recommended educator and support staff-to-learner ratio (Right to Education for Children with Disabilities (R2E CWD), 2016). Furthermore, special needs schools require additional specialist support staff that do not appear on the staff establishments of provincial departments of education, thus are not catered for at many schools. These include:

- Speech-language therapists
- Audiologists
- Occupational therapists
- Physiotherapists
- Social workers
- Psychologists
- Nurses

The inadequacy of the weighting of learners and the failure to employ educators and specialised support staff with the specific knowledge required to teach learners with special educational needs, is pervasive within the South African education system (Right to Education for Children with Disabilities (R2E CWD), 2016).

The R2E CWD (2016), raises serious concern about the DoE's lack of in-depth, scientifically gathered information regarding disability, barriers to learning and the lack of clarity as to how these are defined. According to R2E CWD (2016), the DoE continues to make decisions without thorough systematic research when communicating the experiences of children and their caregivers who are accessing education. The 2014 Strategy for Screening, Identification and Support (SIAS) (Department of Basic Education, 2014b) provides the tools for the

identification of children with educational challenges and their support needs. On the basis of this screening tool, the DoE seeks to place children in the most appropriate educational setting. Whilst the DoE's Psychological Services is meant to conduct assessments for placement into special needs schools, in many cases, these assessments are being conducted by the special needs schools themselves (Right to Education for Children with Disabilities (R2E CWD), 2016). This takes time and results in the child and caregiver waiting longer periods for an outcome. The SIAS tool, although intended to shorten this waiting period, has had limited success.

Lastly, children with disabilities have the right to free basic education. The substantial economic, physical and emotional barriers in the accessing of appropriate schools are faced daily by parents and caregivers of children with disabilities. According to the R2E CWD (2016), the two major examples of the economic barriers are the costs associated with school admissions as well as the transport costs related to the distance from schools. Given the high rate of poverty and income inequality, many families cannot accommodate these expenses, resulting in children with disabilities from poor families being excluded from accessing their right to education (Right to Education for Children with Disabilities (R2E CWD), 2016).

In summary, according to Donohue and Bornman (2014), the Education White Paper 6 (Department of Education, 2001) represented significant progress in respect of the rights of children with disabilities in South Africa, however, the policy will remain symbolic until both real undertaking and intentional action are taken. The DoE needs to hold itself accountable for the application of the policy that it created.

It is important that society works to ensure that the vision of a society for all children is not a theoretical concept, but rather results in tangible improvements for all children with disabilities in South Africa (ACPF, 2011). Removing barriers, not simply in the legislative context, but transforming institutions, practices and facilities at every level, is vital (ACPF, 2011). From the research done on rehabilitation in South Africa, it is clear that there is disconnect between government policy and the realisation thereof in the form of adequate and appropriate services to the broader community.

2.11 Summary

This chapter has explored the definition, classification, prevalence, aetiology and comorbidities of CP; the importance of ECI; the implementation of the ICF in therapy; and concluded with a

discussion on how the management of this condition relies on collaboration and cooperation within the MDT; as well as the role of the SLT within this team. The rehabilitation of CP in the public sector was discussed, highlighting the shortfalls of the services provided to this population. The effects of a low socio-economic status on rehabilitation and the challenges that caregivers face amid their impoverished situations were reviewed. Furthermore, the structure of the referral pathway was described in order to establish a picture of how the child with CP moves from the public health into the public education sectors in Region A of Gauteng. Research into the quality of rehabilitation services provided within the public healthcare system was discussed. Lastly, this literature review explored the (poor) implementation of policy in public LSEN schools since the realisation of the White Paper 6 in 2001.

The literature has highlighted that children with disabilities are still being marginalised due to the clear disconnect between governmental policy and the implementation thereof. This population is thus on the receiving end of poor service delivery, general ineffectiveness at administrative levels of the system, as well as a distinctive lack of inclusion in the general community. It is time to confront the prejudices regarding the value of children with disabilities and realise that the exclusion of one impacts us all.

Chapter 3: Methodology

3.1 Research design

A qualitative research design was appropriate for this study, specifically the approach of phenomenology. Qualitative research methods allow the researcher to study human experience from the perspective of the members, in the environment in which the experience occurs (Taylor et al., 2015). It emphasises the perspective of the participants by allowing them to voice the multiple realities that exist in their settings (Taylor et al., 2015). Qualitative research methods provide comprehensive, varied perceptions of participants; valuable quotes that bring realism to applied research; and knowledge about how various healthcare settings function. This is done by using open-ended techniques (such as open-ended interview questions) to gather data and use non-statistical methods to analyse it. Qualitative research can highlight the processes causing statistical relationships, update the development of different interventions, and demonstrate how interventions work to deliver perceived outcomes (Taylor et al., 2015).

Phenomenological studies examine the lived experiences of participants, through their narratives of their working realities, as well as how they understand the experiences or what significance the experiences have for them (Brink et al., 2017). Descriptive phenomenology was chosen for this study as the researcher sought to understand and describe the phenomenon as experienced by the participants (Reiners, 2012). This is appropriate when investigating a system as opposed to interpretative phenomenology which seeks to interpret the deeper meanings behind the participants' experiences (Reiners, 2012). Bracketing (*epoché*) was therefore used during the enquiry process (see Appendix A). Through this the researcher attempted to recognise and highlight preconceived assumptions (including her own) about the phenomenon under investigation (Brink et al., 2017). This was done so that the researcher could gain a greater critical understanding of the research participant's lived experience. The aim of *epoché* was thus to enable the researcher to become aware and attempt to set aside her natural attitude and assumptions about the phenomenon. Thus, the researcher attempted to bracket off her preconceptions about the phenomenon being investigated and to be open to the participants' experience as perceived through their own consciousness (Langdridge, 2007). The researcher performed the bracketing process by: 1. Having discussions with colleagues and other researchers about personal preconceptions, knowledge, and past experiences about the research topic. The researcher wrote these biases down; 2. Creating a bracketing journal: As preconceived ideas arose in the researcher's mind, note was taken of it. This was done

throughout the research process; and 3. All that was bracketed was written down so that the reader can be aware of the researcher's biases as they read the results and interpretations of the data (Taylor et al., 2015).

The researcher expected to discover that there was a break in the continuity of speech-language services when the child with CP was referred to CHCs from the central, tertiary and/or district hospitals. The child with CP would receive speech-language services in the hospitals (from birth to three years). A break in service was then expected to be seen in the CHCs (from ages three to five years), and then a continuation of services would be evident again in the education sector (from six years of age and onwards). Whilst the researcher did find a gap in the referral process, that break in service was not in the area in which the researcher expected.

a) Participants

Qualified SLTs working with children with CP in the public health (hospitals and community health centres) and education sectors (specifically LSEN schools) were asked to participate in the study. They were included based on certain criteria. These included:

- Minimum of a four-year degree in Speech-Language Therapy or Speech-Language Therapy and Audiology;
- Registered with the Health Professions Council of South Africa (HPCSA);
- Therapists working in hospitals (tertiary, central and district hospitals), CHCs or school settings in the public sector, in Region A in the city of Johannesburg, Gauteng Province.
- Therapists specifically working with children with CP from birth to six years of age on their current caseload, or within their last six months of practice.

Gauteng provincial hospitals are classified into Regions A, B and C. For the purpose of this study, Region A was the focus. Region A is the largest in Gauteng. Both central hospitals are located in this region, as well as the school that the researcher works at. Region A includes the City of Johannesburg and the West Rand (Gauteng Provincial Government, 2018).

Region A consists of two central hospitals, namely Chris Hani Baragwanath Academic Hospital and Charlotte Maxeke Johannesburg Academic Hospital. There are also four tertiary-level hospitals, namely the Rahima Moosa Mother and Child Hospital, and the Helen Joseph, Edenvale (Sizwe Tropical) and Leratong hospitals. The two district hospitals include the Yusuf Dadoo and South Rand hospitals (Gauteng Provincial Government, 2018). Data was collected

at all of the sites that granted permission for the study, and where the SLTs met the inclusion criteria. SLTs based at hospitals and who met the inclusion criteria ($n = 14$), were interviewed and labelled as Hospital Therapists (HT) for the purpose of this study.

Region A consists of a number of PHC facilities, which include clinics and CHCs. These include: Alexandra CHC, Discoverers CHC, Chiawelo CHC, Mofolo CHC, Zola CHC, Hillbrow CHC, Lenasia CHC, Lenasia South CHC and Stretford Clinic (Gauteng Provincial Government, 2018). One focus group was conducted to include all therapists working in these clinics and who granted permission for the study. SLTs based at these CHCs, who met the inclusion criteria ($n = 8$), were interviewed and labelled as Clinic Therapists (CT) for the purpose of this study.

The LSEN schools in the public sector (Region A), who admit children with CP presenting with Mild and Moderate Intellectual Disabilities (MID) include: Forest Town School, West Rand School and Frances Vorweg School (Gauteng Department of Education, 2019). SLTs based at these school settings, who met the inclusion criteria ($n = 9$), were interviewed. They were labelled as School Therapists (ST) for the purpose of this study.

b) Sample Size

Due to the nature of the qualitative research designs and the time-consuming nature of the analytical process, sample sizes are usually small (Langdridge, 2007). Table 3.1 indicates the number of SLTs working in the various public health and education institutions, who met the inclusion criteria, who agreed to participate in the study, and who were interviewed.

Table 3.1 Number of SLTs who participated in the study

GAUTENG REGION A - HEALTH AND EDUCATION FACILITIES					
	Number of Facilities in the Region	Number of Facilities that Participated	Total Number of SLT's Working in the Institutions	Total Number of SLT's who met the Inclusion Criteria	Total Number of SLT's who Participated *
Central Hospitals	2	2	48	9	8
Tertiary Hospitals	4	2	13	7	4
District Hospitals	2	1	4	2	2
CHC's in Johannesburg Metro Rehab **	9	9	8	8	8
LSEN Schools ***	3	3	10	10	9
Column Totals	20	17	83	36	31
<p>* Speech-Language Therapists who met the inclusion criteria and gave informed consent.</p> <p>** Primary Health Care Facilities include clinics and Community Health Centres (CHC's) of which only CHC's were included in the study. (Gauteng Provincial Government, 2018).</p> <p>*** The schools for Learners with Special Educational Needs (LSEN) in the public sector of the region, who admit children with cerebral palsy presenting with Mild and Moderate Intellectual Disabilities (MID) (Schools Listings, 2019) were included in the study.</p>					

The total number of SLTs who work with children with CP and participated in the study, was 31. All participants were registered with the HPCSA as SLTs. Three therapists working in the hospitals and five working in the CHCs were completing their community service years. Therapists with more than ten years' working experience with children with CP were based at the LSEN schools. This was not evident in the hospital and clinic settings. Large caseloads of children with CP were mostly evident at the central hospitals, as well as at the LSEN schools.

c) Sampling Strategy

The sampling strategy that was used was purposive sampling. This sampling strategy provides a group of credible and knowledgeable contributors that possess particular characteristics that the researcher is investigating (Struwig & Stead, 2013). The participants are recruited so that the researcher can make assertions about them and their shared lived experiences (Langdridge, 2007). The aim of this sampling strategy was to create detailed descriptions of the experience of a small number of individuals who all share that experience. The researcher purposely set out to interview only those participants who shared the lived experience being explored (Langdridge, 2007). For the purpose of this study, only SLTs working with children with CP from birth to six years of age, in the public health and education sectors within a particular geographical area, were recruited.

3.2 Research procedure

a) Permission for the Collection of Data

An application was made to Stellenbosch University's Health Research Ethics Committee (HREC) for permission to proceed with the research. Permission was granted to proceed with the study in June 2019 with the HREC Reference #: S19/05/093 (see Appendix B). Request to conduct research at the Gauteng Department of Health (GDH) was subsequently applied for through the National Health Research Department (NHRD) in June 2019 with reference number GP_201906_027 (see Appendix C). To date, this application has not been reviewed. A request to conduct research was submitted from the Gauteng Department of Education (GDE) and granted (see Appendix D). A further request to conduct research at the specified hospitals, CHCs and special needs schools was submitted to the relevant management committees and permission was granted (see Appendix E). An information sheet and informed consent form was given, in person, to each potential participant, explaining the aim of the research and the research procedure, as well as the request for permission to obtain audio recordings during the interview process (see Appendix F). The interviewer received informed consent from 31 therapists that were approached, before interviews commenced.

b) Pilot Study

A pilot study was conducted to evaluate the feasibility of the components of the full-scale study, specifically the effectiveness and appropriateness of the interview guide.

The researcher had an opportunity to interview two SLTs for the purposes of the pilot study. One worked at a clinic in Sebokeng (CT) and the other worked at an LSEN school in Johannesburg (ST). Both participants were registered with the HPCSA and had several years' experience working with children with CP. One participant had worked with this population six months prior to the interview, and the other participant had children with CP on her current caseload. The researcher conducted two depth interviews, one with each participant, in their respective homes. Both participants were provided with an information sheet explaining the purpose of the study, as well as an informed consent form to complete before the interview commenced. Both participants gave permission for the interviews to be audio-recorded for transcription and analysis purposes.

This process was overseen by an expert in the field of qualitative research at Stellenbosch University. He provided the researcher with guidance and insight into the refinement of the interview guide to ensure that the specific objectives of the study were met. It was found that the interview guide facilitated in the gathering of information the researcher required to meet the objectives of the study, thus, no changes were made to the interview guide for the full-scale study upon completion of the pilot study.

c) Data Collection

Interview guide

A semi-structured interview is organised by topic and consists of open-ended questions rather than those that offer a choice of predetermined responses. These interviews allow the investigator to alter wording and language level as needed during the interview. The interviewer may add, delete or reorder questions as desired, as well as make clarifications and ask follow-up questions (Schiavetti et al., 2011). An interview guide was used when interviewing participants (see Appendix G). The interview was semi-structured as it consisted of open-ended questions and probes.

An interview protocol was used for asking questions and recording answers during the depth interview and focus groups. The components were as follows (Creswell, 2009):

- A heading comprising the date and participant(s) number was audio-recorded;
- The researcher ensured that standard methods were used from one interview to the next;
- The open-ended questions were asked, starting with an ice-breaker question and ending with a closing statement;
- Probes for the questions were used as needed in order to follow up and ask participants to discuss their ideas in greater detail, or to expound on what they have said;
- Time was allowed in between each question so that general observations; words spoken during environmental noise that may have resulted in a poor audio recording; analytical notes; interesting nuances and/or non-verbal cues that the researcher noticed about the participants, herself, the interaction or interview environment could be noted;
- A final thank-you statement was said in order to acknowledge the time the participants spent.

Focus Group Interviews

These interviews were conducted in the hospitals, CHCs and school settings where there was a team of therapists working with children with CP. They were conducted at the therapists' place of work (besides the CHCs). The therapists working at the CHCs all travelled to the one CHC in order to participate in the focus group interview. All interviews were conducted in a quiet room or space free from external noise. The interviews lasted approximately 30–60 minutes each. Eight focus group interviews were conducted in total. Four of the interviews were conducted at the hospitals, one was conducted at a CHC to which all the clinic therapists travelled, and three were conducted at the schools. The researcher travelled to all these sites for the interviews.

Focus group interviews are conducted with groups of up to 15 individuals whose opinions and experiences are expressed at the same time (Brink et al., 2017). Focus groups allow participants to share their thoughts and experiences with each other. This is helpful in generating new ideas and a broad range of views in response to the posed questions (Brink et al., 2017). Where topics are of a practical community concern, focus groups promote participation where members have an equal role in the interview process (Brink et al., 2017). The benefit of using focus groups in qualitative research methods is that focus groups stimulate interactions amongst group participants, which may generate more information for the researcher than individual interviews would provide (Stewart & Shamdasani, 2014). Due to the 'humanistic' nature of focus groups, they are intended to generate openness, empathy, active listening, and various types of interactions between research participants (Stewart & Shamdasani, 2014). A potential disadvantage is that participants may be unwilling to share personal information in the group (Brink et al., 2017).

Due to the nature of the focus group interviews, whereby the discussions involved institutional policy and procedure, the group dynamic assisted in breaking down the reluctance of participants to share information. Instead, the participants drew confidence from one another and shared eagerly in their experiences. This assisted the researcher in gaining rich and comprehensive information that was truly reflective of each participant's lived experience.

One-to-One (Depth) Interview

This interview format was used where there was only one therapist employed at an institution (hospital/CHC/school). As the name suggests, a one-to-one interview is when the interviewer

poses questions to one participant, instead of a group of participants (Ryan et al., 2009). The researcher can hereby gain insight into the participant's perceptions, understandings and experiences of a given topic (Ryan et al., 2009). The researcher conducted one depth interview at the therapist's place of work. The interview was conducted in the therapist's office and lasted approximately 35 minutes.

Audio Recordings

Each participant that agreed to be a part of the study was required to sign consent for the interview to be audio-recorded. The interview was audio-recorded to enable accurate transcription. The researcher listened to the recordings for transcription and analysis purposes and transcribed all of the interviews herself. Recordings were transcribed verbatim using the abbreviations 'HT' for Hospital Therapists, 'CT' for Clinic Therapists and 'ST' for School Therapists to ensure anonymity in potential presentations at professional meetings, as well as in the research report and journal publication(s). Recordings are stored in a locked cabinet in an office at the researcher's place of work, that is locked when not in use, for the duration and completion of the study. Recordings will be erased after five years.

d) Data Analysis

Thematic Analysis

This analytical approach is involved with understanding the participants' world, by spending a substantial amount of time analysing the transcripts of the interview in order to identify major themes that arise (Langdrige, 2007). The researcher identified, analysed and reported on patterns within the data collected. In line with the model proposed by Braun and Clarke (2006), the following phases were implemented in the analysis process:

Phase 1: The researcher familiarised herself with the data through the transcription process, as well as through reading and re-reading the transcripts and field notes. Initial ideas were noted for coding purposes and for possible patterns to start taking shape.

Every effort was made to keep the transcriptions of interviews faithful to the material recorded.

- The interviewer ensured that every participant being interviewed was clearly heard by the recording device, resulting in good audio quality within the recordings.

- The recordings were listened to a few times before transcription occurred, in order for the researcher to be familiar and completely immersed in the data.
- Sufficient time was set aside to ensure accurate transcriptions could be performed.
- As the researcher completed the transcriptions herself, she was familiar with the technical terminology and jargon used by the participants and could transcribe these accurately.

Phase 2: The researcher began to generate initial codes by listing ideas and interesting characteristics of the data in a logical way across the complete data set. This allowed for the data to be organised into meaningful groups for themes to develop.

Phase 3: The researcher then began searching for themes by means of the codes that had been collated. The codes were sorted into potential themes. These codes were applied to specific relevant participant quotations that were identified and extracted and sorted into the identified themes. The relationship between codes, between themes, and between different levels of themes (main themes and subthemes) was identified.

Phase 4: The researcher reviewed the themes by checking that the themes worked in relation to the coded extracts and entire data set. A refinement of the themes took place, by ensuring that the data within the themes cohered meaningfully, with distinct differences between the different themes.

Phase 5: The researcher defined and named the themes by refining the specifics of each theme and analysing the data within them. By determining the fundamental nature of what each theme was about, as well as deciding what aspect of the data each theme characterised, the researcher defined and refined the data. The researcher identified a story within each theme in order to retell the broader story about the overall data obtained.

Phase 6: The researcher produced the resulting analysis and write-up of the study once a set of completed themes had been established. The researcher attempted to tell the complicated story of the data in a manner that will convince the reader of the merit and validity of the analysis.

Following the process described above, six key themes emerged. Each theme was examined to gain an understanding of participants' perceptions and motivations and will be described in the Results and Discussion chapter of this thesis.

3.3 Ensuring trustworthiness

Demonstrating trustworthiness in qualitative investigations is necessary so that the findings of the study have the integrity to have an influence on practice, policy, or both (Hadi & José Closs, 2016). Trustworthiness of a study is about ensuring credibility, confirmability, dependability, as well as transferability.

The researcher attempted to ensure credibility of the study by conducting a pilot study before the data collection of the full-scale study was carried out. Pre-interviews were used to determine that the questions from the interview guide would result in obtaining rich data that answered the proposed research question (Elo et al., 2014).

In order to guarantee that the interpretations of the data were trustworthy, the researcher attempted to ensure confirmability of the findings (Elo et al., 2014). This was done by providing the analysis of the transcripts, as done by the researcher, to another person to be checked in order to ensure that the data interpretation was comprehensive and sound (Elo et al., 2014). This person, a colleague of the researcher, has work experience of over ten years in the public education sector, specifically working with children with CP. She is familiar with qualitative research methods and her insight was considered invaluable. No divergent opinions were identified concerning the analysis.

The dependability of the study relies on the principles and criteria used to select the participants (Elo et al., 2014). The use of purposive sampling in the study ensured a narrow representation of the participants, resulting in stability of the data collected (Elo et al., 2014).

Furthermore, member checking was done in order to improve the accuracy, credibility and transferability of the study. Member checking is often mentioned as one in a list of validation techniques for qualitative research (Birt et al., 2016). A summary of the results of the study were emailed to the participants so that they could check for accuracy of the results and provide the researcher with feedback as to whether these results resonated with their lived experiences. The researcher gave the participants two weeks to reply to the email stating whether they agreed ('yes, I agree') or disagreed ('no, I disagree') with her findings, as well as any further comments they would like to add. The researcher followed up via email after a week had passed. Fourteen out of the 31 responses were returned, with no objections raised with regard to the findings of the study. Three were from HTs working at tertiary hospitals and one was from an HT working

at a district hospital. Two responses were from CTs and eight were from STs (see Appendix H).

Lastly, face validity was determined by presenting the results to the researcher's colleagues and peers who were familiar with delivering speech-language rehabilitation services in the public health and education sectors in Gauteng, and who then evaluated whether the results, upon face value, were a logical deduction, matching the broader realities experienced in the sectors (Elo et al., 2014). The colleagues and peers agreed that upon face value, the results of the thesis were a logical deduction of the broader realities they experienced whilst working in the sectors.

3.4 Ethical considerations

- Each SLT who agreed to participate in the study was required to sign a consent form and was explained the purpose of the study and the reason for their involvement, in detail. The form acknowledged the participant's rights during data collection. It was explained that each participant would be referred to as HT if they work in the hospital, CT if they work in the clinic and ST if they work at a school. They would not be referred to by name during analysis, interpretation and writing of the dissertation, in order to protect their identity. All questions that the participants had about the research study were answered to the best of the researcher's ability and in an honest manner.
- Each participant signed a permission form for the interview to be audio-recorded. The participants were well informed about the possibility of the inclusion of data, such as direct quotations in the final thesis, that they may not have expected. The consent form stated that the supervisor may be included in the listening of the recordings or reading of transcripts for analytical purposes.
- Due to the fact that interviewing is increasingly being viewed as a moral inquiry, the researcher considered how the interview would enhance scientific knowledge and improve the human situation; how the discursive interaction may be distressing for the participants; as well as the possible consequences of the information gathered from each participant with regard to the institutions they belonged to. It was the aim of the researcher to involve participants collaboratively in the study.
- The transcripts and recordings will be kept for five years and will thereafter be destroyed.

- All participants were invited for a one-hour, Continued Professional Development (CPD)-accredited feedback session relating to the results of the study, to compensate for the time and effort spent as a research participant.
- No fraudulent practices were entertained, such as censoring, altering or fabricating findings to meet the researcher's needs in the writing up of this thesis.

Chapter 4: Journal Article

The format for this thesis is that of master's degree by publication, which requires that a journal article be prepared for submission. The article which follows has been prepared for submission to the South African Journal of Communication Disorders (SAJCD) and conforms to the requirements as stipulated by the SAJCD. This original research article will be submitted to the SAJCD following examination of the thesis.

A Chasm: Consequences of Poor Collaboration between Health and Education in Paediatric CP Care

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Abstract

Background

Nearly twenty years since the establishment of the National Rehabilitation Policy strides have been made within the health and education sectors to improve accessibility to rehabilitation services as well as the quality of life of children with cerebral palsy (CP) . Shortfalls however still exist in implementing policy. An in-depth study into the implementation of policy would be beneficial in identifying and understanding weaknesses and shortfalls of the rehabilitation process.

Objectives

To investigate the perceptions of Speech-Language Therapists (SLTs) working in the Gauteng Department of Health (GDH) and Gauteng Department of Education (GDE), in Johannesburg region A, about the services they provide to children with cerebral palsy, from birth to 6 years of age.

Method

A qualitative, phenomenological study was conducted. A total of 31 SLT's working in public hospitals, clinics and schools for Learners with Special Educational Needs (LSEN) participated in a total of 8 focus groups interviews. Interviews were audio-recorded for transcription and subsequent thematic analysis.

Results

A lack of resources and knowledge contributed to a perceived chasm between the GDH and GDE, resulting in fragmented and uncoordinated service delivery for children with cerebral palsy leaving the health- and entering the education system.

Conclusion

The results suggest that a cohesive plan should be formulated and executed in order to bridge the perceived chasm between GDH and GDE in the referral process of children with CP from the hospital or clinic setting, into the school environment. This may facilitate communication, collaboration, education, as well as resource-sharing between the departments.

Key words: Perceptions, rehabilitation, disability, referral, education, procedure, South Africa

Introduction

The South African Department of Social Development (2009) states that there remain fragmented and unequal services for children with disabilities in the country. Government departments are uncoordinated and act in isolation. Early identification of disabilities and tracking of progress through early childhood to school-going age remain systematically deficient (Department of Social Development, 2009). This is despite progress made in legislative and policy reform. Furthermore, as noted by Rule et al. (2006), many children are receiving formal rehabilitation for the first time when they enter the formal schooling system. Given the socioeconomic environment of the country, despite policy dictating that a child's formal education begins at 6 years, this can often be later (Munnik & Smith, 2019). Speech-Language Therapists (SLTs) working in the public sector, given their interaction with the systems and procedures in place with regards to the management of children with cerebral palsy (CP), can provide valuable insight into the effectiveness of policies. In-depth investigation into the perceptions of such SLTs could assist in identifying deficiencies in existing policies as well as suggestions to rectify these. This could facilitate improved service delivery and cohesion and collaboration between sectors.

CP is a neurodevelopmental disorder that influences movement and posture due to nonprogressive impairment to the developing brain, affecting the child throughout his/her life (Rosenbaum et al., 2006). As a child develops into an adult, the severity of the disability and functional level of the individual changes. The functional level achieved as an adult is entirely dependent on the levels of function that the individual was able to reach as a child. Achieving the best possible outcomes is facilitated through continuous rehabilitation to achieve maximum potential and prevent functional deterioration from occurring (Vos et al., 2013).

For a long time in South Africa continuous rehabilitation has not been provided to children with disabilities and therefore a need to develop a strategy that addressed the neglect of paediatric rehabilitative services was needed. This gave rise to the Integrated Disability Strategy (INDS) that was established in 1997 by the office of the Deputy President of South Africa (1997). For optimal functional levels to be reached and maintained within children with disabilities by means of rehabilitation, the INDS proposed a National Rehabilitation Policy (NRP) (Office of the Deputy President, 1997). The NRP was finalised and published in 2001.

Simultaneously in 2001, the Department of Education issued a framework policy document called White Paper 6 (WP6): *Special Needs Education, Building an Inclusive Education and*

Training System (Department of Education, 2001). This policy document set out government's proposal for future legislation regarding special needs education. The policy acknowledged that all children and youth can learn and those requiring remediation to cope with educational demands, should be provided with the support. Furthermore, the policy aimed to acknowledge the education structures, practices and learning procedures to meet the needs of all learners (Department of Education, 2001).

In 2013, the South African Department of Health recognised that to address the health inequalities experienced by persons with disabilities in our society, a transformation of the current South African health system had to occur. Hence, the Framework and Strategy for Disability and Rehabilitation Services in South Africa was compiled (National Department of Health, 2016). This framework aims to reform rehabilitation as an essential part of health services across all programmes, within all levels of care. It aims to increase access, equitability, inclusivity, and participation for the population living with disabilities within their communities (National Department of Health, 2016). The framework recognises that rehabilitation services are a crucial link between medical treatment and the adaptation of a person's restored functionality into a health-promoting social and productive economic life (National Department of Health, 2016). This is specifically relevant for children living with CP. Furthermore, the framework states that appropriate referral pathways create access to suitable care and must be aligned to departmental policy.

Nearly twenty years on from the development of the NRP and WP6, strides have been made to implement policy in order to improve accessibility to all rehabilitation services and thereby enhance the quality of life of individuals with disabilities in both the health and education sectors (Department of Basic Education, 2015). Yet, anecdotal evidence suggests that limited collaboration exists between these sectors, resulting in continued fragmented and uncoordinated service delivery.

The main aim of this study was to investigate the perceptions of SLT's working in the public health and education sectors in the greater Johannesburg region, about the services they provide to children with CP, from birth to 6 years of age. The Objectives were:

- To determine the SLTs perceptions about the procedures implemented in their institutions with regards to the communication rehabilitation of children with CP;

- To describe the carryover of rehabilitation of children with CP from one institution to the next;
- To describe the relationship and carryover procedures between SLTs working in the public health sector and SLTs working in the public education sector.

Research Methods and Design

Study Design

A qualitative research design was used, specifically the approach of phenomenology. Qualitative research methods can offer detailed descriptions of the perceptions of individuals, useful quotes that bring a lived experience to the applied study, as well as information about how various health care settings function. Phenomenological studies examine the lived experiences of participants through their descriptions of their working realities, as well as how they explain the experiences or what significance the experiences have for them (Brink et al., 2017).

Setting

Participants were recruited from public health and education institutions in region A of Johannesburg.

Table 4.1: Number of SLT's who Participated in the Study

GAUTENG REGION A - HEALTH AND EDUCATION FACILITIES					
	Number of Facilities in the Region	Number of Facilities that Participated	Total Number of SLTs Working in the Institutions	Total Number of SLTs who met the Inclusion Criteria	Total Number of SLTs who Participated *
Central Hospitals	2	2	48	9	8
Tertiary Hospitals	4	2	13	7	4
District Hospitals	2	1	4	2	2
CHCs in Johannesburg Metro Rehab **	9	9	8	8	8
LSEN Schools ***	3	3	10	10	9
Column Totals	20	17	83	36	31
<p>* Speech-Language Therapists who met the inclusion criteria and gave informed consent.</p> <p>** Primary Health Care Facilities include clinics and Community Health Centres (CHCs) of which only CHCs were included in the study. (Gauteng Provincial Government, 2018).</p> <p>*** The schools for Learners with Special Educational Needs (LSEN) in the public sector of the region, who admit children with cerebral palsy presenting with Mild and Moderate Intellectual Disabilities (MID) (Schools Listings, 2019) were included in the study.</p>					

Study population and sampling strategy

A purposive sampling strategy was used. Qualified SLTs working with children with CP in the public health- (hospitals and CHCs) and education (LSEN schools) sectors were asked to participate. Permission was sought at every institution and the SLTs that were approached, provided permission. They were included based on the following criteria:

- Minimum of a 4-year degree in Speech-Language Therapy or Speech-Language Therapy and Audiology;
- Registered with the Health Professions Council of South Africa;
- Working in hospitals (tertiary, central and district hospitals), CHCs and LSEN school settings in the public sector, in Region A of Johannesburg, Gauteng Province;
- Therapists specifically working with children with CP from birth to 6 years as part of their current caseload, or within their last six months.

All participants met the inclusion criteria. Three therapists working in the hospitals and five working in the CHCs were completing their year of compulsory community service. Therapists with more than ten years' working experience with children with cerebral palsy were based at the LSEN schools. This level of experience did not exist in the hospital and clinic settings.

Data Collection

An interview guide was used to conduct the semi-structured interviews with the participants.

Pilot Study

A pilot study was conducted to evaluate the feasibility of the study, specifically the effectiveness and appropriateness of the interview guide.

Focus Group Interviews

These interviews were conducted in the hospitals, CHCs and school settings where there was a team of SLTs working with children with CP. They were conducted at the therapists' place of work. The therapists working at the CHCs all travelled to a central CHC to participate in the focus group interview. All interviews were conducted in a space free from external noise. The interviews lasted approximately 30-60 minutes each. Eight focus group interviews were conducted in total, and one individual depth-interview. Four of the focus groups and the individual interview were conducted at the hospitals, one focus group was conducted at a CHC, and three were conducted at the schools.

Audio Recordings

Each participant was required to sign consent for the interview to be audio-recorded for later transcription and analysis. Author A listened to the recordings and transcribed all the interviews verbatim. The abbreviations ‘HT’ (Hospital Therapist), ‘CT’ (Clinic Therapist) and ‘ST’ (School Therapist) were used to protect the participants’ identify.

Data Analysis

Thematic analysis using the approach proposed by Braun & Clarke (2008) was used in the analysis of the data.

The subjective nature of the interpretative process means that the authors may have introduced bias in the analysis of the data. To reduce bias, the following strategies were followed:

- Author A strove to bracket personal views and experiences through continuous reflection (epoché);
- The trustworthiness of the themes is demonstrated through verbatim quotations from the raw data;
- Every effort was made to keep the transcriptions of interviews faithful to the material recorded;
- Author A ensured that every participant being interviewed was clearly captured by the recording device, resulting in good audio quality of the recordings.
- The recordings were listened to a few times before transcription occurred, in order for Author A to be familiar and completely immersed in the data.
- Sufficient time was set aside to ensure accurate transcriptions could be performed.
- As Author A completed the transcriptions independently, there was familiarity with the technical terminology and jargon used by the participants, resulting in accurate transcriptions.
- Member checking was conducted to improve the rigour of the study.
- A summary of the results of the study were emailed to the participants, so that they could check for accuracy of the results and provide the authors with feedback as to whether these results resonated with their experiences.
- Author A gave the participants 2 weeks to reply to the email stating whether they agreed (‘yes, I agree’) or disagreed (‘no, I disagree’) with the findings, as well as an invitation for any further comments they would like to add.

- Author A followed up via email after a week had passed.
- Twelve out of the 31 potential responses were received, with no objections raised with regards to the findings of the study. One response was from a HT working at a tertiary hospital and one was from a HT working at a district hospital. Two responses were from CTs and eight were from STs.

Ethical Considerations

An application was made to Stellenbosch University's Health Research Ethics Committee (HREC) for permission to proceed with the research. Permission was granted in June 2019 with the HREC Reference #: S19/05/093. A further request to conduct research at the specified hospitals, CHCs and LSEN schools was sought and granted. An information sheet and informed consent form was given, in person, to each potential participant, explaining the aim of the research and the research procedure. Only participants who provided informed consent were interviewed.

Findings

The findings are summarised in Figure 1. The circles represent the relationship between the three major themes: the lack of resources and knowledge that results in a 'chasm'. The arrows represent the cyclic process of how a lack of knowledge together with weighting² entrenches a lack of resources while failures in inter-departmental collaboration perpetuate a lack of knowledge.

Lack of Resources

Time, infrastructure and adequate staffing are the resources that were identified as lacking in the public sector by the participants. High caseloads with low staff compliments, accompanied by poor physical infrastructure and time constraints, resulted in increased frustration levels, low morale, and a sense of despair among the participants. The sense of defeat about the current institutional facilities available for children with CP such as LSEN schools, training and stimulation centres³, and the genuine concern about the lack of vocational institutions available for these children once they leave school, was palpable.

² Weighting refers to a process of assigning values to different disabilities based on pre-determined formulas for the purposes of staffing allocation.

³ Training- and stimulation centres refer Institutions that provide care and/or education for children with lower cognitive abilities

The Chasm

A consistent theme that arose from the data indicated a chasm between the Gauteng Department of Health (GDH) and the Gauteng Department of Education (GDE). The participants reported that this chasm resulted in a belief amongst caregivers that the “transfer into the next stage of life” (HT) will fail. Some participants stated that the caregivers experienced apprehension in leaving the hospital and/or clinic setting and entering the education system. The participants expressed that the fear of the unknown accompanied by the slow process, such as waiting lists at the district-level of the education sector, resulted in delayed procedures and reluctance and distrust by caregivers to move their children’s rehabilitation from the familiar health care sector. A further finding was that there was a desire of hospital-, clinic- as well as school-based participants to close this chasm that seems to exist between the two departments, by creating collaborative, inter-departmental systems. They were aware that improved communication between therapists during carryover procedures will improve handover of the child’s care.

Lack of Knowledge

A strained relationship with the GDE as a bureaucratic collective, was communicated by most of the participants. Participants working in school settings felt that the GDE did not look at the best interest of the children with CP during the admissions process. The perception of the participants was that the GDE did not appropriately allocate children to specific LSEN schools, given the children’s cognitive and physical level of functioning. This constituted an important aspect of the narrative. Participants conveyed dissatisfaction about a number of facets, namely, a general lack of consultation from the GDE; a lack of urgency in LSEN school placement; inappropriate admissions into LSEN schools hampering the efficacy of the curriculum; inappropriate admissions into LSEN schools with weighting scores for learners that have negative consequences on staffing, as well as the lack of infrastructure. Participants working in the school setting reported that inappropriate weighting of learners in LSEN schools, negatively affected the staffing at the school. They stated that if the schools did not appropriately admit learners with specific disabilities, they did not achieve the desired child-to-staff ratio, and this resulted in fewer allocations of therapists and teachers in schools.

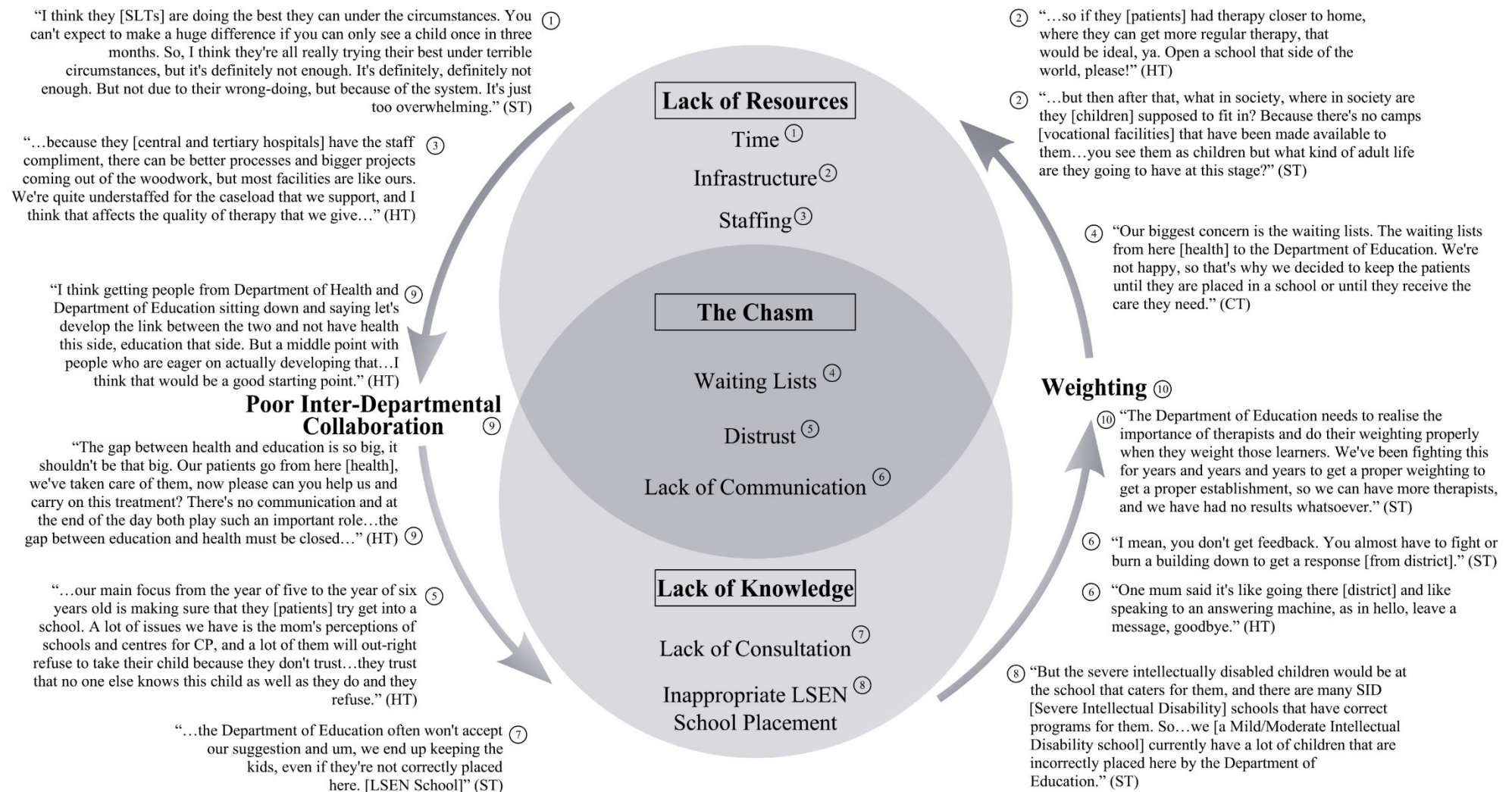


Figure 4.1: Visual Representation of Research Data obtained through Thematic Analysis

Discussion

Given that CP is a lifelong condition that requires ongoing intervention to assist the child and family to function in the most effective way possible (Levitt & Addison, 2019), it is paramount that governments provide adequate staffing and infrastructure within public hospitals, clinics and schools. Yet, the provision of specialised facilities with adequate staff for this population, is an ongoing challenge in South Africa. Not all healthcare and educational facilities equally accommodate the varied needs of the children with CP. Without sufficient and appropriate facilities, therapists are often unable to refer children to a facility where their specific needs will be met.

Each child with CP is unique and this place special importance on the referral process from one rehabilitation institution to the next. There was an overwhelming sense of frustration from participants in both the provincial health- and education sectors that highlighted a desperate need to address the lack of communication between these two sectors. According to the National Department of Health's Framework and Strategy for Disability and Rehabilitation Services in South Africa (National Department of Health, 2016), rehabilitation should be decentralised and begin as early as possible and should extend from community to tertiary and specialised rehabilitation levels. As reported by some of the participants, the therapists are often excluded from the school admissions process due to procedures that rely on the simplified classification of cognitive abilities of each child from a limited group of medical professionals. Yet, the Department of Basic Education (2014) specifically states that the medical assessment on its own must not be used to make decisions about admission to a special school. The assessment should be conducted by all the relevant professionals. Without in-depth diagnostic assessments performed by allied health professionals it is unsurprising that inappropriate school placements for children with CP are common. Procedural review and reform at the GDE could be instrumental in removing barriers to inter-professional communication and ensuring that rehabilitative gains made at hospital- and clinic-level are carried over reliably into the therapeutic environment at LSEN schools in the province. Furthermore, a consultative process with allied health professions, including SLTs, occupational therapists, physiotherapists, as well as educational psychologists working at LSEN schools, could substantially reduce the incidence of inappropriate admissions.

Failure to place children into schools where the existing resources and infrastructure are aligned with the specific needs of the child, placed enormous strain on the participants. Participants

reported that there was often a resistance by the GDE when they submitted feedback regarding a specific case that suggested that a particular school was not a suitable placement. According to the guidelines of the Department of Basic Education (2014) suitability of placement should be evaluated annually or at least every two years. The reason that the GDE appears to act in a manner contrary to this departmental policy was not investigated in this study. The underlying perceptions of the participants was, however, that there is a general lack of understanding by the administrators at the GDE as to the nature of CP and the therapeutic interventions required to ensure the best possible outcomes for children with this condition. The overall effect of this perceived lack of understanding seems to be that there is an inappropriate distribution of resources, a lack of direction in the establishment of new infrastructure, and the destruction of the existing cohesive elements within the system.

Strengths and Limitations

As phenomenological research is focussed on attaining depth understanding into the lived experiences of participants, the number of participants is necessarily limited. The limited sample size of 31 participants forming eight focus groups was however representative of the region under investigation, as many therapists approached via the purposive sampling strategy agreed to participate (31 out of 36). This yielded good insight into the perceptions of the participants with data saturation being achieved, giving credence to the findings. However, conclusions about the perceptions, practices and procedures of therapists working in other parts of the province and country should not be made.

The subjective nature of the interpretative process means that the authors may have introduced bias in the analysis of the data. Yet, efforts to minimise bias was implemented.

Recommendations

As the GDE is responsible for placing children in schools, further research should be conducted at the administrative district level of the GDE to further investigate the details of the perceived chasm between the provincial Departments of Health and Education. With the insights obtained from such an investigation, further recommendations can be made for the implementation of improved communication procedures and strategies between sectors and institutions. This communication needs to be bidirectional and create opportunities for the GDE to inform the GDH of the services available in LSEN schools, and for GDH to be able to share relevant referral information about a child, when assisting with school placement. This communication should be conducted in a manner that fosters trust.

Although the study was set out to investigate the (dis)continuity of speech-language therapy services for children with CP in the public sector specifically, the results highlighted that some of the contributing factors fall outside the purview of SLTs. Further research could include investigating the perceptions of the doctors making diagnoses and referring to the educational districts for LSEN school placement. Their perceptions of the various LSEN schools and motivations for recommending one school as opposed to another, can further increase understanding and possible improvement of the referral process.

Lastly, further investigations similar to the current study should be conducted in other provinces, as well as with other health professionals, such as physiotherapists and occupational therapists, to establish whether there are correlations with the findings of the current study.

Conclusion

Cerebral palsy is a lifelong condition that requires ongoing intervention. It is therefore paramount that governments provide adequate staffing and infrastructure within public hospitals, clinics and LSEN schools. Each child with cerebral palsy is unique, which reinforces the importance of the referral process from one institution to the next. By far the most prominent theme which emerged was the perceived chasm between the health and education sectors with regards to communication rehabilitation. Carryover of therapeutic goals and strategies within the referral pathway is negatively affected by a general lack of communication, collaboration and resource-sharing between the two departments. There is also little relationship between the SLT's working in the public health sector and those working in the education sector.

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Chapter 5: Results and Discussion

This section presents a phenomenological analysis of themes of the lived experiences of SLTs working in the government sector, with regard to the services they provide to children with CP. Table 5.1 contains the themes and subthemes that emerged during data analysis of the transcribed interviews.

Table 5.1 A table of the themes and subthemes that emerged from data analysis

Themes and Subthemes	
1 The small victories and breakthroughs	<ul style="list-style-type: none"> • The perceived value of therapy. • The complexity and varied nature of the diagnosis and the challenge of the therapy process. • The role of the caregivers in the therapy process. • The use and effectiveness of Augmentative Alternative Communication (AAC) as a therapeutic tool.
2 Speech-language therapists' genuine desire to make a difference in the lives of their patients	<ul style="list-style-type: none"> • An overwhelming sense of wanting to do what was best for the child. • Strategies in the handling of high caseloads. • The effects of limited staffing on the frequency of therapy provided. • Handling the challenges of ineffective school placements. • Compromises resulting from the deficiencies in the referral pathways.
3 A general lack of resources	<ul style="list-style-type: none"> • Time • Staffing • Infrastructure

4 The impact that a family's low socio-economic status has on the efficacy of therapy

- The effects that a low socio-economic situation has on the priority of speech-language therapy.

5 The chasm between health and education and the distrust it creates

- Challenges surrounding the effective implementation of the referral pathway system.
- Consequences of a perceived failing referral pathway system.
- Improved communication as a solution to addressing the perceived failings in the referral pathway.

6 Perceived lack of learners with special educational needs (LSEN) school knowledge at Department of Education

- The perceived lack of appropriate direction from the Department of Education.
- The consequential result of inappropriate placement of children in LSEN schools.
- The exclusion of the speech-language therapist from the referral process.

Where direct quotations are presented from the transcripts, these will be referenced by the initials HT (Hospital Therapist), CT (Clinic Therapist) and ST (School Therapist).

5.1 The small victories and breakthroughs

The perceived value of therapy.

A dominant theme that arose from all the participants working with children with CP is that they experienced great satisfaction when they witnessed first-hand the difference that therapy made in the quality of life of the child. Participants expressed that making even a small difference in the child's quality of life motivated the participants to persevere with their therapeutic interventions. Across both health and education sectors, participants in all settings reported the experience of satisfaction associated with these breakthroughs in therapy.

- "And I quite enjoy when you make like it's just a small difference." (CT)
- "The kids, even they wouldn't be able to say thank you, you know the simple smile that you get, or the fact that they are able to swallow a little bit better than before ... just the small things, it just changed my attitude a little bit more." (HT)

- “Um, for me I think it’s because they have such a severe diagnosis, to give them a little bit of hope for the moms, just to help them give them a better quality of life.” (HT)
- “I think it’s when they actually achieve something which makes life easier for them. They weren’t able to reach out to the world, and make their needs known, and thanks to therapy they have a way of doing that. I think that’s the biggest thing, to make a difference in their life.” (ST)

The complexity and varied nature of the diagnosis and the challenge of the therapy process.

A further finding related to the complexity of the diagnosis and the challenge of the therapy process. This constituted an important aspect of the therapeutic experience, as reported by the participants. It was evident that, for the participants, therapy for children with CP is “not a quick fix” (HT), but rather an evolving process that keeps them motivated to keep learning due to the complexity and varied nature of the individual cases.

- “... I think CP is quite interesting ’cause I think it’s quite challenging if you, it’s not an easy quick-fix to anything and every child is completely different ... so I think the challenging part is trying to find the exact treatment plan, and that’s really nice for me.” (HT)
- “I really like that [it]⁴ kind of keeps you busy, keeps you motivated to keep learning.” (HT)
- “... it can be very challenging because each child is so different in their presentation ... so you feel so challenged every time, and what worked for one doesn’t work for the other, and what works in one session may not work in another session ...” (HT)
- “And they take a lot more thought. The type of therapy you do with them is more challenging ... you gotta think more about it.” (ST)

The role of the caregivers in the therapy process.

The role of the caregivers in the therapy process is an element that emerged from the data. Although participants working in the health sector are provided with significantly more opportunities to witness the mother-child interaction during therapeutic sessions than participants working in the education sector, this experience was also shared by participants

⁴ The researcher added words in square brackets to indicate context or clarify meaning where required.

working in school settings. A recurring theme mentioned by many of the participants was the mother and child interaction in each session, along with the caregiver's commitment to the therapeutic process; how the parents supported each other; and over time, the acceptance of their child's diagnosis.

- "... I mean even just like see the mom from the first session to a few sessions down the line, to see how much they are interacting with the child. It's just beautiful." (HT)
- "... when I was working with a parent, and then I saw the child, you know when they light up, but also seeing the parent light up, and it was rewarding just to get that interaction." (ST)
- "For me it's working with the, especially with the caregiver and sort of empowering them, because, um, within our sort of context you don't get to spend that much time with the kid ... so it's sort of more focusing on getting the mom to, to get to that stage where she can, you know, implement or do things at home, so that's what I enjoy." (HT)
- "I think it's just the commitment and acceptance that the mother develops over time and helping them get that acceptance with the child with disabilities, it's nice to see." (HT)
- "I also love how the parents give each other advice. That's always really great to see how the people of the community are helping each other with little tips and techniques they found it easier for them." (CT)

The use and effectiveness of Augmentative Alternative Communication (AAC) as a therapeutic tool.

Lastly, the use of AAC as a tool to tap into the child's inner world, was commonly mentioned by the participants. They expressed enthusiasm when a child was able to make themselves 'heard' for the first time, as well as how the tool was used to promote self-confidence, create independence, which in turn helped the child access the curriculum in the school environment.

- "I think like the small, even like the small communication milestones, like with a kid, you can even see, like, like how excited they get, like oh my gosh, I can finally communicate! So that's really exciting." (HT)
- "And seeing the kids, how they interact in a social environment as well." (CT)

- “... people [educators] look at the child and think what could they do? And then through AAC or something that you try, their potential pops out, and you’re like, told you! [giggles]. There’s more than you thought.” (ST)
- “It’s definitely a positive in those breakthroughs. Those little eyes even, or just that the child seeing, aww, someone is getting something from what I’m doing.” (ST)
- “And the joy when they can see now, I actually did that for myself, and in their eyes you can just see, like no one’s given me that opportunity, now I did this for myself and they like, like look at me! Like, I’ve done this.” (ST)

The small victories and breakthroughs are consequential. Given the magnitude of the challenges faced by children with CP, it is unrealistic to expect immediate or eventual remediation for either the child or their caregivers. It is important therefore, to consider the small victories and breakthroughs in that they create an opportunity to reflect on how much has been accomplished through the therapeutic process. Vast differences in the presentation and complexity of CP require consideration by the therapists when formulating procedures and treatment plans. The participants were acutely aware that a simplistic, generalised solution is not sufficient. This is evident in the recurring narrative that the participants described regarding the specific aims and outcomes of their therapy, with each child with CP. The treatment of CP, by its nature, requires specialised knowledge. Research suggests that knowledge from individual specialties, including the SLT, who collaborate with each other to provide comprehensive care to patients with CP, leads to beneficial therapeutic outcomes (Keys & Lewis, 2019). This specialised knowledge is acquired over time. Similarly, the specific knowledge relevant to each child is also acquired through time spent with that child. This makes the therapist’s insights into the individual cases incredibly valuable. Thus, it would be inappropriate to refer these children onto other institutions without consulting the SLTs and transferring their knowledge about the children they treat. This was however reported not always to have been the case, with the participants often being excluded from the referral process.

5.2 Speech-language therapists' genuine desire to make a difference in the lives of their patients

An overwhelming sense of wanting to do what was best for the child.

A recurring theme that emerged from the data was that a concerted effort was being made by the participants working in government institutions, when creating systems that refined procedures which were effective in addressing the needs of the population. This emerged when participants were asked to describe the procedures of the institution pertaining to the treatment of children with CP. There was an overwhelming sense amongst all participants working across these institutions to do what was best for the child.

- “[sighs] I think we try very hard.” (HT)
- “I think all of us therapists are in the same boat. I think everyone tries their best.” (HT)
- “I think everyone is trying to do their best. I don’t think you can say the hospitals are providing a poor service. They’re inundated as well. Um, so I do believe people are trying to do the best they can, but obviously there’s just limitations on time and resources and people.” (ST)
- “I think they are doing the best they can under the circumstances. You can’t expect to make a huge difference if you can only see a child once in three months. So, I think they’re all really trying their best under terrible circumstances, but it’s definitely not enough. It’s definitely, definitely not enough. But not due to their wrongdoing, but because of the system. It’s just too overwhelming.” (ST)

Strategies in the handling of high caseloads.

As reported by participants working in the GDH, central and tertiary hospitals assisted the clinics by providing services to many patients. This was done as therapists working in the clinics were short-staffed, with resultant longer waiting periods for clients. Participants working in central and tertiary hospitals reported that they were required by departmental policy to discharge children to the clinics by three years of age, so that these therapists (tertiary) could manage their caseloads more easily, with the focus being on ECI. To assist with the referral from the hospital setting into the clinic setting, it was reported by the participants that they created communication groups and protocols to facilitate the referral process.

- “... and then after three years then we refer down to the clinics, which is also again not ideal 'cause a lot of them enter the service [public therapeutic system] quite late which is not great.” (HT)
- “But what we noticed that is ... they [central or tertiary-level services] usually keep them for a little bit until they're three, three and a half and then they down refer them to the clinic.” (CT)
- “We have a WhatsApp group ... so a few of us are on there and if there's a, like a query or a patient we refer, then either they will put it on there, or we would put it, and then we would contact the patient.” (CT)
- “We have a referral list now. So, whenever they [central or tertiary-level services] refer to us, there's a list if ever we refer back. And if they refer to us, as we have, we're able to check exactly when they came for an appointment, and when they were seen.” (CT)

The effects of limited staffing on the frequency of therapy provided.

According to the participants working in the clinic settings, the frequency of therapy for children with CP at some clinics was once a month. This was the same frequency they would receive at hospital level. However, at other clinics, due to the higher turnover of therapists and lower staff complement, these clinics will have speech-language therapy services available only one or two days a week. This resulted in high caseloads at those clinics in relation to the number of therapy days available. Service delivery at those clinics could therefore only be administered to an individual patient, once every three months.

- “So, we have a group just because it works out easier because I'm not there every day. So, I'm only there twice a week. So I sort of do it in the morning when I can, one of the mornings when I can to make sure that everyone's coming, getting to see somebody, even if [only] some people come.” (CT)

Handling the challenges of ineffective school placements.

According to participants working in schools, therapists treated children with CP on a weekly basis, individually or in a small group. However, once again, due to high caseloads and low staff complements, the younger children were prioritised whilst the older children were either seen in groups or discharged. Participants from one of the schools reported that they run an out-patient clinic once a week for children under the age of three years who were possible

candidates for the school. This was not the school's main intervention; however, it was established as the therapists saw a need in the community for these children to receive the necessary services. The therapy and parent guidance that the out-patient clinic provided is done within an MDT.

- “We also run an outpatient clinic once a week, so for children under three who are possible candidates for the school ...” (ST)

Compromises resulting from the deficiencies in the referral pathways.

Participants working at the other two schools included in this research, stated that they run a screening process whereby all members of the MDT have a turn to interact with a child younger than six years of age and deliberate as a team whether the child should be admitted into the school. These school-based therapists reported that if the child was a candidate for the school, they would be admitted once they were of school-going age. If the child was not a suitable candidate for that school, other more appropriate schools would be suggested to the parents. Participants were of the opinion that this screening process did not however address the issue of ECI in schools, as children with CP are not admitted into the formal school system before six years of age.

- “If they're over six they get placed by the district because they are of school-going age, but sometimes, um, the hospitals refer them before the age of six. We then do a screening assessment just to see that they're correctly placed ... and if they are, then they start school earlier.” (ST)
- “Optimally we would like to have them from about three, so we could treat them younger.” (ST)
- “... younger than that [six years old] we can't take them anymore, which I, for me is a travesty and an injustice.” (ST)

It was further reported that this screening process was not feasible after the child turns six years of age. A child over the age of six, when entering the education system, is referred by the GDH and placed into schools by the GDE. LSEN schools receiving children over the age of six are therefore not consulted in the admissions process. The school is required to accept the child regardless of whether or not the school is the best fit for the child. This has led to many challenges within the LSEN school environment.

- “We’re at the stage where, ya, we have extra classes for the special phase [classes for cognitively lower-functioning children], and, to accommodate children, even in the special phase are low[er] functioning [children] than [the] other children, just so that there could be more stimulation where possible.” (ST)

According to the participants working in the hospital and clinic settings, they received an official memorandum⁵ from the GDH stating that children with CP are to receive speech-language therapy intervention from birth until six years of age. Thereafter, the children’s therapeutic needs fell under the directive of the GDE. The participants reported that trying to terminate therapy in the hospital setting was often met with resistance by the caregivers, as purportedly the caregivers lacked confidence in the quality of services that they would receive once they have entered the school system.

- “... our main focus from the year of five to the year of six years old is making sure that they try get into a school. A lot of issues we have is the moms’ perceptions of schools and centres for CP, and a lot of them will out-right refuse to take their child because they don’t trust ... they trust that no one else knows this child as well as they do and they refuse.” (HT)
- “We actually had one of our moms attempt to start her own centre because she got very frustrated trying to find a place for her child.” (HT)
- “... but I think that’s a big issue we have. The transfer of them over to the next stage of life.” (HT)

Furthermore, the hospital- and clinic-based participants reported that they felt pressured to make alternative arrangements to cater for the children whose caregivers were unwilling or unable to move out of the GDH to the GDE. This reportedly lead to making concessions on the participants’ caseloads to accommodate these children, easing caregivers’ anxieties around the new setting or institutions the child would be moved to, as well as accommodating the child’s therapeutic needs whilst trying to get them placed in a school timeously.

- “... so they’re very hesitant to even try another place, go see what it’s like. They’ll even say I don’t know where the speech department is, so it’s little things like that that add to it as well when we’re trying to transfer them, it becomes quite complicated.” (HT)

⁵ The participants were unable to clarify whether this was a provincial or national memorandum.

- “So for us it means, we kind of want to help our kids as well. We end up squeezing them in and making exceptions. They end up staying here way past the point they should have been discharged. So I guess it’s also us to blame.” (HT)
- “So it’s a good way to manage those patients as well, just keeping track of them and making sure that we see them until they’re in the special school.” (CT)
- “We are actually struggling with putting them in schools because they need ongoing intervention. So here we are working on seeing them past the age of six until they are placed in a school, because we are trying to keep what we have [progress].” (HT)

The participants demonstrated a genuine desire to make a difference in the lives of their patients and to do what they perceived as best for the child and caregiver. Participants endeavoured to create strategies to deal with the problems associated with high caseloads amid staff shortages, as well as make compromises to reduce the effects of shortcomings in the referral pathway. The appropriate placement of children with CP in schools is paramount to effectively providing them with skills to integrate into society. Before the child enters the school system, they are reliant on the services being provided by the DoH in hospitals and clinics. It is not the mandate of DoH to provide speech-language therapy services for an indefinite period. For rehabilitation, patients are treated for a short period of time within central hospitals (National Department of Health, 2016). They are well positioned to identify, diagnose, assess, counsel, and treat the acute presentation of each case. Additionally, this is done at an early age, providing an opportunity to define an appropriate referral pathway for each child.

The health services are however not without their challenges. According to the ACPF (2011), the overburdened and understaffed public health and education systems in South Africa, which service 85% of the population, struggle to provide quality services. Due to a number of reasons, including high caseloads, low staff complements, limited infrastructure, as well as the socio-economic challenges faced by the community, it is often impractical to provide therapy more frequently than once a month. Due to the infrequency of therapy, implementing alternative communication strategies is often highly ineffective (ACPF, 2011).

The relationships formed between the participants and caregivers create the foundation of trust for the therapeutic process. This rapport and trust need to be maintained throughout the referral process. Without it, there might be a tendency for caregivers to abandon the newly referred institution and attempts to return to the familiar. It is evident, from the data collected, that there is a strong desire amongst the therapists to make a meaningful difference in the lives of their

patients. Thus, when it appears to them that the referral process has failed, they accommodate the returning children. This is despite their cognisance that continued therapy in the health sector is insufficient, they feel it is better than receiving no therapy at all.

5.3 A general lack of resources

Time, adequate staffing and infrastructure are the resources that were identified by the participants as lacking in the public sector. High caseloads with low staff complements, accompanied by poor physical infrastructure and time constraints, resulted in increased frustration levels, low morale, and a sense of despair amongst the interviewed participants working in government institutions with children with CP.

- “... because they [central and tertiary hospitals] have the staff complement, there can be better processes and bigger projects coming out of the woodwork, but most facilities are like ours. We’re quite understaffed for the caseload that we support, and I think that affects the quality of therapy that we give ...” (HT)
- “... the fact that we are understaffed and under-resourced ... but I think it filters through to all level of resources and I think we don’t even have the sufficient step-down services available for that continuity ...” (ST)
- “Yeah, comm serves [sic; referring to community service therapists] definitely break services. So there could be a therapist at certain clinics for one year and the next year we don’t. So we build the services then afterwards that’s lost.” (CT)

The general lack of infrastructure was a dominant theme that emerged during the interviews. The sense of defeat about the current institutional facilities available for children with CP such as LSEN schools, training centres as well as stimulation centres, and the genuine concern about the lack of vocational facilities available for these children once they leave school, was palpable.

- “... so if they had therapy closer to home, where they can get more regular therapy, that would be ideal, ya. Open a school that side of the world, please!” (HT)
- “... but then after that, what in society, where in society are they supposed to fit in? Because there’s no camps [vocational facilities] that have been made available to them ... you see them as children but what kind of adult life are they going to have at this stage?” (ST)

- “Um, most of the facilities cost way more than the disability grant, which the children have, which would obviously be used towards that [vocational facility]. Um, but so, ya, it becomes a huge problem.” (ST)
- “I don’t want to think actually too much about it ’cause I’m quite scared for our children, because you know what happens with them.” (ST)

At the outset, it may appear that a simplistic solution to the challenges faced would be to place more staff in institutions to accommodate the caseload. However, given the broader complexities associated with CP, it is evident that the basic infrastructure is also lacking, such as community-based LSEN schools, training centres, stimulation centres, as well as vocational facilities to accommodate children with CP. The low socio-economic status of the serviced community also impacts the ability of institutions to provide intervention regularly, as the challenges faced by caregivers extend beyond speech-language therapy. These challenges may include financial constraints, access to transportation, nutritional deprivation, and a lack of support and family structure with the absence of one or both parents (Bradley, 2020).

Not all healthcare and educational facilities equally accommodate the varied needs of the population with CP. Without sufficient facilities, therapists are unable to refer children appropriately to a suitable facility where their specific needs will be met. Advances in medical technology have led to higher survival rates during complicated births. This statement is supported by the National Department of Health (2016) who affirmed that with improved medical technology and a higher survival rate for children with disabilities, there is an increasing number of children presenting with developmental delays and CP. These advances need to stretch beyond birth, into the lifelong need for therapeutic intervention, as well as the acknowledgement that many children living with CP may never achieve independence. The level of independence that each individual will achieve is dependent on the manner in which each of the factors contributing to the disability is addressed. These factors include external- (environmental), internal- (psychological) and task-based factors. External- and task-based factors are the factors which can most readily be addressed by means of rehabilitation, and thus offer the best opportunity to improve the independence of individuals with CP (Posluszny et al., 2017). This notion is supported by Milner et al. (1996, as cited in Saloojee et al., 2011) and Levitt and Addison (2019) who stated that CP is a lifelong condition which requires rehabilitation services to assist the child and family to function in the most effective way possible. The goal of rehabilitation of CP is not a curative one, but rather one of increased

functionality and improved capabilities of cognition, social interaction and independence. This is consistent with the ICF model which encourages that all aspects of the individual's life, including body function and structure, participation, environmental factors, as well as personal factors, are considered in the therapeutic process. These are included in determining a comprehensive treatment strategy for each individual living with CP (WHO, 2002). This creates a need for additional and appropriate facilities that are tailored to the specific needs of this population throughout their lives.

5.4 The impact that a family's low socio-economic status has on the efficacy of therapy

The effects that a low socio-economic situation has on the priority of speech-language therapy.

A consistent theme that was mentioned by participants was that some caregivers did not always prioritise speech-language therapy tasks or activities at home. The general perception that the participants held was that there was a lack of education at a caregiver level regarding the nature of CP and the importance of speech-language intervention. This perceived lack of priority was raised consistently by participants through a number of examples that highlighted many of the socio-economic difficulties faced by the caregivers.

- “There's five million other things for them to worry about, so sitting there at the end of the day and putting speech therapy first is not on their priority list. It's never going to happen.” (HT)
- “... 'cause moms will tell us, ‘Oh no, we live in two bedrooms, there's six kids, one person working ...’ Wow! This is a lot for you to deal with.” (HT)
- “So you always have to push it up to say that while you are working on what the physio and OT has given you, work on this as well, as it's the foundation of language and speech development ... it's easy for a speech therapist to fall onto last priority if you don't voice out ...” (HT)
- “I think speech, I think most allieds [sic; referring to allied healthcare professionals] are seen as um, not compulsory, as like a luxury thing, so there's no push for it. Like we don't really get taken seriously.” (HT)
- “I also think the commitment from the parents varies, there are parents who will get up at three in the morning and walk all the way with a child on the back to get to the hospital on time to try and keep to an appointment. And others do not see the need to

do that. And if they are not committed and you are working within an environment where you can see them so seldom then it just not going to, if they not complying then there is going to be no progress. And the system makes it difficult, because how do they get to the clinic, how do they get to the hospital. It isn't easy and you know if you have to choose whether to pay money to buy a bread or whether you going to use it for taxi fare, you are going to buy bread.” (ST)

Another reason for caregivers not prioritising speech-language therapy tasks at home, as reported by the participants interviewed, was the purported caregiver's perception of speech-language therapy. The participants felt as if the caregiver's understanding of their child's diagnosis, as well as their overall education about their child's condition, perpetuated a perceived lack of priority for speech-language therapy tasks. Participants reported that caregivers often placed value on tangible outcomes that they themselves understood, such as walking, talking and feeding, rather than strategies that were suitable for the child's functional capabilities.

- “... I also find moms are quite reluctant to go with like a picture-based system 'cause they want their child to talk.” (HT)
- “... moms say, ‘No, I want my child to speak.’ The parents don't understand how we understand the theory of AAC.” (HT)
- “... I'd always say to the parents what do you want out of the session? Or what do you want to see out of therapy? And they're like, ‘No, that my child can walk.’ ... I understand that 'cause that's something that you can see, it's something tangible ...” (HT)
- “... the feeding is on point you know. Then the mums disappear. And then they don't come back for therapy, and then maybe when they realise this is CP, and it means it's a lifelong condition, then they come back way later. And then like we've lost a couple of years where we could've done something with the kid.” (HT)

Lastly, the caregivers' perceptions of other institutions were brought to the fore by the participants. The participants reported that there appeared to be a perception amongst caregivers regarding certain facilities and the quality of services offered at these institutions. This affected the carryover procedures into these facilities and perpetuated the problem of high caseloads in the hospitals and clinics.

- “... the parents don’t want to go to specific schools in their area. Like, they feel like this is a better school ... it’s just the perception out there.” (ST)
- “... and it’s this weird stigma of other institutions, they don’t want to go there no matter how hard we try.” (HT)

In South Africa, immense inequalities exist in socio-economic status and are accompanied and exacerbated by inequalities in health. Whilst it is the responsibility of healthcare systems to improve the health status and to minimise health inequalities of the socio-economically disadvantaged, those who are most in need of good quality healthcare, seldom get it (Ataguba et al., 2011). In general, individuals from poorer socio-economic communities live shorter lives than those from higher income communities as they are at greater risk of poor health, illness and disability (Mackenbach, 2015).

The first point of intervention for any child with CP is the primary caregiver. Taking into consideration the challenges that these caregivers face is an important initial step in establishing the rapport required for effective intervention to occur. For caregivers burdened with the daily struggles that come with a low socio-economic status, building that relationship may be much more difficult. Although the perceptions of the participants suggest that caregivers often fail to prioritise speech-language therapy tasks at home, the realities on the ground faced by caregivers, particularly those struggling with the burdens of a low socio-economic position, may make it near impossible for them to prioritise these therapeutic interventions.

In South Africa, the public health sector is the only treatment option available to caregivers without financial means. Based on a report by the Council of Medical Schemes (2016), only 16% of South Africans are members of a medical aid scheme; implying that approximately 84% of the population is reliant on the network of public hospitals and community health centres (Council for Medical Schemes, 2016). Similarly, the rehabilitation of children with CP in South Africa is largely facilitated through this network.

Due to the nature of rehabilitation service provision in the public healthcare setting, many of the intervention strategies include group therapy. These sessions invariably become support groups for the caregivers and provide opportunities for education, increasing awareness and general acceptance of the realities of the condition. It is not uncommon for caregivers to fail to comprehend fully the severity of their child’s impairment, particularly in the younger years (Jindal et al., 2018). These support groups provide opportunities for caregivers to share their

journeys with one another. According to the participants interviewed, ‘veteran’ members of the group are able to provide credible insight into these realities. It was felt by some participants that these conversations strongly influence the manner in which a caregiver attempts to engage with the system. Beliefs and experiences of shortcomings at specific institutions will deter caregivers from accepting placement at such institutions. Furthermore, barriers in accessibility perpetuate the idea that low levels of service are to be expected. This was reiterated by a participant who overheard a conversation between two caregivers: “... and I actually overheard her saying to the other mom, no, that’s normal, seven years is a normal time to wait for your child to be put into [primary] school.” (HT). This implies that the caregiver had to wait seven years for school placement after application, which typically happens when a child turns six years of age. Therefore, the child was only placed in a formal education setting at thirteen years of age.

5.5 The chasm between health and education and the distrust it creates

Challenges surrounding the effective implementation of the referral pathway system.

A consistent theme that emerged from the data, highlighted the gap between the GDH and the GDE. The participants reported that this gap resulted in a belief that the ‘transfer into the next stage of life’ will fail. Some participants stated that the caregivers experienced apprehension in leaving the hospital and/or clinic setting and entering the education system. The participants expressed that the fear of the unknown accompanied by the slow process, such as waiting lists at the districts of the education sector, resulted in delayed procedures and a reluctance for caregivers to move from the familiar.

- “A lot of valuable time goes wasted and they will tell the parents for example from another district that the child will go to this school, the child is placed on a waiting list. Then two years later this child is still not in a school. The child is on a waiting list. There is no real waiting list there that can be shown, there’s no contact and the child is staying home, and their condition deteriorates ’cause no therapy has been provided, no stimulation has been provided due to the system being so slow.” (ST)
- “So we’d refer them as early as possible because of waiting times, and then they get sent back to us saying oh no, the child is not six yet. So we’ve had that issue quite a bit with the DoE where we’ve had to wait a little bit or writing letters to DoE like especially like even though they’re four, we wanna start the process because we know the long

waiting times ... so we have had that issue with the waiting times and just getting them seen a bit sooner would be better.” (CT)

- “... I asked the parents what happened. And then they will be like, no, they [district] took our forms and they asked us to collect some information, and we had given it to them, and no-one has gotten back to us.” (HT)
- “I mean, you don’t get feedback. You almost have to fight or burn a building down to get a response [from district].” (ST)
- “One mum said it’s like going there [district] and like speaking to an answering machine, as in hello, leave a message, goodbye.” (HT)

Consequences of a perceived failing referral pathway system.

The hospital- and clinic-based participants expressed feelings of frustration with this gap between the two departments. As the children were not being transferred efficiently into the GDE, the participants were forced to keep these children on their caseloads to prevent regression of therapeutic progress from occurring. The participants highlighted the lack of communication between the two departments, and the further hinderance that this caused.

- “We are actually struggling from putting them in schools because they need ongoing intervention. So here, we are working on seeing them even past the age of six until they are placed in a school, because we are trying to keep what we have [progress].” (HT)
- “It essentially boils down to this gap, of receiving therapy to six years then we don’t know where they are going, where they are placed, if they are receiving the services, that’s the biggest thing. Communication.” (HT)
- “Our biggest concern is the waiting lists. The waiting lists from here to the Department of Education. We’re not happy, so that’s why we decided to keep the patients until they are placed in a school or until they receive the care they need.” (CT)
- “The gap between health and education is so big, it shouldn’t be that big. Our patients go from here, we’ve taken care of them, now please can you help us and carry on this treatment? There’s no communication and at the end of the day both play such an important role ... the gap between education and health must be closed ...” (HT)

Improved communication as a solution to addressing the perceived failings in the referral pathway.

A further finding was that there was a desire of hospital-, clinic-, as well as school-based participants to close this chasm that has been created between the two departments. They were aware that improved communication between therapists during carryover procedures may in turn improve handover of the child's care.

- “I think getting people from Department of Health and Department of Education sitting down and saying let's develop the link between the two and not have health this side, education that side. But a middle point with people who are eager on actually developing that ... I think that would be a good starting point.” (HT)
- “So they [health and education therapists] kind of need to almost get together. If I was the minister of health and education, I'd work kind of together as far as the therapists go, and they almost need to get together a group of experts to say how do we fix this mess that it's become.” (ST)
- “But it's knowledge. I don't think the hospitals and clinics know about all the special schools in their area and which children they take, because I've had somebody ... saying oh, you never take my children. Well, you're sending the wrong ones and you don't understand that.” (ST)

The overwhelming and passionate responses from all participants interviewed highlighted a congruent perception that there is an undeniable gap between the GDH and the GDE. There was reportedly a well-established relationship between the hospitals and the clinics. The participants stated that they understand the abilities and capabilities of each other in these settings. It is also reportedly a generally collaborative relationship. In contrast, there was a perception amongst the participants that there is a limited relationship between the health-based therapists and those therapists working in schools. Furthermore, the health-based therapists expressed that they lacked knowledge and resources that would inform them as to what facilities and therapists are available at schools. This lack of knowledge arose, in their opinion, due to the perceived lack of communication between therapists working in the GDH and therapists working in the GDE.

Identifying this chasm, participants working on both sides have attempted various strategies to traverse this divide, sometimes with greater or lesser success. A noteworthy frustration was

that the participants encountered a sustained administrative obstruction to their efforts, leading to the perception that officials working at the GDE lack the clinical understanding required to appropriately place children with the complex condition of CP into suitable schools.

The developing brain has a limited window of opportunity to acquire certain foundational skills, which greatly influence the future outcomes of later therapeutic interventions (Ismail et al., 2017). According to the National Department of Health's *Framework and Strategy for Disability and Rehabilitation Services in South Africa* (2016), rehabilitation should be decentralised and begin as early as possible and should extend from community to tertiary and specialised rehabilitation levels. Within the health sector, the infrequent therapy sessions, as reported by the participants, are not conducive to achieving satisfactory therapeutic results. As such, the importance of timeous placement in the appropriate schooling environment cannot be understated. The Department of Basic Education's policy guidelines (2014a) states the following: "Schools must further incrementally introduce early intervention programmes and classes for learners from the age of three. This is particularly important for children with intellectual disability, visual impairment, autism, communication impairments, physical disability and those who are Deaf and dependent on specialist interventions at as early an age as possible." (Department of Basic Education, 2014a).

As reported by some of the participants that were interviewed, the therapists are often excluded from the school admissions process, as departmental procedures rely on the simplified classification of cognitive abilities of each child, from a limited group of medical professionals. Departmental policy specifically states that the medical assessment on its own must not be used to justify admission to a special school. The assessment should be conducted by all the relevant professionals (Department of Basic Education, 2014a). Without access to the in-depth diagnostic assessments performed by allied health professionals, it is unsurprising that inappropriate school placements for children with CP are common. The consequences of this chasm may result in a lack of trust amongst caregivers, and therefore an increased likelihood of returning to hospitals and clinics, which, in turn, exacerbates the challenges associated with high caseloads, perpetuating the cycle.

5.6 Perceived lack of LSEN (learners with special educational needs) school knowledge at Department of Education

The perceived lack of appropriate direction from the Department of Education.

A strained relationship with the GDE, as a bureaucratic collective, was communicated by most of the participants interviewed. Participants working in school settings specifically, expressed that they felt as if the GDE did not look at the best interest of the children with CP during the admissions process. It was reported by the participants that they felt as if the GDE had no clear idea as to what cognitive and physical level of functioning would be appropriate for admission into specific LSEN schools. This constituted an important aspect of the narrative. Participants conveyed dissatisfaction about a number of facets, namely a lack of urgency in LSEN school placement, inappropriate admissions into LSEN schools, inappropriate weighting of learners and the consequences this had on staffing, the efficacy of the curriculum, as well as the lack of infrastructure.

- “... the Department of Education often won’t accept our suggestion and um, we end up keeping the kids, even if they’re not correctly placed here [LSEN school].” (ST)
- “The Education Department came down on us like a ton of bricks and said that what we were doing was entirely wrong [screening assessments] and we weren’t allowed to do it any longer. We weren’t allowed to give parents names of schools at all. We were not allowed to do any forms of assessments or anything until the child was placed in the school.” (ST)
- “Then we say ‘no’ and they [district] like no, you have to [admit children].” (ST)
- “But the severe intellectually disabled children would be at the school that caters for them, and there are many SID [Severe Intellectual Disability] schools that have correct programmes for them. So ... we [a Mild/Moderate Intellectual Disability school] currently have a lot of children that are incorrectly placed here by the Department of Education.” (ST)
- “... everybody kind of seems to do their own thing depending on the district they fall under. So unfortunately, we fall under a district that didn’t like the way we did things. Other people fall under districts that don’t mind that they do things the correct way.” (ST)

The consequential result of inappropriate placement of children in LSEN schools.

Participants working in the school settings reported that the weighting of learners in LSEN schools affected the staffing in the school, from year to year. Weighting refers the child-to-educator/support staff ratio that is specific to the disability classification of each learner. They stated that if the schools did not admit appropriately weighted learners, they did not achieve the correct child-to-staff ratio, and this resulted in fewer allocations of therapists and teachers in schools.

- “The Department of Education needs to realise the importance of therapists and do their weighting properly when they weight those learners. We’ve been fighting this for years and years and years to get a proper weighting to get a proper establishment, so we can have more therapists, and we have had no results whatsoever.” (ST)
- “But for us, we need fifteen to cover a teacher, so at the moment, the weighting doesn’t match. So we’re paying it out of our SGB [school governing body] money to pay for the teacher, which we’ve been told by district and head office you will [emphasis placed] place these children, you will [emphasis placed] take these children. So, they need to also look at staffing, more than anything, I think that’s a big issue.” (ST)

The participants felt that, due to the inappropriate referrals for admissions into LSEN schools, children were not benefitting from the curriculum offered by the schools. They stated that the educators in the schools were then required to modify the curriculum to best suit the needs of the child. The participants expressed frustration as this was not always achievable due to the low cognitive functioning level of some children. They reported that no matter how much the curriculum was modified, the children were still required to meet curriculum outcomes. A sense of irritation and defeat was evident amongst the participants in this situation, as accommodating children with lower cognitive abilities was detrimental to the learning of the other children with higher cognitive abilities in the school.

- “Just in terms of ages. I mean to have a seven-year-old with a fifteen-year-old, it’s, it’s [pause] the children are very different ages then. And also, because, so they, they start with different behaviours a lot earlier, the children that are more cognitively impaired, so it can become a bit dangerous [laughs] for the older children to be with the younger children. They’re more aggressive, they’re more dominant in a class, and for the little

child it can become quite scary. So, you know, hormones start earlier unfortunately in our children.” (ST)

- “We have to have special needs schools and we have to be able to have more say in who is in the different special needs schools, because there are different special needs schools for the Deaf, for the blind, cerebral palsied, but we work within a cognitive limit, so ya.” (ST)

The exclusion of the speech-language therapist from the referral process.

Furthermore, the participants expressed that they felt as if the GDE placed children into LSEN schools based on a simplistic hospital communication that lacked any detail as to how such a diagnosis of mild, moderate, severe or profound intellectual disability, was reached. The participants reported that there was often a discrepancy between the diagnosis made by the referral team at the GDH and the assessment results reached by the participants at the school. They also expressed frustration at a lack of detail and supporting documentation for children referred to their schools.

- “Our frustration there as well is that the doctors don’t always, don’t usually, accurately diagnose their cognitive abilities, and we are forced to admit children based on what the doctors put as the cognitive abilities of the child.” (ST)
- “I think sometimes the therapists aren’t even part of that neurodevelopmental team. ’Cause previously we used to get a summary of what each therapist had thought, um, and then the paediatric neurodevelopmental paediatrician’s report, um [pause] now we just get a note, um with the letterhead of the hospital basically just saying things like Diagnosis. MID. CP. Ya.” (ST)

The participants reported that the appropriate placement of children with CP into LSEN schools hinges around the accurate assessment of the child’s level of cognitive ability. Accurately determining the child’s cognitive level of functioning requires the collaboration of both medical and allied health professionals (Sulkes, 2020). Reportedly, children being referred to LSEN schools are not arriving with sufficient supporting documentation and reports, which suggests that a complete or appropriate assessment has not been administered. The lack of detailed reports, coupled with what becomes suspected as an incorrect diagnosis of cognitive ability, leads to the perception amongst participants that assessments were completed without consultation of the MDT.

Entirely different curriculums need to be formulated for the varying levels of cognitive ability, as reported in The Department of Basic Education's *Guidelines to Ensure Quality Education and Support on Special Schools and Special Schools Resource Centres* (2014a). Although children with CP have varying physical disabilities, establishing a curriculum is not influenced by these variations, but rather by the variations in the individual child's ability to grasp key concepts.

The GDE's policy on employing therapists within a school determines the number of therapists employed, based on the weighting of the learners at that school. The perception amongst the participants seems to be that there is a priority at the GDE to place numbers of children at schools over and above placing the children correctly. This is contrary to departmental policy which states that children should be admitted into special schools aligned with the area of support and specialisation offered at the school (Department of Basic Education, 2014a). The lack of correctly weighted children in schools is detrimental to the process of establishing infrastructure. Departmental policy guidelines (Department of Basic Education, 2014a) state that only qualified specialists that are appropriate to the specific programmes offered at the school should be employed at the school. Individual LSEN schools which, over time, have developed specific resources to accommodate the needs of learners with a specific classification of cognitive ability, are finding that they no longer have a large enough caseload of appropriately weighted children to maintain therapy posts. This was reiterated when a participant stated the following: "I think we've become quite diverse. The majority is still cerebral palsy, but it is changing, in terms of it is becoming lower functioning, which is less academic ..." (ST).

Participants reported that there was often a resistance by the GDE when the participants submitted feedback to the GDE regarding a specific case that suggests that a school was not a suitable placement. According to the departmental guidelines (Department of Basic Education, 2014a) appropriateness of placement should be reviewed annually or at least every two years. It became evident through the interview process with participants working in school settings specifically, that, although the different schools were under the directive of different district offices, there was a common experience that lines of communication were not bidirectional. It was reported that the districts are prescriptive and 'force' placements even when a compelling argument is made that such placements were inappropriate given the services offered by the school. This is consistent with and ties in with the experiences of participants working in the

hospital settings. The perception amongst the hospital-based participants interviewed was that the lack of well-resourced schools catering to all the various levels of cognitive ability of children with CP, perpetuates the problem of inappropriate placement, given that the department does not have sufficient placements for the number of applications they are receiving.

Whilst the reason that the GDE appears to act in a manner contrary to its departmental policy was not investigated in this study, the underlying perceptions of the participants were that there is a general lack of understanding by the administrators at the GDE as to the nature of CP and what therapeutic interventions are required to ensure the best possible outcomes for this population. The overall effects of this perceived lack of understanding seems to be that there is an inappropriate distribution of resources, a lack of direction in the establishment of new infrastructure, and the destruction of the cohesive elements within the system.

5.7 Summary

Speech-language therapy for children with CP is not a quick-fix. The participants focused on small, incremental goals set out to achieve an ultimately improved quality of life in the areas needed most. This process is individualised to each child and it is particularly relevant to acknowledge this when handover occurs from one institution to the next. In acknowledging the small victories and breakthroughs, participants expressed a definite desire to administer effective therapy. Once the participants developed an effective treatment plan, there was a desire amongst the participants to ensure that the gains in therapy were not lost. Institutional procedures were thus often altered to accommodate these aspirations, despite the participants' cognisance that these alterations were not aligned with policy mandated by the GDH or GDE. This strong desire manifested as a response to many of the institutional challenges faced by participants on a day-to-day basis. Given that CP is a lifelong condition that requires ongoing intervention, it is paramount that the government provide adequate staffing and infrastructure within public hospitals, clinics and schools. The provision of specialised facilities with adequate staff for this population, is an ongoing challenge. Further to the challenges caused by a general lack of resources, another obstacle faced by participants was the impact that a client's low socio-economic status has on the efficacy of therapy. Therapy for children with CP is not given in isolation and is intertwined with the socio-economic status of the family and the community receiving the service. Effective service delivery can only be administered if rapport is established with caregivers, education about the condition is offered, emotional support is

provided, and therapeutic strategies acknowledge the day-to-day struggles of each family. Given that each child with CP is unique, it reinforces the importance of the referral process from one institution to the next. By far the most prominent theme which emerged was that of the chasm between the health and education sectors. There was an overwhelming sense of frustration from both sides of the divide that highlighted the desperate need to address the lack of communication between the health and education sectors. A recurring perception of the participants was that, in the GDE's priority to place children in schools, the Department failed to address whether placement met the specific needs of the child. Failure to place children into schools where the existing resources and infrastructure are aligned with the specific needs of the child, placed enormous strain on the referral process, with outcomes such as: increased caseloads in the health sector; strains on the curriculum; ineffective deployment of resources; and a breakdown in trust between the community and the system.

Chapter 6: Conclusion

6.1 Summary

This study sought to investigate the perceptions of SLTs working in the public health and education sectors, in the greater Johannesburg region, about the services they provide to children with CP, from birth to six years of age. Specifically, the study focused on institutional procedures and how closely these aligned with current policy in the Gauteng Departments of Health and Education, as well as understanding the challenges faced by therapists in delivering services to the community. This study aimed to achieve an understanding of the therapists' perceptions around the effectiveness of interinstitutional handover. The handover of patient care between hospital and clinic therapists and the carryover of care from the health sector into the education sector were investigated. Using a qualitative approach, the researcher interviewed the therapists in the region working with children with CP by means of focus groups conducted at the various institutions. In these focus groups, therapists were given the opportunity to give their account of their lived experiences in interactive discussions.

By far the most prominent theme which emerged from the analysis of the data collected, is that of a perceived chasm between the DoH and the DoE in the referral process of children. There was an overwhelming sense of frustration from participants working in both sectors highlighting the desperate need to address the perceived lack of communication between the health and education sectors in the region. The frustration appeared to be with the administrators at the district level of the education sector. Various strategies and institution-based procedures were employed by the participants to deal with the day-to-day challenges that are associated with working in the public sector. The researcher found that interinstitutional collaboration assists in the mitigation of therapeutic regression of each child that can occur as a result of handover from one institution to the next. Where given the opportunity, relationships between participants at different institutions in Gauteng Region A have been created. However, administrative hurdles in the provincial DoH and the DoE make it difficult for collaborative interinstitutional relationships to develop.

Participants working at public hospitals reported that they were not asked to provide detailed progress reports of children for the purposes of LSEN school placement, whilst participants working at LSEN schools were reportedly not consulted during the admissions process of each child. The lack of consultation was attributed to a perceived lack of willingness by the DoE to

engage in collaborative protocols with SLTs working with children with CP. It can therefore be concluded that a failure of the system to place children into LSEN schools that cater for their specific needs, is detrimental in establishing and maintaining the effectiveness of those institutions. Effective policy implementation, specifically at the GDE, could be instrumental in removing barriers to communication and ensuring that therapeutic gains made at hospital and clinic levels are carried over reliably into the therapeutic environment at LSEN schools in Gauteng. Furthermore, a consultative process with allied health professions, including SLTs, occupational therapists, physiotherapists, as well as educational psychologists working at LSEN schools, could substantially reduce the incidence of inappropriate admissions.

6.2 Recommendations for future research

The study revealed that SLTs working at hospitals, clinics and schools in Gauteng Region A experience a lack of communication between the DoH and DoE in the referral process of school-aged children with CP into LSEN schools, from hospitals or clinics. As a result, improved communication between the two departments is encouraged. As the DoE is responsible for placing children in schools, further research should be conducted at the DoE to further investigate the details of the perceived chasm. With the insights obtained from such an investigation, further recommendations can be made for the implementation of improved communication procedures and strategies between institutions. These recommendations could include the formulation, implementation, and evaluation of programmes to improve communication between the provincial Departments of Health and Education. This communication needs to be bidirectional and create opportunities for the DoE to inform the DoH of the services available in LSEN schools, and for the DoH to be able to share relevant referral information about a child when assisting with school placement. This communication should be conducted in a manner that fosters trust.

Although the study was set out to investigate the (dis)continuity of speech-language therapy services for children with CP in the public sector specifically, the results highlighted that some of the contributing factors fall outside the purview of SLTs. Further research could also include investigating the perceptions of the doctors making diagnoses and referring to the educational districts for LSEN school placement. Their perceptions of the various LSEN schools and motivations for recommending one school as opposed to another, can further increase understanding regarding and possible improvement of the referral process in general.

Lastly, further investigations similar to the current study should be conducted with other health professionals, such as physiotherapists and occupational therapists working in the Departments of Health and Education in Gauteng as well as other provinces, to establish whether there is a correlation in results found in this study.

6.3 Clinical implications of findings

The study revealed that there is a perceived gap in communication between the DoH and the DoE in the referral process of children with CP from the hospital or clinic setting, into the school environment. Improved interdepartmental communication is thus encouraged. This may result in improved collaboration between professionals working in health and those working in education.

The results of this study suggest that a cohesive plan needs to be formulated and executed in order to bridge this chasm. This may facilitate communication, collaboration, education, as well as resource-sharing between the two departments. Bidirectional communication enabled by a cohesive plan may improve the referral pathway and result in improved handover and carryover of therapeutic strategies into appropriate LSEN schools, preventing children from ‘falling through the cracks’ (HT). This will also assist caregivers in making the transition from the health setting into the education setting and improve their trust in the ‘system’ and individual institutions.

6.4 Limitations

As phenomenological research is qualitative, focusing rather on attaining a depth of understanding into the lived experiences of participants, the number of participants is necessarily limited. The limited sample size of eight focus groups was however representative of the region under investigation, as many therapists within the purposive sampling strategy agreed to participate in the study. This yielded fundamental insights into the perceptions of the participants within the region with data saturation being achieved, giving greater credence to the findings. This is however insufficient to draw conclusions about the overall practices and procedures of therapists working in other regions and provinces.

The subjective nature of the interpretative process means that the data could have produced different findings if it had been analysed by a different researcher. The researcher may have

introduced bias in the analysis of the data, as it relied on interpretative processes. To reduce such bias, the following strategies were followed:

- The researcher strove to bracket personal views and experiences through continuous reflection.
- Trustworthiness of themes identified in the analytic process was demonstrated through verbatim quotations from the raw data.
- Every effort was made to keep the transcriptions of interviews faithful to the material recorded. Details of these efforts can be found in the Methodology chapter of this paper.
- Member checking was conducted to improve the rigour of the study.

“It is not beyond our power to create a world in which all children have access to a good education. Those who do not believe this have small imaginations.” (Nelson Mandela).

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World Health Organisation (WHO). (2007). *International classification of functioning, disability and health: Children & youth version; ICF-CY*. World Health Organisation.

World Health Organisation (WHO). (2013). *How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment.* World Health Organisation. <https://www.who.int/classifications/drafticfpracticalmanual2.pdf?ua=1>

World Health Organisation (WHO). (2016). *Department of maternal, newborn, child and adolescent health (MCA): Progress report 2014–15* [Progress Report]. World Health Organisation. <https://apps.who.int/iris/handle/10665/205631>

Appendix A: Epoché

The process of bracketing, which is essential in phenomenological research, can be facilitated by keeping a journal of the process where the researcher's personal shifts can be recorded as they occur (Tufford & Newman, 2010). Developing a self-reflexive stance whereby the researcher can demonstrate an awareness of her role in the research process contributes positively towards the rigour of the project (Tufford & Newman, 2010). The process allows the researcher to mitigate her own initially unacknowledged preconceptions and allows her to reach greater levels of self-awareness across all stages of qualitative research. These stages include selecting a topic and study population, designing the interview, collecting and interpreting data, as well as reporting findings (Tufford & Newman, 2010). The opportunity for continuous in-depth reflection may improve the comprehension of the research and facilitate more insightful and multifaceted analysis and results. The contents of the section that follows were derived from such journalling across the stages of the research process.

Before Data Collection

I qualified as Speech-Language Therapist and Audiologist at the end of 2007. In January 2008 I began my community service year at Hillbrow Community Health Clinic (CHC) (part of the Johannesburg Metro Region A clinics). This experience was exciting and terrifying at the same time. I was expected to run the department on my own with no proper handover of clinical procedures or caseload, and no senior therapist to guide my decision-making on a day-to-day basis. I was left to treat complicated cases (mostly children with cerebral palsy) whilst relying on my undergraduate textbooks and my instincts. I constantly felt overwhelmed and in a state of panic with every new child with cerebral palsy that walked through the door. In March of that year I decided to ask for help. I called a speech-language therapist working at Charlotte Maxeke Johannesburg Academic Hospital and asked permission to shadow her for the day. She kindly agreed and was able to provide me with some tools to see me through the year. With no permanent position available at the clinic, I was left with little alternative after completing my year of community service other than to find employment elsewhere. I was offered a job in January 2009 at Forest Town School, by my undergraduate clinical supervisor and mentor. It is a public school for children with special educational needs (LSEN), ranging from five to eighteen years old. The primary school accommodates children up until Grade 7, whilst the vocational section of the school accommodates children up to eighteen years of age. My caseload consisted mostly of children presenting with cerebral palsy and other learning

difficulties. I was mentored and guided through treating this population and it has moulded me into the therapist I am today. I completed the Basic eight-week NDT (Neurodevelopmental Therapy) course in 2010, which has changed the current way I assess and treat a child with cerebral palsy. I have been working at the school for 11 years now. My mentors have retired, and I am currently the acting head of the speech therapy department.

The education sector does however not come without its own challenges and shortcomings. The school would often receive children from the health sector with little to no paperwork, nor reports or a clear diagnosis. Many of these children would arrive after the age of six years, with no assistive devices or history of previous therapy. This increased my frustrations with a system that I perceived to be ‘broken.’ I had a strong desire to ‘fix’ it and change the way things were working, albeit from a naïve and idealistic viewpoint. The idea that one minor cog in the wheel of the entire system that is the education sector can change the way things worked now seems far-fetched and incomprehensible. It is through the research process that I am able to take the first step towards identifying and describing the problem, by gaining greater insight into the systemic challenges faced throughout the referral pathway.

Before embarking on data collection, my one-year experience in the health sector shaped my initial expectation of this study. Due to my experience, I was expecting to find a gap at clinic level when it came to the referral pathway from health into education and the continuity of speech-language therapy services offered at the CHCs. I thought that once the child left the central or tertiary hospitals and entered into the CHC setting, the parents and children would be met with an inexperienced therapist, if one at all, and as a result, not receive the care they needed. This would result in a lack of carryover into the education sector once the child was of school-going age. Due to the lack of guidance and handover I received in my community service year, and the anecdotal evidence that newly qualified, inexperienced therapists were coming into the clinics every year to complete their community service with little to no guidance, I assumed that this would result in the gap that I was experiencing as a therapist at a public LSEN school.

Being an inexperienced researcher, particularly in the field of qualitative research, I felt it was important to gain some in-depth understanding into qualitative research procedures. I attended a course presented by an expert in the field of qualitative research methods. It was during this course that I was offered the opportunity to conduct a pilot study to assist in the refinement of my interviewing skills and to determine the suitability of my interview guide. It was during

this process that I gained valuable insight into the emotional responses of the two speech-language therapists whom I interviewed. One of the participants worked at a CHC in the six months prior to the interview, whilst the other participant worked at a public LSEN school. During the interviewing process, I gained experience on how best to channel the participants' responses and allow them to connect with me and share their lived experiences within a safe space.

During Data Collection

I started data collection by interviewing participants at institutions that gave me permission first to conduct the research. There was no preset order in which the interviews took place. In my first interview, it became apparent that the participant was initially anxious, however, upon revealing that this study was investigating the health system and not an intervention study, there seemed to be a palpable change in her demeanour and attitude towards the interview process. Subsequent interviews unfolded in a similar manner. Since I have been working as a public servant for many years, it was easier to establish rapport early on and the participants appeared to be receptive to sharing their experiences. Despite the initial reluctance I experienced at the start of the interviews, as the discussions developed the conversations became rather emotional in nature and triggered an enthusiastic response. This led to the participants speaking louder and over each other in an attempt to get themselves heard. It felt as if they could not get their ideas out fast enough. I sensed the passion they had for the jobs they were doing and their genuine desire to make a difference in the lives of their patients. At the end of every interview, the participants expressed gratitude at having an opportunity to have someone listen to them and act as a sounding board.

As I completed more interviews, I started realising that my preconceived ideas about the procedures in the health sector with regard to the referral pathway and the carryover of speech-language therapy services offered to children with cerebral palsy, were misplaced. I soon realised that there was a somewhat collaborative relationship between the therapists working in hospital settings and those working in clinic settings. This collaborative relationship may have existed whilst I was working in the public health sector eleven years ago, however, this was unfortunately not my experience. The participants stated that they had made attempts to hand over caseloads from one institution to the next and indicated that there was a seemingly open relationship between most therapists working in their regional public health sector. This made me anxious. The gap that I was expecting to find was not where I thought it would be.

Then why do I experience what I do in education? Why do I perceive a lack of intervention and carryover once children are admitted into the school? It was not until I started interviewing the school therapists that I realised where the chasm exists. The perceived communication chasm exists between the Department of Health and the Department of Education in the referral process of children with cerebral palsy from the hospital or clinic setting, into the school environment. It was an eye-opening experience and one I was grateful to discover. I appreciate the value and nature of the scientific research process and the valuable knowledge and lessons I have gained through this experience.

During Data Analysis

In qualitative research, the researcher is the instrument of data collection and analysis. In an attempt to understand my own biases, I could be more sensitive towards my preconceptions in the interview process. Furthermore, I had to learn to be cognisant of the blind spots that may inevitably occur in the analysis process. On analysis, it was exciting to see that the results did not mirror those preconceived notions with which I entered the study. The consistent themes that emerged reassured me that the entire process was valuable to both the me and the participants.

Appendix B: HREC Approval



Approved with Stipulations

New Application

18/06/2019

Project ID: 10244

HREC Reference #: S19/05/093

Title: Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in South Africa, Specifically, the Greater Johannesburg Region, from Birth to Six Years.

Dear Mrs Martha Lydall,

The **New Application** received on 22/05/2019 11:02 was reviewed by members of the **Health Research Ethics Committee 2** via Minimal Risk Review procedures on 18/06/2019 and was approved with stipulations.

Please note the following information about your approved research protocol:

Protocol Approval Period: **18-June-2019 – 17-June 2020.**

The stipulations of your ethics approval are as follows:

1. Please consider changing the title, using the terms "South-Africa" can be misleading.
2. Please make sure that you explain how participants will be anonymized, for example, the use of participant code.
3. How will you ensure anonymity in the case of individual interviews? If there is only one SLT in the clinic, they will be easily identified if the place of work is going to be mentioned.
4. Please provide a reason for collecting "age" of participants as part of the data set.

Please remember to use your project ID [10244] and ethics reference number [S19/05/093] on any documents or correspondence with the HREC concerning your research protocol.

Translation of the consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note you can submit your progress report through the online ethics application process, available at: <https://apply.ethics.sun.ac.za> and the application should be submitted to the Committee before the year has expired. Please see [Forms and Instructions](#) on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics)

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mr. Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1) REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:

IRB0005240 (HREC1) IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the [World Medical Association \(2013\) Declaration of Helsinki](#); [Ethical Principles for Medical Research Involving Human Subjects](#); the South African Department of Health (2006). [Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix C: Application to NHRD



Martha Lydall <[REDACTED]>

NHRD Submission Received - Automated Message (DO-NOT-REPLY)

NHRD Support (DO NOT REPLY) <nhrd@hst.org.za>

Mon, Jun 24, 2019 at 6:56 PM

To: [REDACTED]

Good day Martha Lydall

This is an automated email sent to you to confirm that we have received your research proposal submission (GP_201906_027). Please do not reply to this email.

Please monitor your application on a weekly basis for feedback from your Provincial Health Research Committee. The turnaround time to receive a response should be 6-8 weeks. If you have not heard from the PHRC in this time, please contact your relevant PHRC using the contact details on <https://nhrd.hst.org.za/Home/Resources>. You can view the status of your application at any time by visiting the NHRD website at <http://nhrd.hst.org.za>.

Kind regards
NHRD Support Team

Disclaimer and confidentiality note:

Everything in this e-mail and any attachments relating to the official business of Health Systems Trust (HST) is proprietary to HST. It is confidential, legally privileged and protected by law. HST does not own and endorse any other content. Views and opinions are those of the sender unless clearly stated as being that of HST. The person/s addressed in the e-mail is/are the sole authorised recipient/s. Please notify the sender immediately if this message has unintentionally reached you and do not read, disclose or use the content in any way. HST cannot assure that the integrity of this communication has been maintained nor that it is free of errors, virus, interception or interference.

Appendix D: GDE Research Approval Letter


GAUTENG PROVINCE

 Department: Education
 REPUBLIC OF SOUTH AFRICA

8/4/4/1/2

GDE RESEARCH APPROVAL LETTER

Date:	01 June 2020
Validity of Research Approval:	04 February 2020 – 30 September 2020 2019/457
Name of Researcher:	Lydall M
Address of Researcher:	50A Glenluce Drive Douglasdale
Telephone Number:	0837041650
Email address:	Martha.lydall@gmail.com
Research Topic:	Investigate the perceptions of speech – language Therapist working in the Public Health and Education Sectors, about the services they provide to Children with Cerebral palsy in the greater Johannesburg region ,Form Birth to Six Years.
Type of qualification	M in speech –Language therapy
Number and type of schools:	3 LSEN School
District/s/HO	Johannesburg South, Johannesburg Central, Johannesburg West

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

Making education a societal priority

Office of the Director: Education Research and Knowledge Management

 7th Floor, 17 Simmonds Street, Johannesburg, 2001

Tel: (011) 355 0488

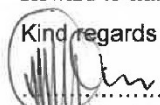
 Email: Faith.Tshabalala@gauteng.gov.za

 Website: www.education.gpg.gov.za

2. The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.
3. A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.
4. A letter / document that outline the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.
5. The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.
6. Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.
7. Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.
8. Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.
9. It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.
10. The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.
11. The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.
12. On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.
13. The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.
14. Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards



Mngumani Mukatuni

Acting CES: Education Research and Knowledge Management

DATE:01 June 2020.....

Office of the Director: Education Research and Knowledge Management

7th Floor, 17 Simmonds Street, Johannesburg, 2001

Tel: (011) 355 0488

Email: Faith.Tshabalala@gauteng.gov.za

Website: www.education.gpg.gov.za

Appendix E: Permission Forms from Institutions



Date: 21/06/2019
To: Head of Institution

RE: Permission to Conduct Research Study

To Whom It May Concern

I am writing to request permission to conduct a research study at your institution. I am currently enrolled in the Masters for Speech-Language Therapy at Stellenbosch University in the Western Cape, and am in the process of writing my Master's Thesis. The study is entitled: Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to Six Years.

I hope that the hospital administration will allow me to recruit Speech-Language Therapists working with children with cerebral palsy from the hospital to anonymously participate in a focus group. Interested Speech-Language Therapists, who volunteer to participate, will be given a consent form to be signed (copy enclosed) and returned to the primary researcher at the beginning of the focus group.

If approval is granted, the primary researcher will conduct focus groups and one-to-one interviews with speech-language therapists working with children with cerebral palsy, in public hospitals, clinics and schools, in order to gain insight into the everyday realities experienced by these professionals. These focus groups and interviews will be held at the therapists' place of work and will be audio recorded for transcription and analysis purposes. All information shared will be treated confidentially.

Your approval to conduct this study will be greatly appreciated. I will follow up with a telephone call next week and would be happy to answer any questions or concerns that you may have at that time. You may contact me at my email address: Martha.lydall@gmail.com

If you agree, kindly sign below and return the signed form to the email address provided. Alternatively, kindly submit a signed letter of permission on your institution's letterhead acknowledging your consent and permission for me to conduct this study at your institution.

Sincerely,

Martha Lydall
(Speech-Language Therapist & Audiologist)

Enclosures
cc: Dr. B. Gerber (Supervisor), Stellenbosch University

Approved by:

mrs Reesa Sadler

Print your name and title here

BS

Signature

4/11/19

Date



Date: 21/06/2019
To: Head of Institution

RE: Permission to Conduct Research Study

To Whom It May Concern

I am writing to request permission to conduct a research study at your institution. I am currently enrolled in the Masters for Speech-Language Therapy at Stellenbosch University in the Western Cape, and am in the process of writing my Master's Thesis. The study is entitled: Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to Six Years.

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If you agree, kindly sign below and return the signed form to the email address provided. Alternatively, kindly submit a signed letter of permission on your institution's letterhead acknowledging your consent and permission for me to conduct this study at your institution.

Sincerely,

Martha Lydall
(Speech-Language Therapist & Audiologist)

Enclosures
cc: Dr. B. Gerber (Supervisor), Stellenbosch University



Approved by:

Ms. L. COETZER

Print your name and title here

[Signature]

Signature

2019-11-12

Date



Date: 21/06/2019

To: Principal of Forest Town School

RE: Permission to Conduct Research Study

I am writing to request permission to conduct a research study at your institution. I am currently enrolled in the Masters for Speech-Language Therapy at Stellenbosch University in the Western Cape, and am in the process of writing my Master's Thesis. The study is entitled: Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to Six Years.

I hope that the hospital administration will allow me to recruit Speech-Language Therapists working with children with cerebral palsy from the hospital to anonymously participate in a focus group. Interested Speech-Language Therapists, who volunteer to participate, will be given a consent form to be signed (copy enclosed) and returned to the primary researcher at the beginning of the focus group.

If approval is granted, the primary researcher will conduct focus groups and one-to-one interviews with speech-language therapists working with children with cerebral palsy, in public hospitals, clinics and schools, in order to gain insight into the everyday realities experienced by these professionals. These focus groups and interviews will be held at the therapists' place of work and will be audio recorded for transcription and analysis purposes. All information shared will be treated confidentially.

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Sincerely,

Martha Lydall
(Speech-Language Therapist & Audiologist)

Enclosures

cc: Dr. B. Gerber (Supervisor), Stellenbosch University

Approved by:

MRS R.S. LUCAS
Print your name and title

R. Lucas
Signature

19.11.2019
Date





GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Chris Hani Baragwanath Academic hospital

Department of Speech Therapy/ Audiology

PO Bertsham

2013

3/09/2019

Ph : 0119339269

mwsadna@mweb.co.za

To whom it may concern

Permission is granted for Martha Lydall to conduct her research on *Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to Six Years* at the Department of Speech Therapy & Audiology at Chris Hani Baragwanath Academic Hospital.

The researcher must liaise with Ms Vallabhjee to arrange interviews with therapists at the time that suits them. It is expected that results will be shared on completion of the study.

Yours Sincerely

Dr Sadna Balton

(Head of Department Speech Therapy /Audiology)



UNIVERSITEIT
iYUNIVESITHI
STELLENBOSCH
UNIVERSITY

100

1918 · 2018

Date: 21/06/2019

To: Principal of Frances Vorweg School

RE: Permission to Conduct Research Study

I am writing to request permission to conduct a research study at your institution. I am currently enrolled in the Masters for Speech-Language Therapy at Stellenbosch University in the Western Cape, and am in the process of writing my Master's Thesis. The study is entitled: Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to Six Years.

I hope that the hospital administration will allow me to recruit Speech-Language Therapists working with children with cerebral palsy from the hospital to anonymously participate in a focus group. Interested Speech-Language Therapists, who volunteer to participate, will be given a consent form to be signed (copy enclosed) and returned to the primary researcher at the beginning of the focus group.

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Sincerely,

Martha Lydall
(Speech-Language Therapist & Audiologist)

Enclosures
cc: Dr. B. Gerber (Supervisor), Stellenbosch University

Approved by:

QINISO MTHIMKHULU
Print your name and title

Signature

20-11-2019
Date





GAUTENG PROVINCE

HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:

Ms. N. Mzila

Office of the Clinical Director

Tell: (011) 488-4812

Email: Nolwazi.Mzila@gauteng.gov.za

23 October 2019

GP_201906_027

Dear Martha Lydall

STUDY TITLE: Investigating the Perceptions of Speech-Language Therapists Working in the Health Educators Sectors, About the Services They Provide to Children Cerebral Palsy in the Greater Johannesburg Region, From Birth to Six Years.

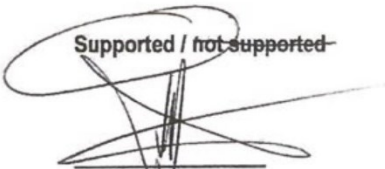
Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic Hospital will not anyway incur or inherit costs as result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the HOD and Unit Manager or sister in charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

~~Supported / not supported~~


Dr. M.I. Mofokeng
Clinical Director

DATE: 24/10/2019

~~Approved / not approved~~


Ms. G. Bogoshi
Chief Executive Officer

Date: 25.10.2019



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

SOUTH RAND HOSPITAL
1 Friars Hill Road, Rosettenville, 2149

ENQUIRIES:
Office of the CEO
T: 011 681 2004
M: 071 872 6649
E: Nobantu.Maleka@gauteng.gov.za

To whom it may concern

**RE: APPROVAL FOR STUDY: INVESTIGATING THE PERCEPTIONS OF
SPEECH-LANGUAGE THERAPISTS WORKING IN THE PUBLIC HEALTH AND
EDUCATION SECTORS, ABOUT THE SERVICES THEY PROVIDE TO
CHILDREN WITH CEREBRAL PALSY IN SOUTH AFRICA**

The above noted study has been noted and approved. The research may be undertaken at South Rand Hospital. South Rand Hospital pledges to provide the required support in terms of access as well as guidance should it be required.

Regards.

Dr M.N. Maleka
CEO: South Rand Hospital
Date: 3 July 2019

South Rand Hospital
Friars Hill Rd



Gauteng Department of Health
Departement van Gesondheid
Umnyango wezempilo
Lefapha la Maphelo
Edenvale Regional Hospital
Enquiries: Dr. C. Mondzanga
Telephones: 0113216228
Fax: 011443 6162
E-mail: claudc.mondzanga@gauteng.gov.za

Memo

To: Mrs. Martha Lydall
From: Dr. C Mondzanga
Acting Chief Executive Officer
Date: 16 July 2019

Subject: Request to conduct Research Study at Edenvale Regional Hospital.

This serves to grant permission Mrs. Martha Lydall to carry out research study. Fit for the purpose? Investigating the Perceptions of Speech-Language Therapist working in the Public Health and Education Sectors, about the services they provide to children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to six years. This permission is granted in light of improving skill capacity of the Gauteng Department of Health.

The permission is granted in line with code of ethics or research.

The information of the Gauteng Health Department will be used for the purpose of research and it will be utilized discreetly and confidentiality will be maintained at all times.

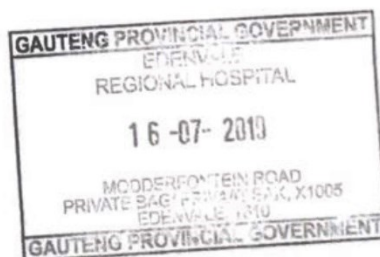
The permission is granted in good faith with the notion and understanding that the abovementioned clause is upheld.

Furthermore, there should be no financial implication to the hospital.

The collection of data will be the responsibility of the researcher.


Yours Sincerely

.....
Dr. C. Mondzanga:
Acting Chief Executive Officer



Appendix F: Participant Information and Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF RESEARCH PROJECT:	
Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to Six Years.	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Mrs. Martha Lydall	Ethics reference number:
P. O. Box 131037, Bryanston, 2021	

I would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary, and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

This research is investigating speech-language therapy services for children with cerebral palsy in the greater Johannesburg public health and education sectors. I will be conducting focus groups and depth interviews with speech-language therapists working with children with cerebral palsy, in public hospitals, clinics and schools, in order to gain insight into the everyday realities experienced by these professionals. These focus groups and interviews will be held at the therapists' place of work and will be audio-recorded for transcription and analysis purposes. All information shared will be treated confidentially.

Why do we invite you to participate?

As a speech-language therapist working with children with cerebral palsy in the public sector in the greater Johannesburg area, your insight and experience is invaluable to this study.

What will your responsibilities be?

Your responsibilities will be to attend an individual or focus group interview and participate in answering and discussing interview questions as honestly as possible.

Will you benefit from taking part in this research?

The findings of this study could benefit speech-language therapists working in the public sector of the greater Johannesburg area, by highlighting strengths and weaknesses of the current rehabilitation process. This information can be used to improve and strengthen services to children with cerebral palsy and their families, and even to advocate for any identified changes in policy and procedure.

Furthermore, to thank you for your time, I will invite you for a CPD accredited, 1-hour feedback session relating to the results of my research. Tea, coffee and muffins will be served.

Are there any risks involved in your taking part in this research?

All recordings and transcripts will be handled confidentially to ensure that nothing that is discussed in the focus groups and interviews could in any way damage the reputation of any of the participants. Your personal information will only be known to the researcher and her supervisor. No names or any other identifying information will be revealed in the writing of the research report or when presenting the findings of the research in the form of journal articles or conference presentations.

Will you be paid to take part in this study and are there any costs involved?

The intention is to acquire permission from the various government institutions to conduct the research during regular working hours, at a time that suits you. The researcher will travel to your place of work to conduct these focus groups or one-to-one interviews. As such, no costs should fall on you as a participant.

Is there anything else that you should know or do?

- You can phone the Health Research Ethics Committee at 021 938 9677 / 9819 if there still is something that your researcher has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled Investigating the Perceptions of Speech-Language Therapists working in the Public Health and Education Sectors, about the Services they provide to Children with Cerebral Palsy in the Greater Johannesburg Region, from Birth to Six Years.

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary**, and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) on (*date*) 2019.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document in a simple and clear manner to
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used, then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2019.

.....
Signature of investigator

.....
Signature of witness

Appendix G: Interview Guide

1. What about treating children with cerebral palsy do you find most enjoyable?
2. Tell me more about the procedures of the institution with regard to treatment of children with cerebral palsy?
 - a. Intervention programmes
 - b. Age of intervention
 - c. How long is intervention for?
 - d. Where to from the hospital or CHC?
3. How do you feel about these procedures?
 - a. Strengths
 - b. Challenges
4. Describe the assistive devices used (if any) in your treatment of children with cerebral palsy.
 - a. How do you feel about these devices?
 - b. Adequacy
 - c. Availability
 - d. What needs do you have with regard to assistive devices in your setting?
5. Please tell me about the assistive devices (if any) that your pediatric clients with cerebral palsy arrive with from other institutions.
 - a. How do you feel about these devices?
 - i. Age-appropriate?
 - ii. Adequate?
 - iii. Child-specific?
 - iv. Practical and/or user-friendly?
6. What are your concerns (if any) when a child with cerebral palsy leaves your care?

7. Please tell me more about the carryover procedures you follow, once a child and his/her family leave your institution?
8. What is your perception of speech-language services that are currently being offered to children with cerebral palsy in government institutions?
 - a. Strengths
 - b. Weaknesses
9. What would you like to change or see changed with regard to the services provided for children with cerebral palsy?
 - a. How do you think these changes can be made?
 - b. Do you have any suggestions for building on the strengths that you have mentioned?

Thank you so much for your time!

Is there anything else you'd like to contribute?

Do you have any other questions for me?

Appendix H: Responses from Member Checking

[REDACTED] <[REDACTED]>

Wed,
May 27,
3:33 PM

Hi Marth

Just a personalised response - this is so good and very well written!!!

[REDACTED]

Sent from my iPad

[REDACTED] <[REDACTED]>

Thu,
May 28,
6:50 AM

Dear Martha

I hope you are well and keeping warm!

Thank you for your email with all the valid points raised and elaborated on.

Yes, I agree!

Have a great day!

Kind regards

[REDACTED]

[REDACTED] <[REDACTED]>

Thu, May
28, 10:05
AM

Good day

I hope this email finds you well

I hope you are keeping well during this time and everything is going well.

Yes, I agree

Thank you for choosing me to participate in your study, all the best

Warm regards

[REDACTED]

Sent from my iPhone

[REDACTED] <[REDACTED]>

Thu, May
28, 12:55
PM

Morning Martha,

Thank you for your e-mail with attached 5-page summary.

Yes, I agree.

This summary accurately reflects discussions we had during the interview.

All the best!

Regards

[REDACTED]

Speech Therapy & Audiology Department

[REDACTED]

Tel: [REDACTED]

[REDACTED] < [REDACTED] >

Sat, May
30, 9:43
AM

Hi Martha.....

Yes, I agree

Comments: Well thought out and interesting results.

Kind regards

[REDACTED]

[REDACTED] < [REDACTED] >

Jun 4,
2020,
1:57 PM

Hi Martha,

Apologies for the delay!

I do agree, mostly. The outcome of your research gives a very comprehensive picture of the lived experience of us speechies. Well done!

The only thing that I disagree with, and it's not even really that I disagree, it's just that I was not aware of the down referral policy to the clinics.

I never discharged a patient who was 3 years or older to the clinics, I usually kept these children on for therapy because I knew the struggle with staffing in the clinics.

That's all from me!

All the best,

--

[REDACTED]

[REDACTED] < [REDACTED] >

Wed, Jun
10, 10:18
AM

Yes, we agree

Comments

We agree with the findings of this study. The summary was well written with clear outcomes.

[REDACTED]

Wed,
Jun 10,
1:02 PM

Yes, I agree.

--

Kind Regards,

[REDACTED]

[REDACTED]

Speech Therapy and Audiology

[REDACTED]

[REDACTED] < [REDACTED] >

Fri, Jun
12,
11:28
AM

Yes, I agree with the results from the study.
Thank you for letting me be a part of it.

Kind regards

[REDACTED]
[REDACTED]