CURRENT OCCUPATIONAL THERAPY AND PHYSIOTHERAPY PRACTICE IN IMPLEMENTING HOME PROGRAMMES FOR YOUNG CHILDREN WITH CEREBRAL PALSY IN SOUTH AFRICA

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Declaration

I, Lauren Anne Davies hereby declare that this thesis is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy of the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

LA Davies

12th Day of May, 2016

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Abstract

Cerebral palsy (CP) is a non-progressive permanent disorder of movement that can cause varying limitations in activity participation and function. The current practice of home programmes for young children diagnosed with CP as understood and implemented by paediatric occupational and physiotherapists in five service delivery settings in South Africa was investigated. Forty-eight participants completed an online questionnaire regarding the content, design and implementation of home programmes they prescribe. Fifteen of these participants then took part in semi structured interviews. The findings were compared to the model home programme developed by Novak and Cusick. Results revealed that home programmes within the private sector were comparable to the model, but that there were aspects in resourced constrained settings that led to differences. Collaborative relationships between therapists and parents/caregivers were especially challenging and affected the preceding phases of the model. Recommendations in the form of a South African home programme model are made.

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Operational Definitions

Home Programmes: Therapeutic activities and/or functional tasks that the child performs with parental assistance in the home and context of daily life, with the goal of achieving desired health outcomes (Novak et al. 2007; Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Law & King, 1993).

Cerebral Palsy: A non-progressive, but permanent, disorder of movement and posture that occurs in the developing foetal or infant brain that causes activity limitation. The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, epilepsy, and/or secondary musculoskeletal problems (McIntyre et al., 2011; Rosenbaum et al., 2007).

Family Centred Service: A way of working with families to care for children with special health care needs. The approach focuses on parents/caregivers as primary decision makers, and is a partnership based relationship between parents and professionals. The family is in control of therapy, while professionals support parents and enhance their competency. The child and family are considered in their home and community context (Rosenbaum & Stewart, 2004; Novak et al. 2006).

Non-profit Organization: A company or association registered with the Department of Social Development for public benefit or cause, and of which no profit is generated except as reasonable compensation for services rendered (Department of Social Development, South Africa, www.dsd.gov.za/npo/).

Special Needs School (LSEN): A public school that is registered and run under the Department of Education and Training and provides services for children with special educational needs (Pillay & Terlizzi, 2009).

Government Hospital: Hospitals funded by the government that usually provide services for poorer populations who cannot afford private health care. Services are provided to a range of patients and payment is required, depending on patient income and economic status (Cullinan, 2006).

Private Practice: Health care services that are independent of the government and are privately funded, primarily through medical aids/insurance, the client, or the parents of the client in the case of children (Medical Schemes, 2014-15).

Abbreviations

ADL	Activities of Daily Living
CAPE	Children’s Assessment of Participation and Enjoyment
COPM	Canadian Occupational Performance Measure
CVI	Content Validity Index
FCS	Family Centred Service
FIM	Functional Independence Measure
GAS	Goal Attainment Scaling
GH	Government Hospital
GMFCS	Gross Motor Functional Classification System
ICF	International Classification of Function, Disability and Health
LSEN	Learners with Special Educational Needs
MDT	Multidisciplinary Team
NPO	Non-profit Organization
OT	Occupational Therapist
PEDI	Paediatric Evaluation of Disability Inventory
PP	Private Practice
PT	Physiotherapist
QUEST	Quality of Upper Extremity Skills Test
SANDTA	South African Neurodevelopmental Therapy Association
SMART	Specific, Measurable, Achievable, Realistic/Relevant and Timed
SME	Subject Matter Expert
SNS	Special Needs School
ST	Speech Therapist

CHAPTER 1
INTRODUCTION

1.1 Introduction

Cerebral palsy (CP) is a non- progressive but permanent disorder of movement and posture that occurs in the developing foetal or infant brain (McIntyre et al., 2011; Rosenbaum et al., 2007). Depending on the area and the degree of insult, it can cause varying limitations in activity participation and function, as well as associated impairments such as cognitive, perceptual or communication difficulties (Rosenbaum et al., 2007). The prevalence of CP is estimated to be at least two per 1000 live births in both developed and developing countries (Oskoui et al., 2013; Clark & Hankins, 2003). The usual standard of care involves a multidisciplinary team of health care professionals who assist with the management and treatment for these children. Within this team, physiotherapy and occupational therapy form an important part and they employ a range of treatment modalities to improve the function, participation and independence of children with CP in individual tasks within their daily activities (Fairhurst, 2012). To ensure carry over from individual sessions and to further enhance improvement, home programmes are part of the treatment process (Hinojosa & Anderson, 1991; Novak & Cusick, 2006).

Home programmes form part of an intervention that seeks to involve ‘the whole person’. Based on the International Classification of Functioning, Disability and Health (ICF) framework, home programmes should promote parental participation and involvement in their child’s treatment; consider environmental and personal factors; and promote independence within a personalized, community and family context (Rosenbaum & Stewart, 2004; Palisano et al., 2012; Hinojosa & Anderson, 1991). Novak et al., (2009) describes home programmes as “individualized multimodal interventions that target body structure, activities, and participation problems identified collaboratively by the parents and therapist, informed by diagnoses and referral instructions”. The therapist assists parents or caregivers to encourage the child to practise skills learnt in therapy to achieve desired goals.

Home programmes become even more essential in public health sectors where there are low therapist to patient ratios (Law & King, 1993) and limited rehabilitation services, especially in poorly resourced, underserved areas within countries such as South Africa (Saloojee et al., 2006). It has been found that even in the private health sector, sessions are limited to one or two per week due to a lack of affordability (Law & King, 1993; Novak et al., 2009). Home programmes not only supplement individual therapy, but ensure parental involvement and functional participation in the home environment (Novak & Cusick, 2006; Jansen et al., 2003).

Studies have shown the effectiveness of home programme implementation (Novak et al., 2007; Novak et al., 2009), as well as the value these programmes contribute to the child with CP and his or her family (Hinojosa & Anderson, 1991; Novak, 2011). The literature also highlights the importance of parental involvement and family centred practice that will improve home programme performance and success (Ketelaar et al., 1998; Rosenbaum et al., 1998). However, although there is little doubt regarding the usefulness of home programmes for children with CP and their families, there is limited research regarding what therapists understand by the term home programme and what the actual content of home programmes for children with CP consist of. Moreover, there is no research regarding home programme descriptions for the population of young children with CP within South Africa.

This study describes current practice of occupational therapists and physiotherapists with regards to home programmes in four South African settings where children with CP receive therapy intervention. The utility of the study is to provide a clear understanding of home programmes, to determine possible differences, and the reasons thereof, across service delivery settings in South Africa and to make comparisons to current literature.

This becomes a step in the process to determine what constitutes a home programme, what therapists should consider to improve home programme success and how effective and useful home programmes in South Africa are.

1.2 Statement of the problem

Descriptions of the design, implementation and content of home programmes for young children with CP in the literature are non-specific and unclear. There is an assumption that therapists concur with regards to their understanding of home programmes, however, comprehensive descriptions are not provided. An understanding of home programmes, including design, implementation and content, will elucidate more clearly what therapists actually prescribe, the details of which are currently unknown. Without a clear understanding of what constitutes a home programme, outcome and effectiveness cannot be measured. Without implementing effective home programmes that impact positively in the lives of children with CP and their families, therapists neglect a significant component of enabling active participation and involvement of the child as a valuable part of the family and community and do not make the best use of the contact time available. Furthermore, little is known regarding current practice of home programme design and implementation in South Africa and how this aligns with the best available evidence of an effective model that has been developed by Novak & Cusick (2006). The varying differences in service delivery settings and resources in different contexts in South Africa, and what challenges these pose in terms of home programme design and implementation are also unknown.

1.3 Purpose of the study

The purpose of the study is to describe current clinical practice of occupational therapists and physiotherapists in terms of home programmes for children with CP in South Africa. This will be compared to recent research on home programme design and implementation, including the ‘model home programme approach’ developed by Novak & Cusick (2006), in order to establish how home programmes in South Africa align with this approach and if important aspects that have improved the success of a home programme in South African settings are catered for in this model. A variety of service delivery sectors that will be included in this research vary, i.e. well-resourced, well served and poorly resourced, underserved contexts of the child with CP and his/her family, which allows further comparison.

1.4 Research question

What is the current practice of occupational therapists and physiotherapists with regard to home programme design and implementation when treating young children with CP in South Africa, and how does this align with the ‘model home programme approach’ designed by Novak & Cusick (2006)?

1.5 Study aim

To describe current practice of occupational therapists and physiotherapists with regard to home programmes for young children with CP in terms of design, implementation and content within different service settings within South Africa and to compare findings with the ‘model home programme approach’ designed by Novak & Cusick (2006)

1.5.1 Specific study objectives:

This study will be conducted in two parts

Part 1:

- To determine current practice of occupational therapists and physiotherapists with training in Neurodevelopmental Therapy (NDT) in home programme content for young children with CP in differing service delivery settings
- To determine current practice of design and implementation of home programmes in differing service delivery settings
- To compare current practice across these differing service delivery settings to the aspects emphasised in the ‘model home programme approach’ designed by Novak & Cusick (2006).

Part 2:

- To explore therapist’s experiences, including their perceptions of facilitators and barriers, of home programme design and implementation in their specific service delivery setting

- To compare therapists experiences of home programmes across the differing service delivery settings
- To determine how the current practice of NDT trained occupational therapists and physiotherapists aligns with the aspects emphasised in the ‘model home programme approach’ designed by Novak & Cusick (2006).

1.6 Rationale of the study

Home programmes form an essential component of the treatment for young children with CP. Research has focused on the effectiveness and value of home programmes (Novak et al. 2007; Novak et al. 2009), and factors such as parental involvement and family centred practice have been shown to be essential components of how home programmes are delivered (Ketelaar et al. 1998; Rosenbaum et al. 1998), but no known research has focused on a clear description of what constitutes a home programme, much less so within varying resourced areas in South Africa. The ‘model home programme approach’ designed by Novak & Cusick (2006) allows for comparison of current practice of home programme design and implementation in South Africa to what the literature characterizes as factors that improve home programme success.

Occupational therapists and physiotherapists with training in neurodevelopmental therapy (NDT) were chosen for this study because this is a specialized and popular approach when treating children with CP and there is evidence for its effectiveness (Tsorlakis et al., 2004; Knox & Evans, 2002). The core concepts in this approach, that include analysis of movement, active participation of the child, the promotion of function in activities of daily living and family involvement, are part of home programme implementation (Mayston, 2008). Therapists with training in NDT also have this common frame of reference.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

This literature review will consider the research to date on home programmes for children with CP. This firstly looks at available descriptions of home programmes for this population group, followed by available literature regarding home programme design and implementation. The model home programme developed by Novak and Cusick (2006) was based on and developed around previous research that highlighted factors that improve home programme success. This is the best available evidence of effective home programmes (Novak et al., 2007; Novak et al., 2009). For this reason, the model will be used to provide an outline to discuss these factors, with a diagram provided to illustrate the different phases of the model. Research pertaining to the model will be considered under the headings of the five phases. Finally, attention is given to research regarding home programmes in poorly resourced settings, which are important considerations for our study setting, i.e. the South African context. The literature spans 10 years or more due to the availability of primary information during this time frame and few relevant studies in more recent literature.

2.2 What are home programmes for children with Cerebral Palsy?

Home programmes form part of an intervention option that has proved both valuable and effective for children with CP and their families (Novak & Berry, 2014; Novak et al., 2007; Novak et al., 2009). However, a clear and specific definition of home programmes is not available, despite considerable evidence advocating their use. Novak & Cusick, (2006) describe home programmes as ‘interventions specifically designed for implementation in the home and in the context of daily life by families’. Another definition, based on their own interpretation and other sources (Novak et al. 2007; Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Law & King, 1993), refers to ‘therapeutic activities that the child performs with parental assistance in the home environment with the goal of achieving desired health outcomes’. A further definition describes home programmes as ‘individualized multimodal interventions that target body structure, activities, and participation problems identified collaboratively by the parents and therapist, informed by diagnoses and referral instructions’ (Novak et al., 2009). A definition from the perspective of parents proposed home programmes to be ‘…a form of guidance and advice, which becomes a way of life for parents and children. Through regular practice of activities at home, parents maximise their child’s potential. Parents use the guidance and support that they gain from home programs to build confidence about how to help their child’ (Novak, 2011). Recent research (Novak, 2014) describes home programmes as ‘child-active repetitive and structured home-based practice of functional tasks meaningful to the child and family’.

From these definitions, it is clear that home programmes constitute a form of ‘therapeutic activity’ that the child performs in the home and with parental/caregiver involvement. The question remains, however, if these definitions are specific enough for therapists to accurately judge effectiveness in their prescribed home programmes. Furthermore, it is unclear whether there is sufficient literature describing to the specifics of a home programme for children with CP and their therapists to follow that would enable a fair judgement of effectiveness.

The difficulty may lie in that CP is a complex and heterogeneous condition that encompasses a range of differences in terms of types and severity (Bax et al., 2005). Within these subtypes, other classification systems further describe the level of impairment, i.e. gross motor (Palisano et al., 1997), fine motor (Eliasson et al., 2006) and communication abilities (Hidecker et al., 2011). Associated impairments can include feeding difficulties, cognitive and perceptual delays and/or behavioural problems. A child can be mildly affected with slight coordination difficulties, minimal problems in terms of hand function and communication and have the ability to attend a mainstream or special needs school, or they can be severely impaired, reliant on a wheelchair for mobility and dependant on his or her caregiver for the provision of basic needs (Beckung & Hagberg, 2002). Since the assessment and treatment of CP is highly individualized, it is difficult to specify clinical guidelines for home programme content. Nevertheless, common trends in terms of management between therapists treating children with CP and their classification and level of impairment, should be apparent.

In a pilot study by Novak et al. (2007), 20 children diagnosed with hemiplegic CP were provided with a home programme and ‘therapeutic activities’ were chosen by the parents. These were derived from a list of activities (which were not specified) and splinting or casting was included. The therapist devised a documented home programme that stated the wearing schedule of the splints and photographs or illustrations of the activities. The other study to date (Novak et al. 2009) is slightly more specific. Here, a greater variety of classifications of CP and levels of impairment were included and the home programme goals were derived from the Canadian Occupational Performance Measure (COPM), (Law et al., 1990). The parents, as in the previous study, chose activities from a therapy resource, including activities for the child to execute and practise. Parents were educated and the environment was modified if necessary. Depending on the formulated goals of each child, the home programme included some or all of the following: ‘goal directed training, education, handwriting task training, positive behaviour support, adaptive equipment, recreational/sports therapy, strength training, orthotics, play therapy and/or constraint induced movement therapy’.

Although these studies specify the content of home programmes to some extent, the sample sizes were relatively small (<36). The objectives of both studies were to evaluate the effectiveness of home programmes and not the content of the home programme itself. Thus, a definition of home programmes for children with CP remains unclear.

2.3 The model home programme

In addition, there is a lack of clinical guidelines for therapists to follow when determining best practice in terms of providing home programmes for children with CP and their families. Novak & Cusick, (2006) recognised this and began the process of creating a guide for home programme design and implementation. Based on an extensive review of the literature, which included 28 articles (many of which will be discussed in this review), a model home programme was derived. It was based on a family centred service approach and a frame of reference that included a holistic view of the child, as prescribed by the International Classification of Functioning, Disability and Health (ICF) (Rosenbaum & Stewart, 2004).

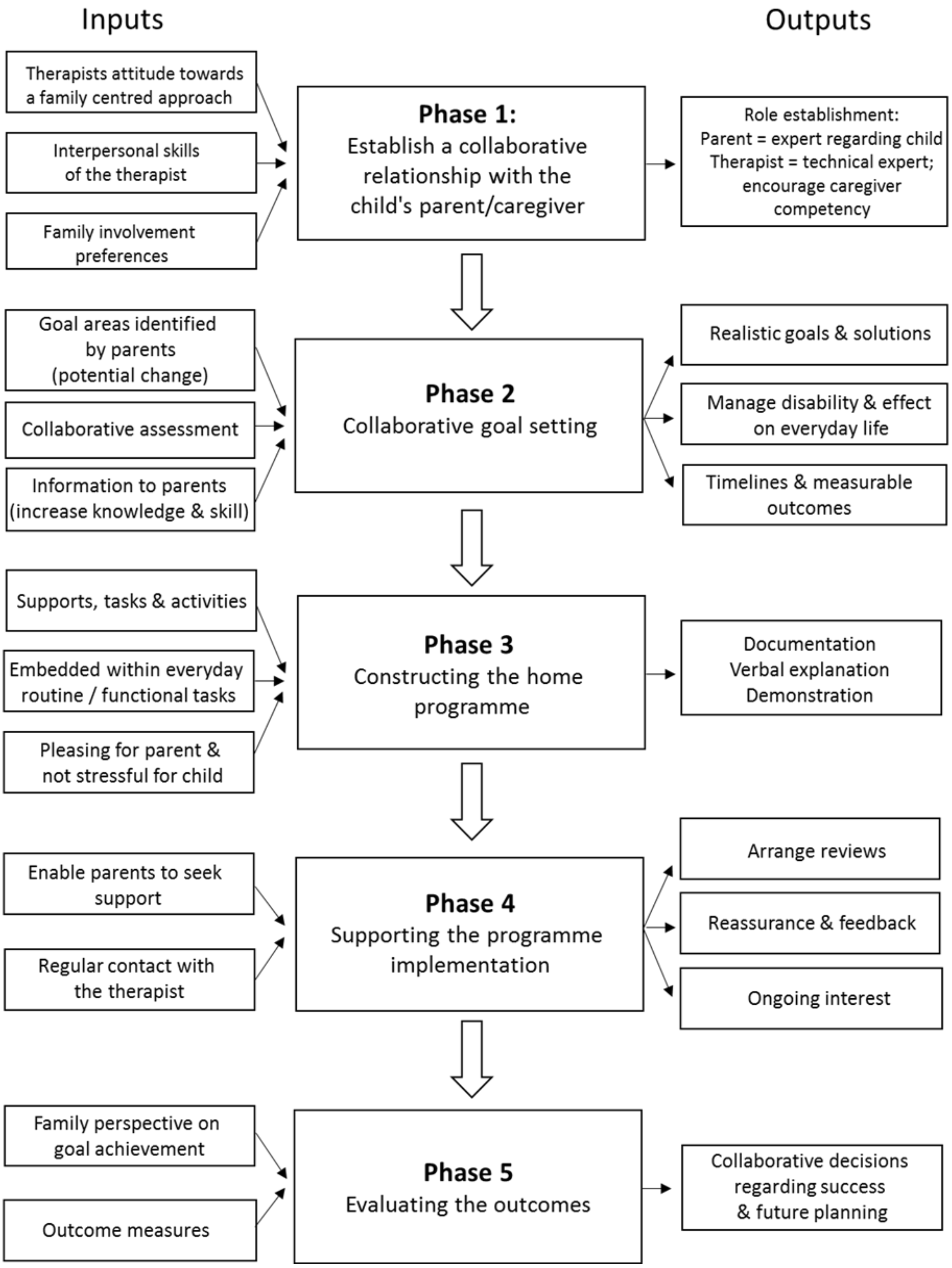


Figure 2.1 The model home programme approach, modified from Novak & Cusick (2006).

A summary of the model is illustrated in Figure 2.1, which includes five phases with ‘inputs’ and ‘outputs’ specific to each phase. An explanation of each phase and the literature that formed the basis for the model will be considered.

2.3.1 Establishing a collaborative relationship with the child’s parents/ caregivers

Novak and Cusick’s model was firmly grounded in a family centred approach where the needs and preferences of the caregiver and family were considered as the most important component when formulating home programmes. Developing a collaborative relationship with the child’s parent and/or caregiver was described as the first step when formulating home programmes and is essential to this approach (Novak & Cusick, 2006; Palisano, 2006). Important aspects of this phase that will be highlighted in this review include the significance of a family centred service. This is an approach that is built on forming effective partnerships between parents and professionals and considers the needs of the whole family (Shelton et al., 1987; Rosenbaum et al., 1998). Characteristics of this partnership relationship that parent’s value and therapists need to consider will be discussed.

Family centred service

A family centred service (FCS) is considered the ‘goal standard’ with regards to therapy, and contains principles of practice that have improved family involvement and the success of home programmes (Rosenbaum et al., 1998; Novak et al., 2009). This is because the family forms the central context of the child with CP and becomes essential in the content, development and implementation of home programmes that, as the name implies, take place within the home of the child and within the family context (Rosenbaum & Stewart, 2004; Novak et al. 2006).

Within FCS, parents are regarded as the primary decision makers, individualization is emphasised and the whole family is incorporated into the therapy process (Rosenbaum et al., 1998). Goals of intervention include supporting the parent in their role as a parent and enabling successful interaction and enjoyment of their child, which includes involvement in activities of daily living, play and inclusion within the family and community that are part of home programmes (Bazyk, 1989; Palisano et al., 2012). The family is in control of the intervention process and competency of the caregiver is encouraged (Novak &

Cusick, 2006). This differs from the traditional child centred approach to therapy where parents were often passive recipients (Bazyk, 1989; Jansen et al., 2003). Active partnership relationships are rather encouraged because parents, rather than therapists, are regarded as experts who know their child the best and are therefore better able to identify child and family needs (Rosenbaum et al., 1998; Viscardis, 1998).

A FCS also means that the goals of therapy and home programmes are not focused solely on treating the child, as with traditional approaches, but rather focus on increasing the knowledge and skills of families to equip parents to care for and assist their child, with an emphasis on parental guidance and support (Novak & Cusick, 2006; Novak, 2011). The uniqueness and individualization of families is important within this approach and therapists need to be aware of differing cultures and backgrounds, socioeconomic status, values and even the desired level of participation of caregivers and families (Rosenbaum et al., 1998; Hanna & Rodger, 2002; Humphry & Case-Smith, 1996; Thompson, 1998). Therefore, home programmes should not be general, but rather individualized and tailored to the needs of the child and family (Novak et al., 2009). A sufficient understanding of the context and social dynamics of the family is essential when formulating home programmes to make them relevant, specific and meaningful.

Both reviews and individual studies have demonstrated the outcome benefits of using a FCS for children with CP and/or other developmental delays (Dunst et al., 2007; Jansen et al., 2003; Kruijsen-Terpstra et al., 2013; Novak et al., 2007; Novak et al. 2009). These include parental satisfaction with services, an increase in parental participation, parental self-efficacy and the emotional well-being of parents (King et al., 1999; Hanna & Rodger, 2002; Dunst et al., 2007). Moreover, an emphasis on a positive interpersonal relationship between parents/caregivers and therapists was strongly related to outcomes, with the interpersonal skills and attitudes of the therapist regarded as important in this process (Dunst et al., 2007; McWilliam et al., 1998).

Effective, partnership based relationships between parents and therapists

Collaboration and a partnership based relationship between parents and therapists is characterised by teamwork and cooperation, shared decision making, equality and empowerment (Bazyk 1989; Hinojosa et al., 2002; Novak & Cusick, 2006). Humphry & Case-Smith (1996) highlighted the importance of this relationship and defined collaboration as a means of 'working together towards a common goal'. Working with parents was perceived as the most important aspect of intervention that had the greatest impact on a child's improvement (Hinojosa et al., 2002).

Perspectives from both therapists and families highlight the importance of both open and effective communication and of service providers who are respectful, non-judgemental, enthusiastic and flexible (Washington & Schwartz, 1996; McWilliam et al., 1998). Parents also value other therapist characteristics, such as commitment, a sense that the therapist values their child, themselves as parents and their family, when therapists strive to develop a personal relationship with them, equality (including empowerment and partnership based decision making), and when therapists have the necessary skills to meet individual and family needs and to provide quality services. Parents also value reliable therapists who treat them and their children with courtesy and dignity (Blue-Banning et al., 2004). The knowledge and skill of the therapist in providing a quality service, which includes effective home programmes, is based on their ability to understand the needs and concerns of the family, to involve the whole family in intervention and their ability to understand the community situation and form community collaborations (McWilliam et al., 1998; Palisano, 2006).

Furthermore, personal qualities such as trust, respect, honesty and sensitivity of therapists are valued by parents (Kruijsen et al., 2013; Piggot et al. 2002; Blue-Banning et al., 2004). This is largely because parents tend to progress through stages as they understand and accept their child's disability, which can influence their participation in home programmes. It can take time for parents to be motivated and emotionally able to participate and increase their involvement, and there is a need for therapists to respect and be aware of this process (Piggot et al., 2002; Viscardis, 1998).

The health of the parents, including their psychological well-being, should be considered equal to the care of the child if services are to be family centred (McWilliam et al., 1998). Studies have found a higher level of parental satisfaction with services and parental competence with lower stress levels when relationships with therapists are more partnership based and collaborative (i.e. following a FCS approach) (King et al., 1999). It is important for therapists to view parents as equal partners, capable decision makers and active members of ‘their child’s team’ (Viscardis, 1998; Dunst et al., 2007; Broggi & Sabatelli, 2010). Within a FCS, there is also an assumption that children will function better within a supportive family and community, and that the child is affected by activities, including any stress, within the family, i.e. the well-being of the child is affected by his/her environment (Rosenbaum et al., 1998; Rosembaum & Stewart, 2004). When parents/caregivers are coping, there is greater participation in therapy intervention and, by implication, home programmes.

Law & King, (1993) used numerous methods of measuring parental participation in home programmes and emphasised the importance of listening to parents, especially when compliance is lacking. Positive interactions between parents and therapists, and therapists that showed greater interest and concern where factors that improved compliance (Gajdosik, 1991; Law & King, 1993). With this in mind, the role of the therapist should be that of a technical expert in a partnership based capacity where the caregiver/family takes the lead and the therapist encourages and empowers (McWilliam et al., 1998; Rosenbaum et al., 1998). Therapists are encouraged to recognise the expertise of parents in their knowledge of their child, and in their unique role as the parent (Rosenbaum et al., 1998). However, parents are not expected to be therapists at home and prefer to remain in their role as a parent (Case-Smith & Nastro, 1993). Instead, home programmes should provide parents with guidance, advice and support with regards to caring for their child as a parent (Case-Smith & Nastro, 1993; Novak, 2011).

2.3.2 Collaborative goal setting

The second phase of the Novak and Cusick model continues to incorporate a partnership based approach where the parent is regarded as the expert and the therapist guides and assists the decision making process by increasing the knowledge and skills of the parent (Rosenbaum et al. 1998; Novak & Cusick, 2006). The goal setting process is aided by a collaborative assessment that focuses on the strengths, needs and priorities of the child and family.

Studies have found that goals identified by families are more meaningful, increase participation in home programmes and improve parental competence in facilitating home programme activities (Jansen et al., 2003; Ketelaar et al., 1998). In the goal setting process, it becomes the responsibility of the therapist to encourage parental decision making, which also involves providing families with the knowledge and skills needed to identity goal areas and to enable realistic goal setting (Novak & Cusick, 2006). Performing an assessment of the child, which is also in partnership with the parent, aids this process (Crais et al., 2006). Such an assessment provides a greater understanding of the child, further enabling parents to identify realistic goals and solutions, as well as potential areas for improvement (Anderson & Schoelkopf, 1996; Jansen et al., 2003).

The needs and priorities of the family should be the focus of goal setting, and therapists need to be aware of the assets and competencies of the child and family (Novak & Cusick, 2006). This enables therapists to build on compensations or strategies that families have already put in place in terms of including and assisting their child with daily activities within the family routine. This also ensures parents, and not therapists, continue to be the expert with regards to their knowledge of the child and family needs (Rosenbaum et al. 1998). Goals are more effective when they are individualized, specific and in line with family priorities (Löwing et al., 2009; Chiarello et al., 2010). They should not only be family focused, but should also be attainable, time limited and with individualized outcome measures (Ahl et al., 2005; King et al. 1999; Ketelaar et al., 2001). Parents value and are more motivated and satisfied with goals that are specific, within the interests of their child, and are important to them and their family (Novak, 2011).

2.3.3 Constructing the home programme

Phase three of the Novak and Cusick model, ‘selecting therapeutic activities’, incorporates the goals of the home programme and indicates the actual tasks, activities and/or adaptive equipment to be included (Novak & Cusick, 2006). These activities are more effective and manageable for the caregiver and family when they are ‘embedded’ within everyday tasks, and are functional and meaningful (Hinojosa & Anderson, 1991; Law et al. 1998). The explanation, documentation and demonstration of the home programme is included in this phase (Figure 2.1).

Home programme content

Previous research specifies the content of home programmes to a limited extent. It implies a set of therapeutic activities, assistive devices or environmental/activity adaptations (Novak et al., 2006; Novak et al., 2007; Novak et al., 2009; Palisano et al., 2012). Research focuses on characteristics of home programme content that are relevant for the treatment of children with CP and their families, and that will improve the functioning and participation within their environments. This is particularly true when home programmes are ‘child active’, which means that goal directed training and functional skill development is incorporated and fundamental (Novak, 2014). Home programmes that are meaningful to the child, specific to their context, and with clear and achievable goals are more effective (Taylor et al., 2004; Palisano et al., 2012). There is also an emphasis on play and fun that is motivating and within the child’s frame of reference (Tétreault et al., 2003).

Therapy intervention needs to focus on active participation to promote function and therefore improve independence in activities of daily living (Mayston, 2008). Studies focusing on neuroplasticity demonstrate the importance of task specific, purposeful and meaningful activities that involve practise and repetition to achieve functional outcomes (Duffau, 2006; Aisen et al., 2011). The value of active movement and how this is most effective when it is meaningful to the child and relevant to their context is continually emphasised because motor behaviours are organised around functional tasks (Damiano, 2006). The characteristics of the child and the demands of the task and the environment are considered and environmental adaptions and possible modifications to the specific task included (Darrah et al., 2011; Lammi & Law 2003; Valvano, 2004). This is even more meaningful within home programmes because activities are performed in a variety of relevant environments that include the natural environment of the child, i.e. the home, and functional skills are practised within the child’s daily routine (Darrah et al., 2011; Law et al., 1998; Ketelaar et al., 2001). The task, environment and routine of the child need to be considered with the aim of intervention being the inclusion and participation of the child within the home, as well as the community and society (Lammi & Law, 2003; Ekström et al., 2005; Pallisano et al., 2012).

It has also been shown that tasks that are meaningful to the child and family involve those that the child enjoys doing and are thus motivated to perform (Rosenbaum & Gorter, 2012). Since play is essential for development and is described as a child’s occupation (Morrison et al., 1996), it is useful to use play as a therapeutic medium within home programmes. Several studies have incorporated games, such as virtual reality systems (computer games adapted through a television monitor), gaming devices such as PlayStation, or an EyeToy, into home programmes for children with CP and either compared these to conventional home programmes, or measured their effectiveness (Bryanton et al., 2006; Sandlund et al., 2011; Bilde et al., 2011). Results demonstrate child improvements, with greater enthusiasm, motivation, sustained interest in the task, and a greater likelihood to engage in home programmes that were more fun and enjoyable.

However, the use of such technology to create and enhance meaningful engagement of children with CP is not always feasible in poorly resourced areas where meeting basic needs is often problematic. The availability and use of computers and television in home programme design is even less feasible (Lygnegård et al., 2013). Nevertheless, play is valuable in all contexts, and not much equipment is needed to create opportunities for play (Edwards, 2000). Toys can even be adapted or constructed from discarded materials (Goldbart & Mukherjee, 2000). Play is regarded as a means to enhance development and is an effective tool to increase interest and engagement in home programmes (Brodin, 1999; Sandlund et al., 2011).

Home programmes as part of daily routines

Many studies have emphasised the need for flexibility with regards to home programmes, the incorporation of activities into daily routines and the importance of practising skills that are part of activities of daily living (Novak & Cusick, 2006; Bazyk, 1989). These findings are largely from the perspective of families, particularly mothers, who tend to integrate prescribed activities into their routines and adapt home programmes to the home context (Hinojosa & Anderson, 1991). This is largely because caregivers struggle to balance home and family demands, dedicate time to direct therapy, and implement separate home programmes (Thompson, 1998). Furthermore, parents with competing responsibilities would often rather spend quality family time together than engage in exercise regimes (Wiart et al., 2010).

Consideration of the family routine is therefore important when formulating home programmes, as is finding ways to involve other family members, such as siblings. This enhances the family centred approach and builds family relationships (Wiart et al., 2010). Mothers have also attributed changes to the family routine to therapists not involving families in service delivery, as an ideal family centred service should (Thompson, 1998). Home programmes incorporating play or adaptions to activities within a daily task, such as meal times, are viewed as practical for parents and easy to adapt into daily activities (Novak & Cusick, 2006; Hinojosa & Anderson, 1991). Parents prefer home programmes that are part of life, making it easier for them to manage competing demands (Novak, 2011; Wiart et al., 2010; Hinojosa & Anderson, 1991). Parents also value activities that focus on function, are relevant to their child and are context related (Peplow & Carpeter, 2013). They tend to choose home programme activities that their child enjoys and are therefore not stressful. Such activities are easier to implement, are less time consuming and are more effective for the child and family (Hinojosa & Anderson, 1991).

Confirming this, parents/caregivers are less likely to comply or participate in home programmes that are complex, performed over many years and/or demand lifestyle changes (Gajdosik, 1991). Instead, programmes that are simple, less time consuming and that incorporate daily activities, hobbies and recreational activities that are fun and meaningful to the child and the family are proposed (Taylor et al., 2004; Peplow & Carpeter, 2013).

Home programme dissemination

Home programmes that are easy to implement are those that are explained and modelled in a form that is based on the parent's preferences and style of learning, e.g. verbal information, a written format, or practising a given skill (Bazyk, 1989). Parents have described the value of hand outs in the form of pictures and diagrams to explain activities and positioning (Case-Smith & Nastro, 1993) and prefer information that is easy to understand and contains limited medical jargon (Peplow & Carpeter, 2013). Home programmes that they are able to implement independently after appropriate demonstration and practise are also favoured (Hinojosa & Anderson, 1991; Case-Smith & Nastro, 1993).

2.3.4 Supporting programme implementation

This phase of the model focuses on implementation of the home programme within the home and includes support, feedback and continual collaboration between the caregiver/family and the therapist. Frequent and positive contact between therapists and families has been shown to be an important aspect that improves the success of home programmes and forms part of this phase (Novak & Cusick, 2006; Gajdosik, 1991; Law & King, 1993).

There is a correlation between ongoing support and parental empowerment and motivation to carry out the home programme and home programme participation (Novak, 2011; Katz-Leurer et al., 2009). Furthermore, parents consider support and follow up to be an important benefit of home programme partnerships when compared with therapist directed programmes, and used support sessions as opportunities to update the home programme and review performance (Novak, 2011). Such support is also in the form of education provision, home visits and the monitoring of progress, with the main aim to sustain motivation for programme use (Novak et al., 2009).

Regular contact with parents is also important and has an effect on parental stress and well-being (Gajdosik, 1991; Jansen et al., 2003). Weekly meetings or phone calls are beneficial and provide an opportunity to discuss the programme, encourage continual participation, answer questions and solve any presenting problems (Katz-Leurer et al., 2009; Taylor et al., 2004). A home programme log book, diary or journal is also an effective way to monitor progress and participation and is a reminder to practice home programme activities (Gajdosik, 1991; Katz-Leurer et al., 2009; Taylor et al., 2004; Novak & Berry, 2014).

2.3.5 Evaluating the outcomes

This is the final phase of the model and involves an ongoing process to evaluate if the needs and goals of the family are being met. This includes family perspectives, but also standardized or formal measures to ensure appropriate progress (Novak & Cusick, 2006). Tests that have been used to measure home programme effectiveness are usually based on child improvements in performance skills and function, such as the Pediatic Evaluation of Disability Inventory (PEDI) (Haley et al., 1992), the Quality of Upper Extremity Skills Test (QUEST) (DeMatteo et al., 1992) or the Canadian Occupational Performance Measure (COPM) (Law et al., 1990). Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968) and/or specific, measurable, achievable, realistic/relevant and timed goals (SMART) (Bovend'Eerdt et al., 2009) can also be used to ensure goal achievement. Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2007), as well as a parent self-report log have been used to measure home programme participation (Novak et al., 2007; Gajdosik, 1991). The Canadian Occupational Performance Measure for parental satisfaction with child performance (COPM) (Law et al., 1990) is an additional measure that includes the perspectives of parents (Novak et al., 2009). Parents have found regular progress updates in the form of evaluation and goal attainment valuable and motivating, and this has encouraged them to continue with home programmes or to spend more time on home programme activities (Novak, 2011).

2.4 Application and effectiveness of the model home programme

The model home programme was implemented in a pilot study by Novak et al., (2007) to measure home programme effectiveness. Results were evaluated through standardized measures of improvements in child performance, and home programme participation was evaluated by the amount of time in which children and families took part in home programme activities. A significant difference was recorded between the baseline and post intervention scores of all the participants, however, results were not conclusive because no control group was present, meaning child improvement might have occurred naturally over time. The sample size was also relatively small (20) and only children diagnosed with spastic hemiplegia were included, limiting the application of the findings to children with other forms of CP. Furthermore, no measures to determine parent’s satisfaction with how the home programme was designed and if the design of the home programme correlated to its effectiveness were implemented.

A later randomised control trial by Novak et al., (2009) improved on this pilot study by including a larger sample group (36), children with varying types of CP, a control group and a measure to determine parental satisfaction with their child’s functional performance (COPM) (Law et al., 1990). Significant improvements were recorded for the group receiving the home programme compared to the group receiving no home programme. In addition to these positive results, most participants who received the home programme did not discontinue with it after the allocated time, perceiving it to be beneficial for their child. Similarly, Behzadi et al., (2014) compared a traditional Bobath approach of therapy to an experimental group who received both individual sessions of Bobath based therapy and a home–based Bobath home programme that was designed and implemented according to the model home programme approach (Novak & Cusick, 2006). Results showed an improvement in gross motor function in both groups, with a larger effect in the group receiving the home programme. Although the Novak and Cusick model was used as the basis of the home programmes in these studies, it is still unclear whether this resulted in home programme success because model effectiveness was not measured.

A clearer indication of the effectiveness of the model was demonstrated by Novak, (2011) through interviews with parents of children diagnosed with CP following their participation in a home programme that used a partnership based approach, as recommended by the model (Novak & Cusick, 2006). Parents not only valued home programmes and viewed them as guidance to help their child and ensure continual progress, but also felt empowered and motivated when they received support from therapists and when home programmes were flexible and part of everyday activities. Furthermore, goals set by parents, and not therapists, were more motivating, more family orientated, and specific to the child and family needs. Open and honest communication, which is a part of working together as partners, was also valued. Findings supported parental preference for partnership based home programmes as compared to a more conventional, therapist directed approach. Although studies are few and the effectiveness of the model home programme is not yet firmly established, it remains the best available evidence for effective home programme design, and is therefore used as the basis of this study.

2.5 Modifications of the model home programme

The model home programme was adapted and enhanced by Palisano et al., (2012). This study did not directly discuss home programmes as we would understand them, but did promote participation-based intervention. The emphasis was on family interests and priorities, and the child's physical and social engagement in activities and life situations, which included elements of leisure and enjoyment. The conceptual model included the following concepts: goal orientated (specific and functional tasks), family centred, collaborative, strength based, ecological (natural environment of the child) and self-determined (promoting optimal child engagement and participation). The framework is not unlike the model home programme approach (Novak et al., 2006), but Phase 3 (constructing the home programme) was replaced with an assessment of the child, family and the environment to formulate goals and assess limitations to improve participation. A greater emphasis was placed on the natural environment of the child, and participation within this environment. The therapist continues to use intervention strategies, such as improving motor abilities and function, the use of assistive devices, activity adaptations and environmental adjustments, with the primary goal to improve home and community participation within this framework.

Evidence of the effectiveness of the modification to the model is limited to a single case study that was used to illustrate implementation of the model and not necessary its effectiveness (Palisano et al., 2012). The case study demonstrated inclusion of the child in the goal setting process, which is an important consideration to optimize child motivation and participation in home programmes.

The focus on participation and community inclusion of the child with CP is a valid contribution to the home programme model.

2.6 Considerations for the South African context: The effect of resource constrained settings

It is uncertain whether the model home programme developed by Novak and Cusick, (2006) can be applied to the South African context. For this reason, a brief background about services available for children with CP in South Africa is provided, as well as an overview of the factors that have influenced home programme implementation in resource constrained settings that can be related to the South African setting.

South Africa is classified as an upper middle income country (World Bank, 2015a) with large differences between rich and poor, as reflected by its high Gini coefficient (World Bank, 2015b). Services for children with CP can range from two or more sessions per week within a private practice or special needs school to less than once per month within a government hospital, government clinic or non-profit organization (NPO). Resources within the country are not dispersed equally, and the ability of a child or family to access therapy differs according to their socioeconomic context. This, and the challenges it creates, is a further factor to consider in terms of home programme design and implementation within the South African context. The majority of published studies have been conducted in well-resourced settings, although participants have differed in socioeconomic status and residence, e.g. living in rural, semi-remote or metropolitan areas (Thompson, 1998), or in economically depressed, middle class or luxury accommodation (Hinojosa & Anderson, 1991). Studies across such contrasting groups allow for comparison with South Africa and its range of socioeconomic conditions.

Several studies have demonstrated that home programme models used in well-resourced areas are also relevant in resource constrained settings, but have emphasised important differences and additional difficulties that affect home programmes in these settings (O’Toole, 1989; Humphry, 1995). These include differences in demands, routines and family expectations. Time for home programme involvement can be limited in low resource settings due to a greater necessity to prioritise basic needs, with a home programme further increasing existing burdens (O’Toole, 1989). The responsibility of care for the disabled child, which is often time consuming due to additional and special needs, often rests on the mother or grandmother, who, as the primary caregiver, is also required to perform other household tasks (Hartley et al., 2005).

Once again, solutions lie in the need to promote functional activities that become part of daily routines rather than as separate home programmes, which caregivers struggle to implement. This finding is not dissimilar to other settings, where busy parents struggle to incorporate lengthy home programmes or separate exercise regimes (Hinojosa & Anderson, 1991). In all settings, caregivers made their own adaptions and strategies to assist their child and include them in everyday activities (Hartley et al., 2005), highlighting the importance therapists should place on gaining an understanding of the family for home programmes to be relevant and appropriate.

In poorly resourced settings, there is an even greater emphasis on understanding the context, socioeconomic realities, different value systems, cultural beliefs and individual and group priorities because additional challenges need to be considered when developing home programmes (Humphry, 1995; Goldbart & Mukherjee, 1999b; Goldbart & Mukherjee, 2001). This includes differing roles and responsibilities of parents and family members, which will affect involvement in home programmes and time available to perform them (O’Toole, 1989). Again, the need for therapists to involve other family members in assisting with therapy and the home programme, thereby improving family participation and sharing the responsibilities of care, is important. The importance of a home visit, although not always practical, is also highlighted as a means to understand the family dynamics and community context in order to make home programmes more appropriate and to provide home programme support (Humphry, 1995; Novak et al., 2009). When therapists had a greater understanding of families, communication and collaboration improved, which concomitantly improved home programme effectiveness and participation.

Another challenge in poorly resourced settings is the limited access to rehabilitation services, which results in irregular therapy attendance and minimal contact with therapists, leading to a lack of support received by families with regards to home programmes. This can be due to transportation difficulties, with families struggling to access services (Goldbart & Mukherjee, 2001), or high client loads and staff shortages in institutions with funding shortages that result in less frequent individual contact time with therapists (Law & King, 1993). Such factors lead to limited education and assistance, as well as isolation, of caregivers with regards to handling and caring for their disabled child within the home (Yousafzai et al., 2003; Hartley et al., 2005; Lygnegård et al., 2013). Supporting the implementation of home programmes, as the home programme model suggests, becomes challenging (Novak & Cusick, 2006). Home programmes that are useful, well explained, easily implemented and with appropriate input from therapists become even more valuable in light of the limited contact time and irregular therapy sessions (Law & King, 1993).

Access to assistive devices, such as wheelchairs, specialized seating or communication devices, that often form part of home programmes aimed at improving the mobility, function and participation of the child within the home and community, can also be limited (Hartley et al., 2005; Saloojee et al., 2006). Discrepancies between the needs of children with disabilities and the availability of resources in the form of assistive devices and services that are easily accessible, once again results in children and families becoming hidden, lonely and/or isolated, with associated exclusion and decreased participation within their communities (Hartley et al., 2005; Saloojee et al., 2006). Peer interactions, involvement in leisure activities and overall social acceptance and inclusion, which should form part of home programme content, become difficult to achieve (Hartley et al., 2005; Pallisano et al., 2012). Although these challenges exist, they also highlight the importance of parental involvement in intervention programmes that enable and assist caregivers in providing care for their child (Goldbart & Mukherjee, 1999b; Goldbart & Mukherjee, 2001).

Difficulties, such as those described above, are relevant and warrant consideration in poorly resourced settings in South Africa, but little is known about specific impacts these factors might have on home programmes for children with CP in the country. To my knowledge, only one study focused on home programmes within South Africa. Potterton et al., (2010), assessed the impact of a home based intervention programme on an experimental group of 60 children compared to a control group of 62. Both groups of children were below the age of two years, six months and were infected with HIV (Human Immunodeficiency Virus). Results showed a significant improvement in motor and cognitive development in the children in the experimental group, and demonstrated the effectiveness of a home programme. Although this study was specific to South Africa and to home programmes, it was not aimed at children with CP. Moreover, the focus was on the effectiveness of the home programme, and not the design and content, or factors that influence the implementation of the home programme itself. There are no studies regarding home programme content, design or implementation for children with CP and their families within South Africa.

2.7 Conclusion

Owing to the range of resource contexts within South Africa, a study that understands home programme content, design and implementation, not only within South Africa, but also within the different service delivery sectors, serving different resource contexts, will be valuable. This will cover a range of socioeconomic groups within the country, where differences and similarities, facilitators and barriers with regards to home programmes for children with CP can potentially be identified and explained.

In addition, the model home programme developed by Novak and Cusick, (2006) provides a basis to explore current practice of home programmes within South Africa. This study aims to compare the design and implementation of home programmes in South Africa to the model, and to determine if it is relevant and applicable to our context. It further explores if, and why, differences might exist, and how these impact the provision of services for children with CP and their families.

CHAPTER 3
METHODOLOGY

This chapter explains the research methods and procedures used to conduct the study which was completed in two parts. The design and setting are collectively explained, followed by the methods and procedures specific to each part.

3.1 Study design

Mixed methods design: explanatory sequential design was used with two parts in the study. Part 1 used quantitative data collection and analysis in a descriptive cross-sectional study to obtain baseline information regarding home programmes and to identify eligible participants for part two.

Part 2 used qualitative data collection and analysis. Both parts were interactive as information from the quantitative data informed the questions in the qualitative data collection as well as selection of participants for this part of the study. Timing was therefore sequential and in two distinct parts (Creswell & Plano Clark, 2011). The qualitative research was characterized as an explorative descriptive design with thematic analysis in the form of deductive coding using *a priori* categories, as well as constant comparisons to generate new categories and modify themes (Elo & Kyngäs, 2007; Corbin & Strauss, 1990).

3.2 Study setting

Within the South African context, information regarding home programmes for children with CP within four different service delivery settings, were explored. These were: Non-profit Organizations (NPOs), Special Needs Schools, Government Hospitals and Private Practice. Government clinics were not included in the study due to no participants within this setting being recruited into the study.

Non-profit Organizations are a company or association registered with the department of social development for public benefit or cause and of which no profit is generated except as ‘reasonable compensation for services rendered’ as according to the Non-profit Organisations Act 71 of 1997 (Department of Social

Development, South Africa, www.dsd.gov.za/npo/). The primary focus of the NPOs included in this study was to provide therapy services for persons with CP from poorly resourced families and areas in South Africa.

Special needs schools (Learners with Special Educational Needs (LSEN)) are public schools that are registered and run under the Department of Education and Training and provide services for children with special educational needs. The schools included in the study serve learners with physical and learning difficulties, including CP. Depending on the location of the school, which includes the catchment area, these can be learners from well-resourced or poorly resourced families and communities. Special needs schools have allocated therapy posts, which may consist of physiotherapists and occupational therapists amongst others. Children within these schools receive therapy on a regular basis within allocated times during the school day (Pillay & Terlizzi, 2009).

Government Hospitals are referred to as public hospitals funded by the government. They usually provide services for poorer populations who cannot afford private health care. Services are provided to a range of patients and payment is required, depending on patient income and economic status. Allied health professionals, which include occupational therapists and physiotherapists, provide services within these institutions. Public hospitals vary in size and level of expertise with patient numbers generally high and staff shortages common (Cullinan, 2006).

Private Practices are independent of the government and are privately funded, primarily through either medical aids/insurance, the client or the parents of the client, in the case of children. These account for 16% of the South African population and are generally, a wealthier population group who have the financial capacity to afford medical aid and/or private practice therapy rates (Medical Schemes, 2014-15). Patients are able to choose which practitioner they would like to attend based on referral or personal preference (McIntyre, 2010).

The range of service delivery settings is significant for a representative view and a true comparison between the available treatment for children with CP in South Africa and to understand if and why differences exist in different service settings.

The inclusion of different provinces in South Africa was guided by the contact information available through the South African Neurodevelopmental Therapy Association (SANDTA), an organization used to recruit participants. This database includes therapists from six different provinces of South Africa: KwaZulu-Natal, Southern Gauteng, Northern Gauteng, the Free State, Western Cape and Eastern Cape.

3.3 PART 1: QUANTITATIVE QUESTIONNAIRE

3.3.1 Study population

The study focused on descriptions and views from occupational therapists and physiotherapists who were actively involved in developing and implementing home programmes for young children with CP and who have a common frame of reference (Neurodevelopmental therapy) as they are all members of SANDTA. The South African Neurodevelopmental Therapy Association is a multidisciplinary association for therapists interested in and treating patients with neuromotor conditions within South Africa (South African Neurodevelopmental Therapy Association, www.sandta.org.za). Participants were recruited through this organization as many were likely to be treating children with CP and involved in home programme implementation. Participation from both occupational therapists and physiotherapists was requested due to similarities of their therapeutic role.

A questionnaire was sent to the total population of occupational therapists and physiotherapists who belong to SANDTA, and those with training and experience in neurodevelopmental therapy, treat young children (between the age of two and ten years old) with cerebral palsy and regularly provide home programmes for these children, were asked to respond. The researcher wished to explore the knowledge and insight into effective home programmes for these children from therapists with a greater level of experience.

3.3.2 Sample size

Total population sampling was used and the questionnaire was sent to the 517 therapists (241 occupational therapists and 276 physiotherapists) who were SANDTA members with the assistance of SANDTA. Forty eight responses, including two incomplete responses, of 17 occupational therapists and 31 physiotherapists were obtained. The two incomplete responses were used in the study.

3.3.3 Research instrument

Home Programme Questionnaire

The questionnaire, developed by the researcher, focused on demographic information, qualifications and work experience of participants as well as baseline information regarding home programmes for children with CP (Appendix A). The information regarding home programmes was related to home programme content, design and implementation. Questions were guided by the literature applicable to home programmes and children with CP, particularly the model home programme developed by Novak and Cusick (2006).

Thirteen of the 39 items within the questionnaire focused on the demographics, qualifications and work experience of participants. The remaining 26 questions were grouped according to the components of the model home programme developed by Novak and Cusick (2006) and focused on home programme content, design and implementation. Participants were able to indicate a choice among multiple, pre-set answer options for each question or choose ‘other’ if their preference was not shown. A comment, ‘textbox’ was included for each question. Five descriptive, open-ended questions were part of the questionnaire. Three of these sought to understand the participant’s views on home programme purpose and description and the remaining two focused on facilitators and barriers to home programmes related to the service delivery setting of the participant.

The questionnaire was transcribed onto Survey Monkey®, an online survey programme, which allows convenient online access and return, and was a preferred method due to cost and time effectiveness. In addition, an online survey was chosen in light of evidence for web survey equivalence when compared to hard copy questionnaires (Kaplowitz et al. 2004).

Copy of Home Programmes

Therapists were asked to provide a copy of a home programme either *via* email, directly to the researcher, or with the use of ‘dropittome’, an internet link created to anonymously send the home programme document to the researcher.

3.3.4 Content validity pilot study

The questionnaire was piloted for content validity and relevance by six subject matter expert (SME) therapists (4 occupational therapists and 2 physiotherapists) who were working with children with CP and had experience providing home programmes. The content validity index (CVI) was used, whereby each SME was required to rate each question within the questionnaire according to relevance, clarity, simplicity and ambiguity on a 4-point scale and provide comments and/or suggestions as necessary. An average for each category within each question was then calculated. (Waltz & Bausell, 1983; Yaghmale, 2003).

Items with a CVI over 0.75 remained in the questionnaire, with those scoring below this threshold discarded (Yaghmale, 2003). No questions in the questionnaire received a score below 0.79. Sores were 0.79 for three questions both regarding clarity and ambiguity. One question was discarded and the other two were modified. Several other questions were modified, three questions were added and two questions were combined with similar items – consistent with comments and suggestions from the participants. The final result of the questionnaire consisted of 39 items (Appendix A).

3.3.5 Research procedure

Ethical procedures were followed and ethical clearance was obtained from the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (M140621) (Appendix B). A formal permission letter (Appendix C) was emailed to the chairperson of SANDTA, introducing the researcher, explaining the study and requesting permission and assistance from the organization to send information to its members.

After permission and assistance was obtained, an information sheet/ letter of invitation (Appendix D) and the questionnaire (Appendix A) was sent to a designated member of the SANDTA office staff who emailed the information to all SANDTA members whose email addresses were within the SANDTA office data base. The questionnaire was in the form of an online link to Survey Monkey® within the information sheet. Frequent and periodic reminders were sent through SANDTA to potential participants. The questionnaire was thus sent a total of six times over a period of approximately five months. The researcher also created awareness of the study by attending the SANDTA conference and speaking to potential participants, encouraging them to complete the survey when they received it. Following a five month period the survey was closed and the data were downloaded by the researcher.

Completion of the survey was regarded as informed consent. This was both confidential and anonymous, however, any participants who were willing to participate in Part 2 of the study, were requested to provide the researcher with their contact details in the space provided, when they returned the questionnaire.

3.3.6 Data management and analysis

Questions from the questionnaire were grouped according to the five phases of the Novak and Cusick model home programme (Novak and Cusick 2006). Responses were analysed on a percentage basis, i.e. the percentage of therapists from each setting and overall, rather than actual counts. This was to present differences across service delivery settings that accounted for the varying number of respondents from each setting, especially the large number of participants (40% of total respondents) who worked in private practice.

Results are presented in the form of frequencies, demonstrating the total responses as well as and the responses within each service delivery setting. Where few differences were evident in the service delivery settings, only the total responses were presented and the differences described.

Five questions within the questionnaire were open-ended and required a descriptive response. These written responses were initially grouped according to service delivery setting, followed by deductive content analysis. This was in the form of a matrix where themes and categories were created within the limits of the matrix but also unique to the obtained data (Elo & Kyngäs, 2007). This was based on the Novak and Cusick model home programme (Novak & Cusick, 2006) and presented according to the frequencies of the codes. The analysis underwent peer review throughout the process and agreement or modification was made accordingly (Shenton, 2004). Both reviewers had knowledge and experience regarding qualitative research, one of which had over 30 years of experience working with children with CP. Questions 35 and 36 of the questionnaire overlapped between Part 1 and Part 2 of the study and were therefore analysed within Part 2.

The examples of home programmes that were received were not analysed and their results were not included in the study because of the limited number. Only five examples were received and this was not enough information for triangulation in Part 2 of the study.

Data from Part 1 further informed the open-ended questions developed for Part 2 and facilitated selection of participants for Part 2.

3.4 PART 2: QUALITATIVE INTERVIEWS

3.4.1 Study population

Occupational therapists and physiotherapists who indicated their willingness to participate in Part 2 of the study, by providing their contact details on the questionnaire, were chosen based on the following inclusion criteria:

- Completion of the eight week Basic Paediatric Bobath/Neurodevelopmental Therapy Course based on the Bobath Concept
- A minimum of three years practical therapy experience in treating children with CP and currently practicing within this field
- Treating children with CP either in a private practice, special needs school, non-profit organization, public/government hospital or a government clinic
- A client load of children with CP ranging between the age of two to ten years old

Based on their training and experience, it was anticipated that this select group would provide valuable insight about home programmes for children with CP within their particular service delivery setting.

3.4.2 Sample size

From the completed and returned questionnaires, eligible therapists who met the inclusion criteria and who consented to the interview were selected using stratified sampling across the different service delivery settings. Elements of purposive sampling were also used because participants were prioritised according to their additional qualifications and experience in providing services for children with CP and their families, i.e. those with a larger client load, more years of experience and further qualifications or training within the field of child neurology were contacted first (Strydom, 2011).

Of the 48 participants within Part 1 of the study, 25 (52%) were willing to take part in Part 2. Fourteen of these met all aspects of the inclusion criteria. This included five therapists working within NPOs, one within a special needs school, two within government hospitals and six private practitioners. There were no participants from government clinics.

The total number of participants was determined by data saturation and no further interviews were conducted with participants within each of the different service delivery settings when no new information was generated (Schurink et al., 2011). Due to a lack of data saturation for the group of participants working within special needs schools and government hospitals, three participants, two working within special needs schools and one working within a government hospital, who did not meet all aspects of the inclusion criteria, were included and interviewed.

The total of 15 interviews were completed with four participants working at NPOs, three school therapists, three hospital therapists and five private practitioners.

3.4.3 Research instrument

Semi structured interview guide

The leading, predetermined questions within the interview were structured according to the phases of the model home programme approach (Novak & Cusick, 2006), with prompts provided specific to the particular service delivery setting and based on the data gained from Part 1 (Appendix E). It was found that there were challenges regarding a family centred approach to home programmes that were particularly evident in poorly resourced settings such as NPOs and government hospitals. Questions were therefore developed to clarify these and other perceptions and views that were highlighted in Part 1 of the study.

3.4.4 Research procedure

3.4.4.1 Pilot study on interview guide

A pilot study of three semi structured interviews was conducted to improve clarity and simplicity of the questions and to minimize ambiguity. The participants were three physiotherapists, one who met all the inclusion criteria and the other two who either had less years of experience working with children with CP or whose client load was not within the required age group. The researcher asked each of them to attend a practice interview, to consider the answers to each question and to comment on the questions.

No overt changes to the questions took place after feedback and comments from these participants. The pilot study improved the quality of the study interviews by allowing the researcher to practise interviewing skills and also assisted with the practical aspects regarding interviews (Greeff, 2011).

3.4.4.2 Semi structured interviews

Semi-structured interviews were conducted with the selected therapists from Part 1 of the study as described above. The researcher sought to guide participants to elaborate and further discuss aspects regarding home programmes for children with CP. Experiences and perceptions of the participants were thus explored in more detail (Greeff, 2011; Britten, 1995). The interview times ranged from 45min – 60min, confirmed with a pilot study.

Dependant on the contact details provided (telephone or email), eligible participants were contacted by the researcher. An additional information sheet (Appendix F) and informed consent for participation and for voice recording (Appendix G and H) was then sent *via* email to each therapist. An appointment was scheduled, at the participant's convenience, for the semi structured interview, once consent was obtained.

Interviews took place using modern technology, i.e. Skype, with voice recording. This was described as a valid and scientific process of data collection (Bertrand & Bourdeau, 2010) and was found to be the most cost effective procedure without compromising the face-to-face experience of the interview. Interaction was simultaneous, as with conventional interviews, with no loss of visual aspects or interpersonal communication (Hanna, 2012). Since participants were located in different regions within South Africa, Skype was the most affordable and practical option. All the participants had internet access and those that did not have Skype accounts were able to create an account for the purpose of the study.

It was more convenient for one of the participants to be telephoned at work with the use of a landline. Although the face-to-face value was lost, it was better to accommodate the request of the participant, and the information obtained was not compromised. Due to internet connection difficulties a further three interviews used only voice and not video.

The interviews were recorded using ‘iFree Skype recorder’ as well as ‘Audio Memos Free’. The recorded interviews ran between 44 and 92 minutes (averaging 68 minutes).

3.4.5 Trustworthiness

The first aspect of trustworthiness that was considered included credibility, whereby information gathered from participants reflect their views and whether the study subject was accurately described (Schurink et al., 2011). This was ensured by the following: the open ended questions formulated for the interview were guided by the literature pertaining to home programmes for children with CP as well as from the answers from participants that were given in the Part 1 questionnaire. Two different data collection methods were used and a range of participants working in four different settings was collected, which provided a variety of perspectives (Shenton, 2004).

Furthermore, the researcher studied participant’s individual questionnaire response from Part 1, before each interview and used this information as leading questions and prompts to clarify their views and gain greater insight into their opinions. Information shared by participants was often reflected back by the researcher or similar questions were rephrased to further improve validity. The findings were directly related and compared to previous research in the field (Shenton, 2004).

The second criterion for trustworthiness in qualitative research is transferability. Although the study focused on a select group of participants, these represent a range of contexts that provide treatment for children with CP that are unique to South Africa. Each context, also regarded as the service delivery setting, was explained and detailed according to each participant. Transferability was further enhanced by the sample size from these settings and the use of two different data collection methods.

Dependability of the study was ensured by providing a detailed description of the research methods and the procedure. This was well documented and systematic throughout the study (Schurink et al., 2011; Shenton, 2004). The final criterion for trustworthiness in qualitative research, conformability, was ensured by the method of data analysis. This was done in the form of deductive coding primarily by the researcher, but each set of analysed data underwent peer review. The data were discussed and modifications were made which improved the objectivity of the data (Schurink et al., 2011).

3.4.6 Data management and analysis

The interviews were transcribed verbatim by a transcription company. Once complete, the researcher went through each recording together with the transcription to both familiarise herself with the data and ensure accuracy.

As with the open ended questions in Part 1, the data in Part 2 were analysed by content analysis using a deductive approach, with an unconstrained matrix (Elo & Kyngäs, 2007) (see example of Part 2 analysis in Appendix I). The five phases of the model home programme approach by Novak and Cusick (2006) were used to provide *a priori* themes and categories. Subcategories were guided by the information pertaining to these phases and were related to the interview questions. A template was therefore created by the researcher which guided the deductive coding of the transcripts (Crabtree & Miller, 1999; Novak & Cusick, 2006).

The template was ‘unstructured’ and followed principles of inductive coding as new codes and conceptual categories were identified and the template modified within the broader themes of the study (Elo & Kyngäs, 2007). This allowed comparison to the literature but was data driven to capture the perceptions and experiences of participants (Fereday & Muir-Cochrane, 2006).

Each interview was analysed individually in the form of line by line analysis. The constant comparative method was used whereby categories were either confirmed or new ones generated during the process of open coding. These were then grouped and integrated in axial coding by making connections between similar data. The final stage, selective coding, related to the core research questions and allowed interpretation (Schurink et al., 2011; Corbin & Strauss, 1990).

Transcripts were analysed per service delivery setting and the ‘template’ modified as analysis progressed. The ‘new’ template was then used for analysis of the data from the next service delivery setting with further, but significantly fewer modifications included. This continued for all service delivery settings until no modifications were necessary and no new categories emerged, that is, when data saturation was reached (Schurink et al., 2011).

Analysis took place subsequent to the interviews and data saturation occurred before analysis was complete. The amount of data verified the existing codes and improved the credibility of the study. Furthermore, content validation took place through peer review after the analysis of each service delivery setting and changes were made according to the given recommendations (Graneheim & Lundman, 2004; Elo & Kyngäs, 2007).

This form of analysis allowed the data to be understood as a whole, with similarities and differences in service delivery settings clear from greater or lesser meaning placed on certain categories. This was displayed by the total comments related to each code per setting and presented and described accordingly.

These results are presented by theme with the corresponding categories and subcategories as subsections of the report. The codes, within each subcategory, were explained and described with evidence and support provided by embedded quotations, short eye-catching quotations, or longer quotations dependant on relevance and applicability (Delport & Fouché, 2011).

CHAPTER 4
RESULTS

This chapter presents the data from Part 1 and Part 2 of the study. The results for Part 1 consider the data obtained from 48 participants who completed a questionnaire regarding home programme content, design and implementation for young children with CP. Part 2 presents data obtained from 15 participants through semi-structured interviews. Apart from two participants, who both worked within special needs schools, all respondents met the inclusion criteria for participation in Part 2 as they had at least three years of experience working with children with CP between the ages of 2 and 10 years old. They had also completed the eight week Basic Paediatric Bobath/Neurodevelopmental Therapy Course based on the Bobath Concept.

PART 1: QUANTITATIVE QUESTIONNAIRE

Results for this Part include demographic information, qualifications and work experience of the participants, as well as experience and practice of home programmes in their particular service delivery setting, namely: Non-profit Organizations (NPOs), special needs schools (SNS), government hospitals (GH) and private practices (PP). Two participants working at schools completed only page one of the two page questionnaire. However, the information from the sections they did complete is valuable and so is included for the relevant sections. The data from the questionnaire is presented under the five phases of the model home programme approach developed by Novak and Cusick (2006).

4.1 DEMOGRAPHICS

4.1.1. Location and work

Over half the participants were from either Southern Gauteng or the Western Cape with the fewest responses being obtained from participants in Northern Gauteng and Mpumalanga (Table 4.1).

Table 4.1 Percentage of participants working in each province and service delivery setting (n=48 participants).

<table>
<tr><th></th><th colspan="7">Percentage (n)</th></tr>
<tr><th rowspan="2">Provincial location</th><th>KwaZulu-Natal</th><th>Southern Gauteng</th><th>Northern Gauteng</th><th>Free State</th><th>Western Cape</th><th>Eastern Cape</th><th>Mpuma-langa</th></tr>
<tr><td>16.7 (8)</td><td>31.2 (15)</td><td>4.1 (2)</td><td>10.4 (5)</td><td>25.0 (12)</td><td>10.4 (5)</td><td>2.0 (1)</td></tr>
<tr><td colspan="8"></td></tr>
<tr><th rowspan="2">Service delivery setting</th><th>Government Hospital</th><th>Private Practice</th><th>Non- Profit Organization</th><th>Special Needs School</th><th>Government Clinic</th></tr>
<tr><td>22.9 (11)</td><td>39.6 (19)</td><td>14.6 (7)</td><td>22.9 (11)</td><td>0 (0)</td></tr>
</table>

The greatest number of the participants (n=19; 39.6%) who responded were private practitioners, whilst the least number (n=7; 14.6%) of participants worked in NPOs. Five participants volunteered or worked within two or more settings on a part time basis. There were no participants working in government clinics.

4.1.2 Qualifications and experience

Three quarters of the participants were NDT certified therapists (attendance of the basic eight week paediatric foundation course, based on the Bobath/NDT approach), whilst over half had additional qualifications or training relevant to the management and treatment of children with CP (Table 4.2).

Table 4.2 Qualifications and work experience of the participants with regards to working with children with CP (n=48 participants).

Qualification	Percentage (n)	Work experience with children with CP	Percentage (n)
Occupational therapy degree	35.4 (17)	Less than 1 year	2.1 (1)
Physiotherapy degree	64.5 (31)	1-3 years	10.4 (5)
NDT certified	75.0 (36)	3-6 years	22.9 (11)
Advanced NDT course (Baby course)	22.9 (11)	6-10 years	22.9 (11)
Advanced NDT course (Dyskinesia)	4.2 (2)	Over 10 years	41.7(20)
Advanced NDT course (Vision)	2.1 (1)		
Wheelchair seating (basic or advanced)	18.8 (9)		
Sensory integration	2.1 (1)		
Master’s degree (paediatrics)	6.3 (3)		

Of those with additional qualification or training, 35% had more than one. Just under half of the participants had 3-10 years' experience working with children with CP, with 42% having over 10 years of experience (Table 4.2).

Almost all participants (95.8%) were involved in home programme design and implementation. The participants indicated that 29 or 60.4% of them always prescribed a home programme while 17 (35.4%) sometimes did. Only two participants had never prescribed a home programme.

4.1.3 Client load and characteristics of children treated

A third of the participants had an average client load of 10-20 children who were seen monthly with 37% having a greater monthly client load (more than 20) (Table 4.3).

Table 4.3 Client load of participants in terms of children treated (n=48 participants).

Client load of children with CP treated per month	Percentage (n)	Client load of children with CP treated per week	Percentage (n)
< 5 children	2.0 (1)	< 5 children	2.08 (1)
5 - 10 children	29.1 (14).	5 - 10 children	64.58 (31)
10 - 20 children	31.2 (15)	10 - 15 children	14.58 (7)
> 20 children	37.5 (18)	15 - 20 children	6.25 (3)
		> 20 children	12.50 (6)

The majority of the children seen were between the ages of 2-10 years old and included all levels of the Gross Motor Functional Classification System (GMFCS) (Palisano et al., 1997) (Table 4.4). This incorporated the target age group of children with CP within the study as well as participant experience with children presenting a variety of impairments.

Table 4.4 Percentage of participants that treated children in the different age groups and GMFCS levels (n=48 participants).

Ages of children with CP treated	**Percentage (n)**	**Gross Motor Functional Classification System levels of the children with CP treated**	**Percentage (n)**
Below 2 years old	8.3 (4)	GMFCS I	4.1 (2)
2 - 10 years old	85.4 (41)	GMFCS II	14.5(7)
10 - 15 years old	6.2 (3)	GMFCS III	25.0 (12)
		GMFCS IV	27.0 (13)
		GMFCS V	29.1 (14)
		All GMFCS levels	58.3 (28)

4.2 DESIGN, CONTENT AND IMPLEMENTATION OF HOME PROGRAMMES

The model home programme developed by Novak and Cusick (2006) was used as a framework in analysing responses to the questionnaire. The results are therefore presented in the five phases that, according to Novak and Cusick, provide a ‘starting point’ for therapists to follow when formulating and implementing home programmes for children with CP.

A brief explanation in the form of a diagram is presented at the beginning of each phase as a reminder of the key characteristics of the phase.

4.2.1. Phase 1: Establishing a collaborative relationship with the child’s parent and/or caregiver

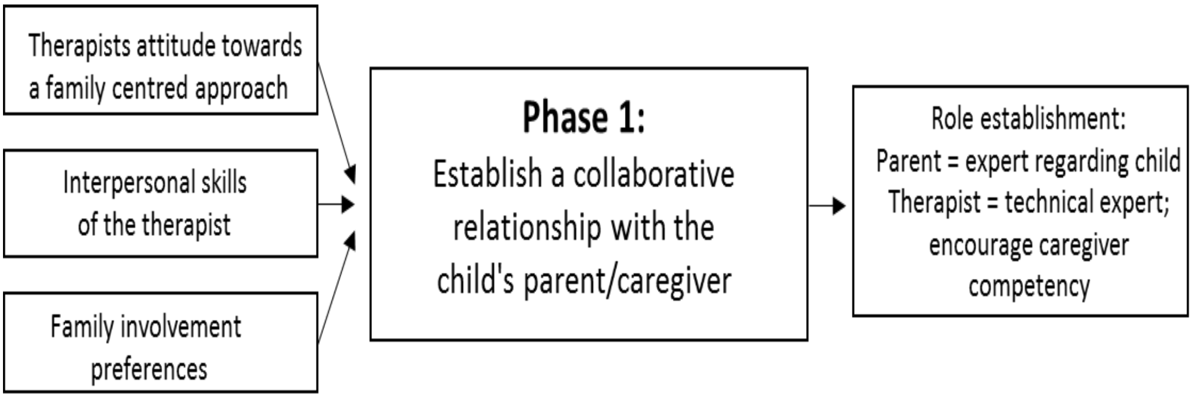


Figure 4.1 Phase 1 of the model home programme, modified from Novak & Cusick (2006).

4.2.1.1 Home programme approach

The majority of the participants regard their home programmes as being child and family centred (83%) and individualized (78%). It is clear that home programme approach for the school based participants is more child-centred and less individualized or family centred than the other settings.

Results are based on the percentage of responses, where participants were able to indicate more than one answer, if appropriate. Two school participants did not complete this question (Figure 4.2).

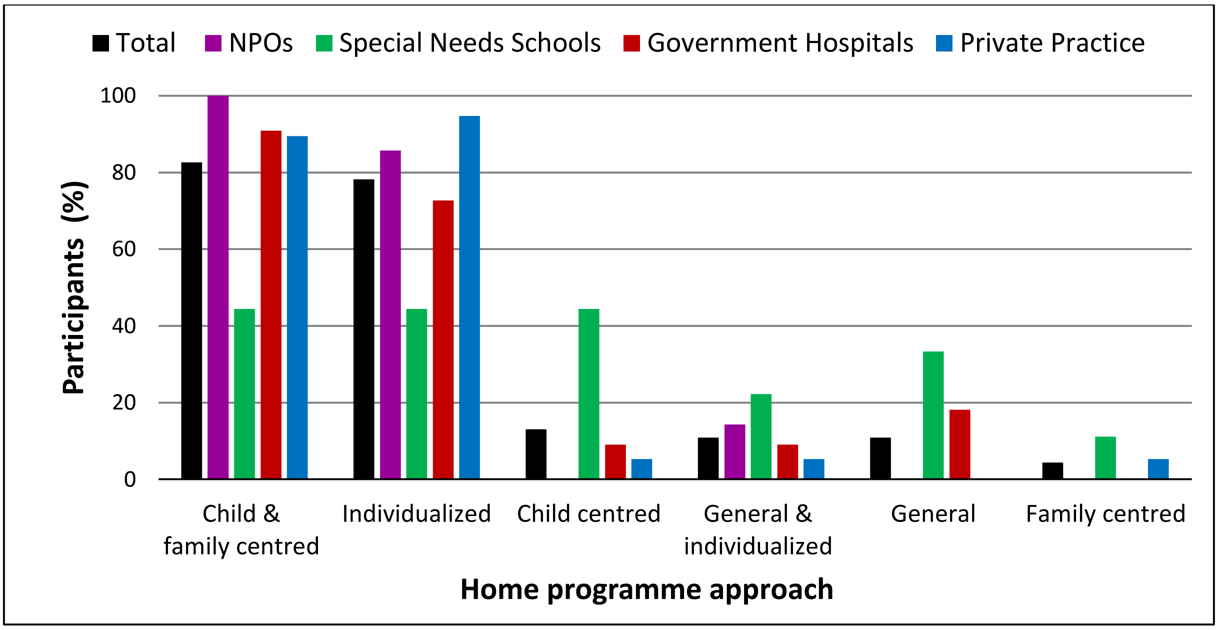


Figure 4.2 Percentage of participants, across the service delivery settings, that described their approach to home programmes as consisting of each of the presented approaches (n = 46 participants).

4.2.1.2 Home programme starting point

Over 40% of the participants consider an assessment of the child to be the starting point when designing a home programme, particularly those in schools and hospitals.

Only 10% of participants (mostly those working in NPOs), first established a relationship with the parent and/or caregiver (Figure 4.3). On the questionnaire, the participants had the option of indicating 'other' if they did not agree with the given options. This accounted 23% of participants and their reasons for doing so included parental empowerment, family involvement and a combination of the available choices as their starting point.

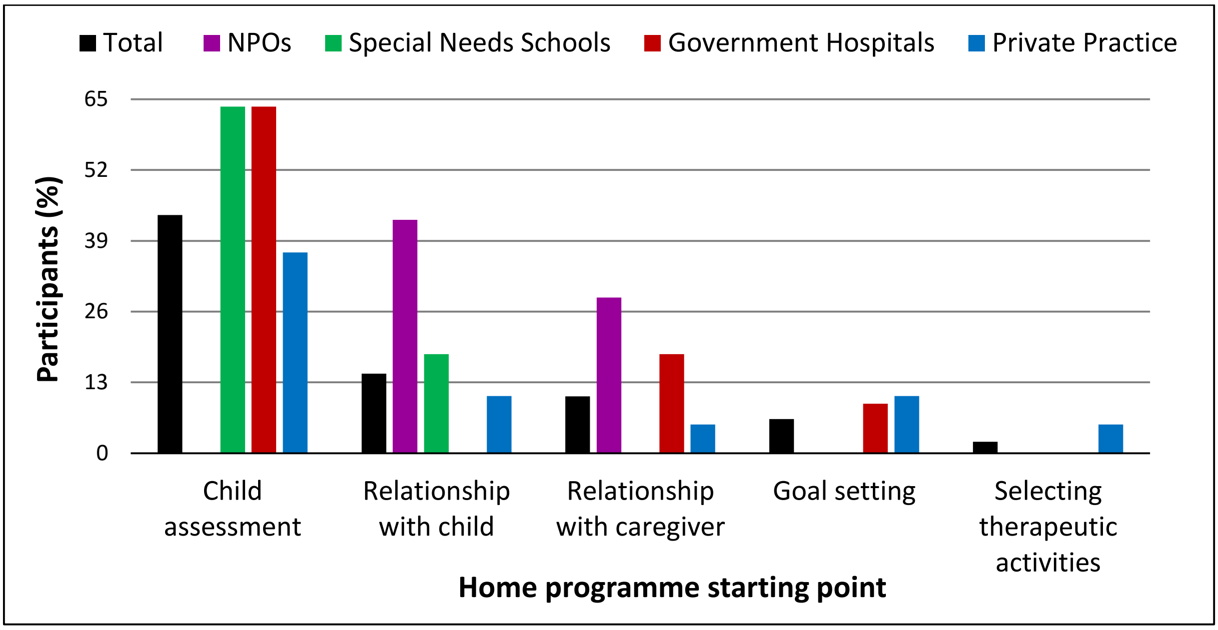


Figure 4.3 Percentage of participants, across the service delivery settings, that described their starting point to home programmes as each of the presented starting points (n = 48 participants).

4.2.1.3 The role of the therapist

Participants within all settings considered their role primarily to be a support to the child and the family (96%). Less than half of the respondents (n = 22; 46 %) identified with the role of the therapist being that of a partner as emphasised by the model home programme (Novak & Cusick, 2006) (Figure 4.4).

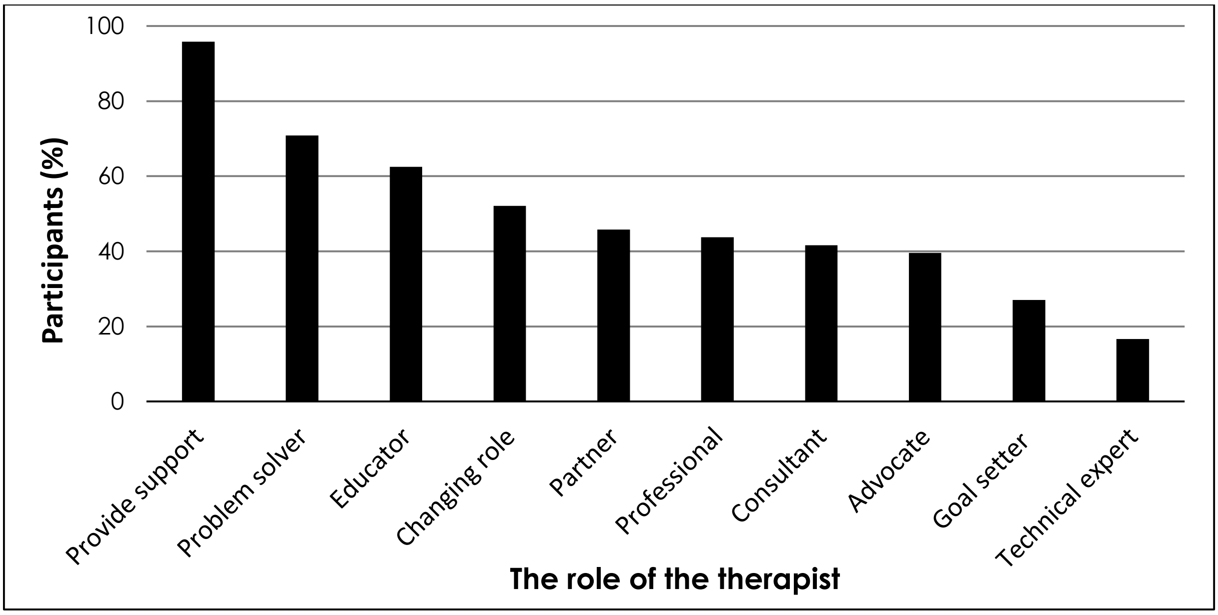


Figure 4.4 Percentage of participants that identified themselves as performing each of the presented roles with regards to home programmes. Data from all settings were combined (n = 48 participants).

4.2.1.4 Home programme purpose and description related to developing a collaborative relationship with parents and/or caregivers

Participants answered open ended questions regarding the purpose and description of home programmes for children with CP. These were analysed using deductive content analysis based on Novak and Cusick's model home programme (Novak & Cusick, 2006) and any differences across service delivery settings highlighted.

Due to similarities in responses for the three open-ended questions related to home programme purpose and description and due to similarities across the service delivery settings, responses to these questions were combined and presented together. The questions were:

- **What is your understanding of a home programme for the young child with CP?**
- **Please describe a typical home programme**
- **What is the purpose of a home programme? Why do you prescribe home programmes?**

The first theme represented ***a family centred approach*** where participants emphasised the importance of family involvement (Appendix J). This is explained under the following headings:

- Teaching the parents what to do, or empowerment
- Supporting the parents' specific needs
- Encouraging active participation

Teaching the parents what to do – 'empowerment"

Nearly half the participants (42%) described the purpose of a home programme as that of enabling and equipping parents/caregivers in their role as parents/caregivers. Providing education and access to information was also regarded as important. Nineteen percent of participants specified this to be in the form of advice and practical guidelines. A further 10% prioritized engaging the child in a fun way (Figure 4.5).

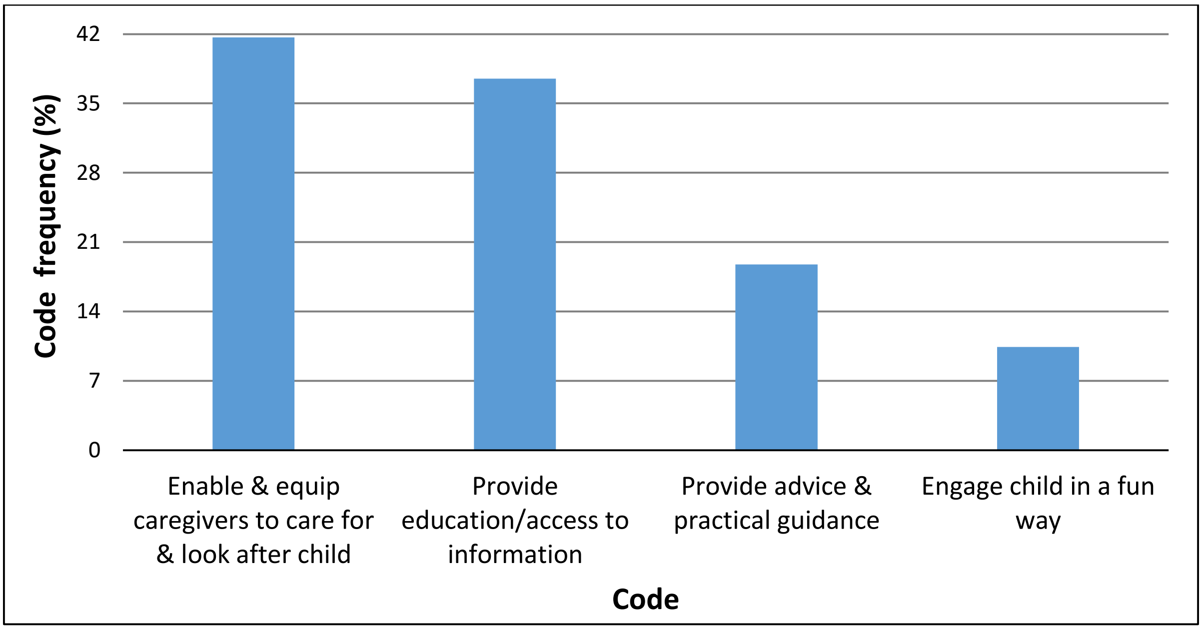


Figure 4.5 Code frequency of participant responses regarding parental empowerment. Data from all settings were combined (n = 48 participants).

Supporting the parents' specific needs

Seventeen percent of the participants felt that home programmes should be manageable, short and easy without overwhelming parents or creating an extra burden or strain. They felt that appropriate support should be provided and the specific needs of the family should to be considered (Figure 4.6).

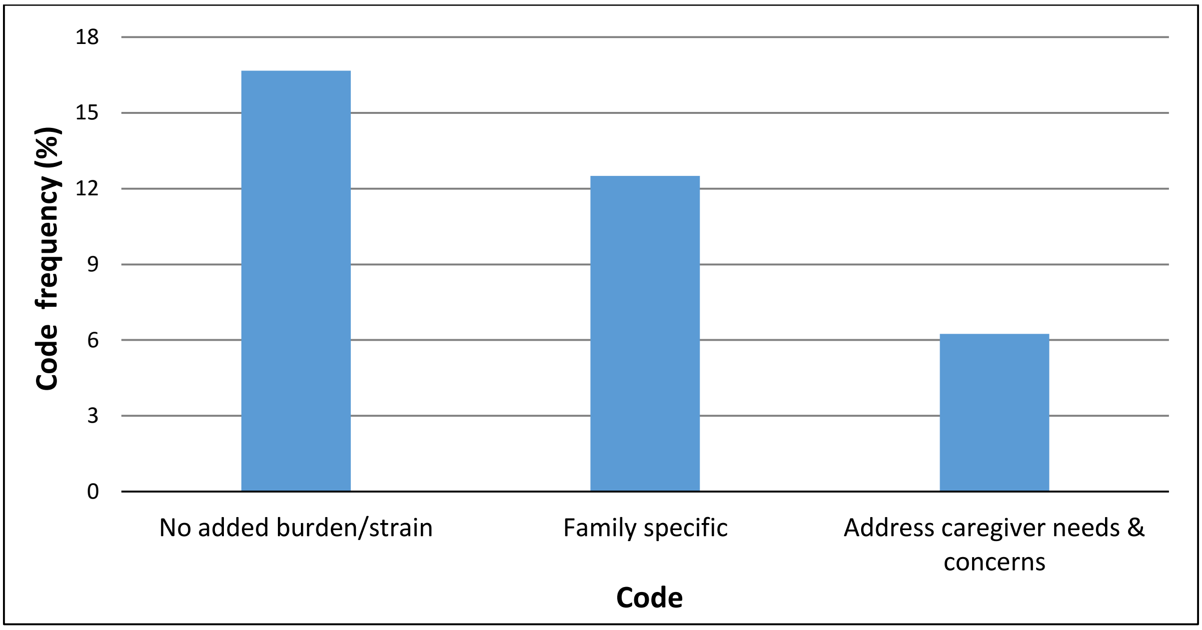


Figure 4.6 Code frequency of participant responses regarding support of specific parental/caregiver needs within home programmes. Data from all settings were combined (n = 48 participants).

Encourage active participation

Participants valued parental and/or caregiver collaboration and involvement because they were in daily contact with their child, handled their child the most and therefore were able to make the most impact. Although comments related to parental involvement, ownership and responsibility of home programmes and rehabilitation, only 21% prioritized collaborative goal setting in this process (Figure 4.7).

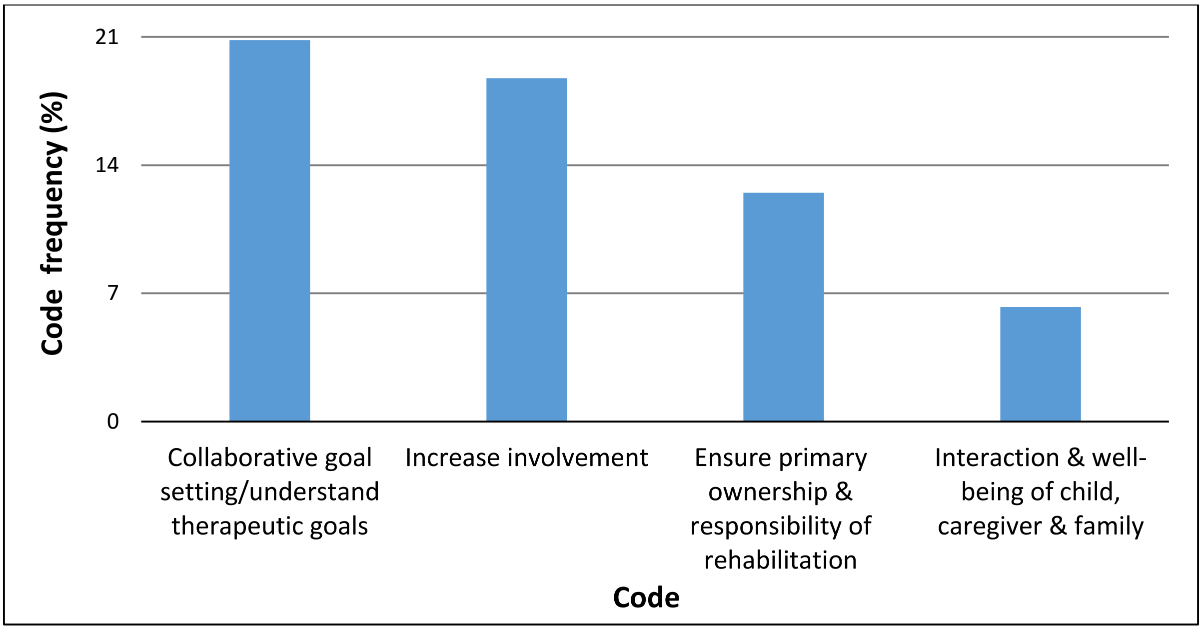


Figure 4.7 Code frequency of participant responses regarding active participation of parents/caregivers in home programmes. Data from all settings were combined (n = 48 participants).

4.2.2. Phase 2: Collaborative goal setting

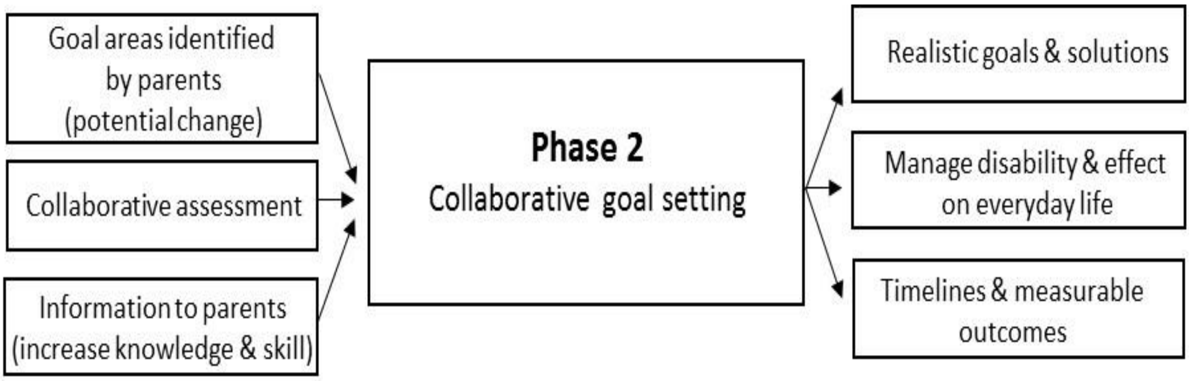


Figure 4.8 Phase 2 of the ‘model home programme approach’, modified from Novak & Cusick (2006).

4.2.2.1. Goal establishment

According to the participants, the goals of a home programme were determined mainly by an assessment of the child (65%) and the parent and/or caregiver and family (56%). Participants within NPOs (86%) placed a greater emphasis on parent and/or caregiver and family involvement in goal setting than other settings (Figure 4.9).

Participants were able to indicate more than one answer if appropriate. Five respondents (10%) indicated ‘other’, which were collectively categorized as: A partnership between the therapist, parent, family and child; dependence on the willingness and active involvement of parents; the multidisciplinary team; determined by potential future difficulties and goals that assist access to the school curriculum.

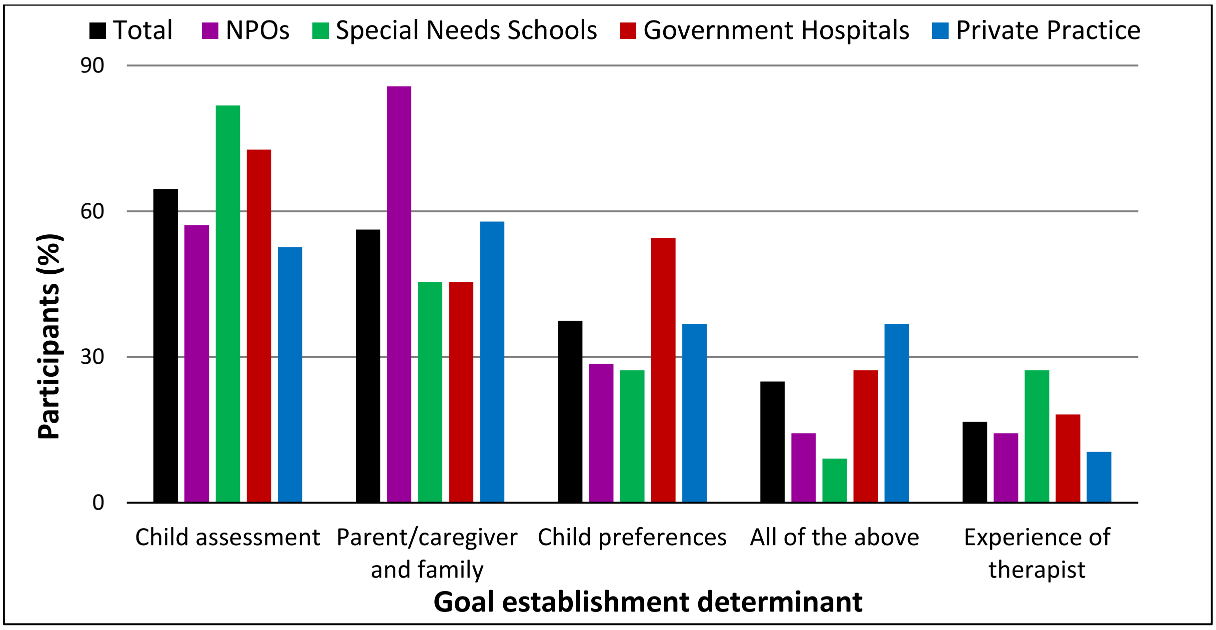


Figure 4.9 Percentage of participants, across the service delivery settings, that described goal establishment within home programmes as consisting of each of the presented goal setting determinants (n = 48 participants).

4.2.3 Phase 3: Constructing the home programme

Figure 4.10 Phase 3 of the ‘model home programme approach’, modified from Novak & Cusick (2006).

4.2.3.1 Home programme content

The content of a typical home programme was most frequently described as activities incorporated into activities of daily living (ADL) (72%). Participants within NPOs also regarded recreational activities and play as important, while the majority of participants within schools considered adaptive equipment and assistive devices as part of home programme content (Figure 4.11).

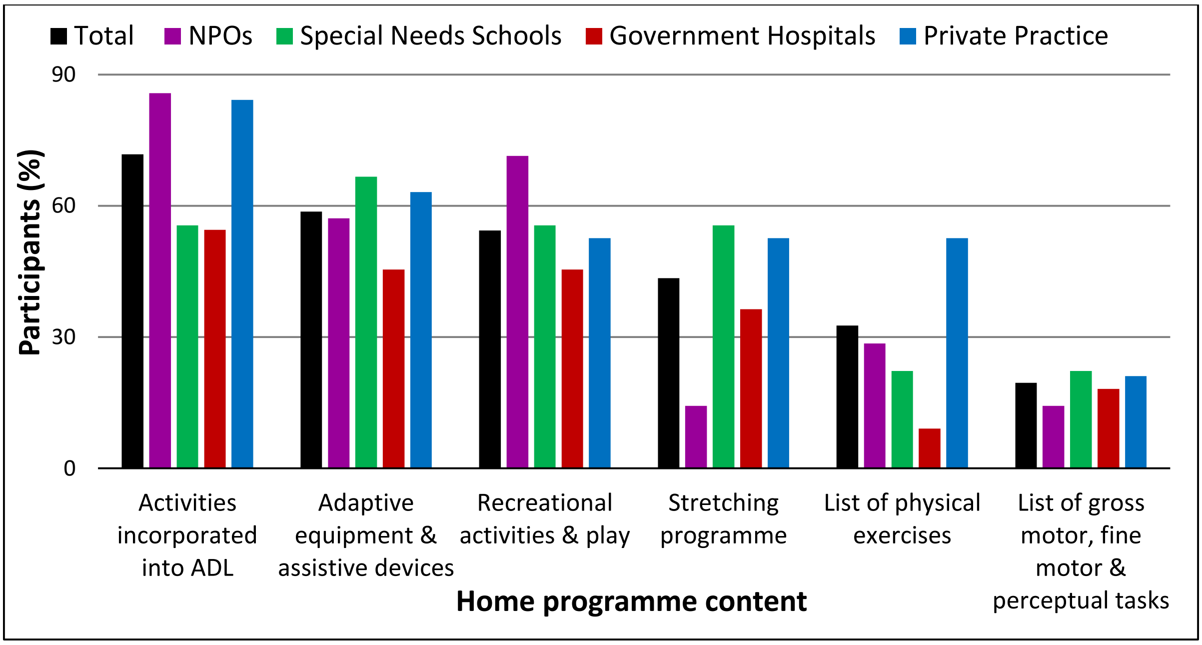


Figure 4.11 Percentage of participants, across the service delivery settings, that described the content of home programmes as consisting of each of the presented tasks or activities (n = 46 participants).

Participants were able to indicate more than one answer if appropriate. Six respondents (13%) indicated 'other' which were collectively categorized as: Need and function dependent; corrective seating and communication strategies. Eight participants indicated all of the available options and two school participants did not complete this question.

4.2.3.2 Home programme purpose and description related to constructing the home programme

The second theme of the open ended questions regarding home programme purpose and description was ***selecting therapeutic activities*** and was described as meeting the individual needs of the child (Appendix J).

This is explained under the following headings:

- Specialized stimulation, handling techniques and exercises
- Individualized programme to improve client factors and performance skills
- Individualized programme to improve participation

Specialized stimulation, handling techniques and exercises

Participants (44%) included stretches within prescribed home programmes in order to maintain or increase range of motion. Guidelines, advice and ideas with regards to positioning were also regarded as important (40%) (Figure 4.12).

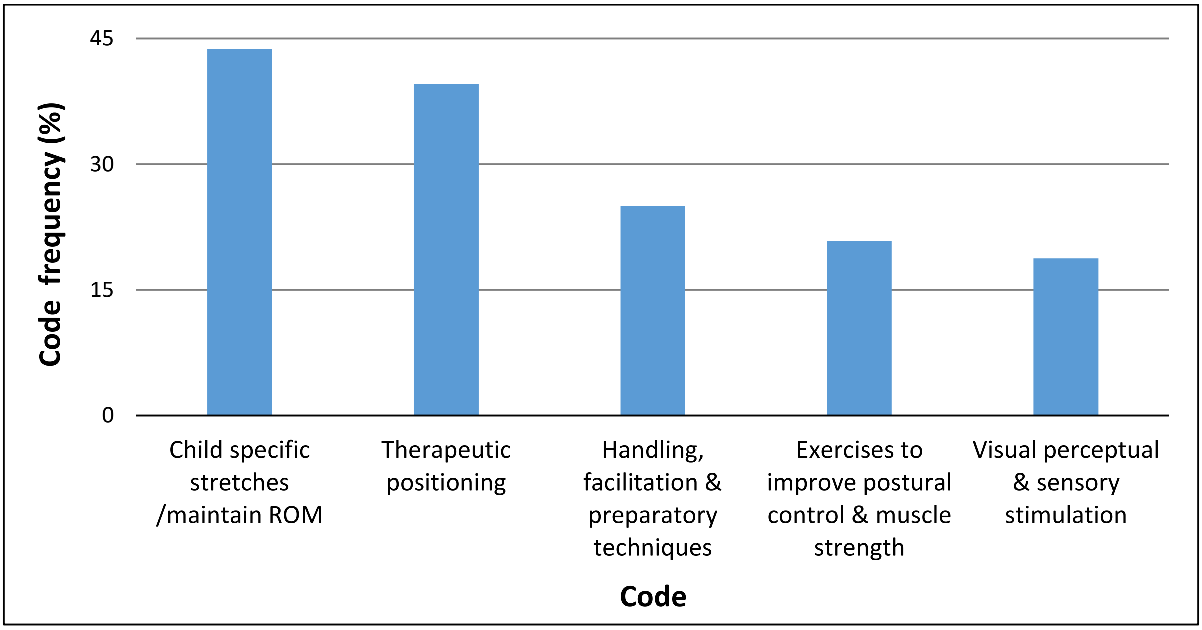


Figure 4.12 Code frequency of participant responses regarding specialized stimulation, handling techniques and exercises as part of home programmes. Data from all settings were combined (n = 48 participants).

Individualized programme to improve client factors and performance skills

A third of participants (n=15) felt that home programmes should provide appropriate stimulation to facilitate the child's development in all areas. Cognitive development and communication was emphasised, as well as activities to enhance gross and fine motor skills (Figure 4.13).

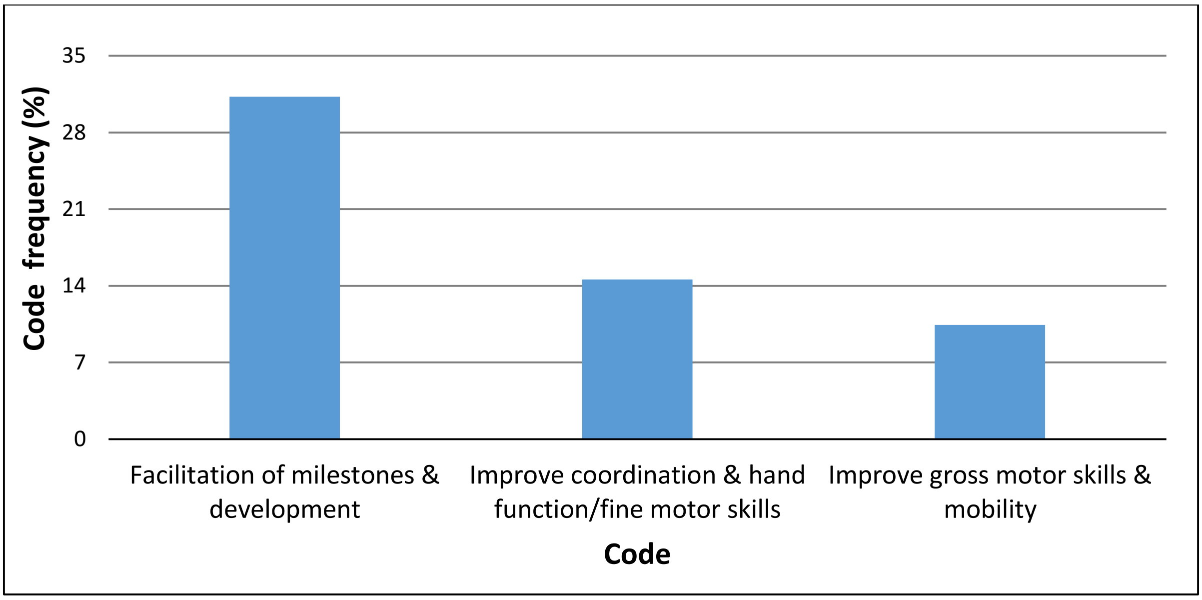


Figure 4.13 Code frequency of participant responses regarding individualization of home programmes to improve client factors and performance skills. Data from all settings were combined (n = 48 participants).

Individualized programme to improve participation

The purpose of a home programme was related to improving function and independence of the child with CP to maximize their abilities. Active participation in activities and tasks that were meaningful to the child and included repetition and practice were emphasised. Therapeutic play was encouraged by 33% of participants (Figure 4.14).

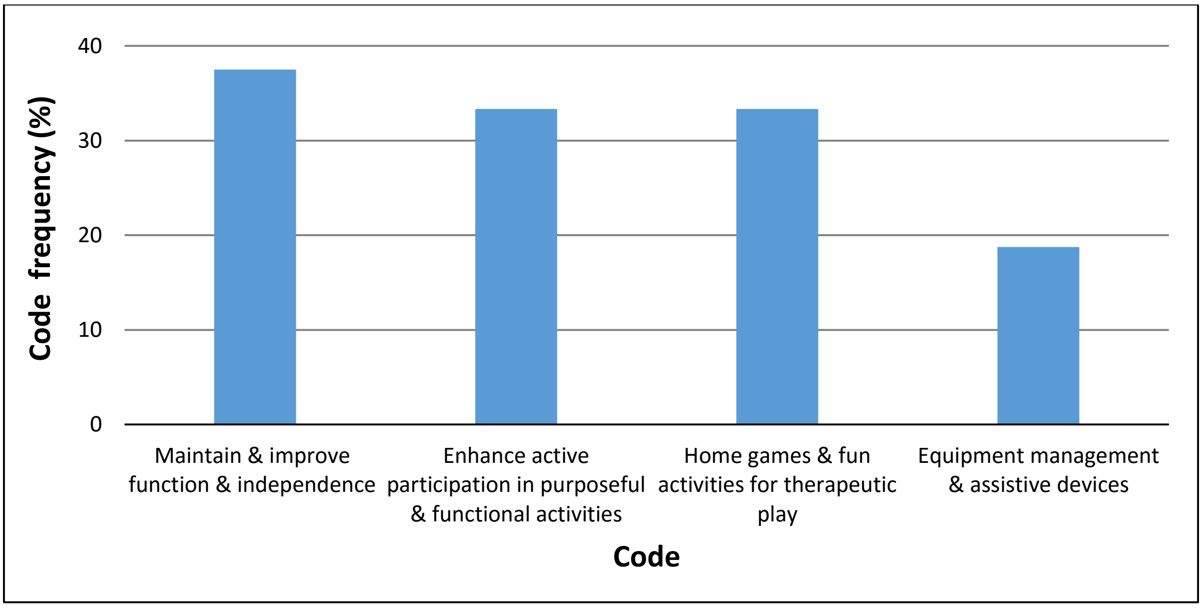


Figure 4.14 Code frequency of participant responses regarding individualization of home programmes to improve participation. Data from all settings were combined (n = 48 participants).

4.2.3.3 Home programme individualization

In all service delivery settings, there was a high degree of individualization with regards to home programmes (Figure 4.15). This was especially true of participants within NPOs (86%) and private practice (81%) who indicated 'always' and slightly less so of participants in hospitals (77%) and schools (64%).

Relevant comments described greater differences in home programmes for children of GMFCS levels four and five, with an emphasis on handling techniques, adaptive equipment, positioning and ADL activities compared to those of GMFCS levels one, two or three where the emphasis lay more on dynamic stretching, strengthening exercises and activities incorporated into play and school related tasks.

Participants highlighted differences in home programmes based on established goals, caregiver commitment, willingness and available time, the home circumstances, and other environments involved in the child's life such as day care centres. The level of interaction, interest and participation of the child was considered and the incorporation of functional tasks and activities that the child enjoyed. Two school participants did not complete this question.

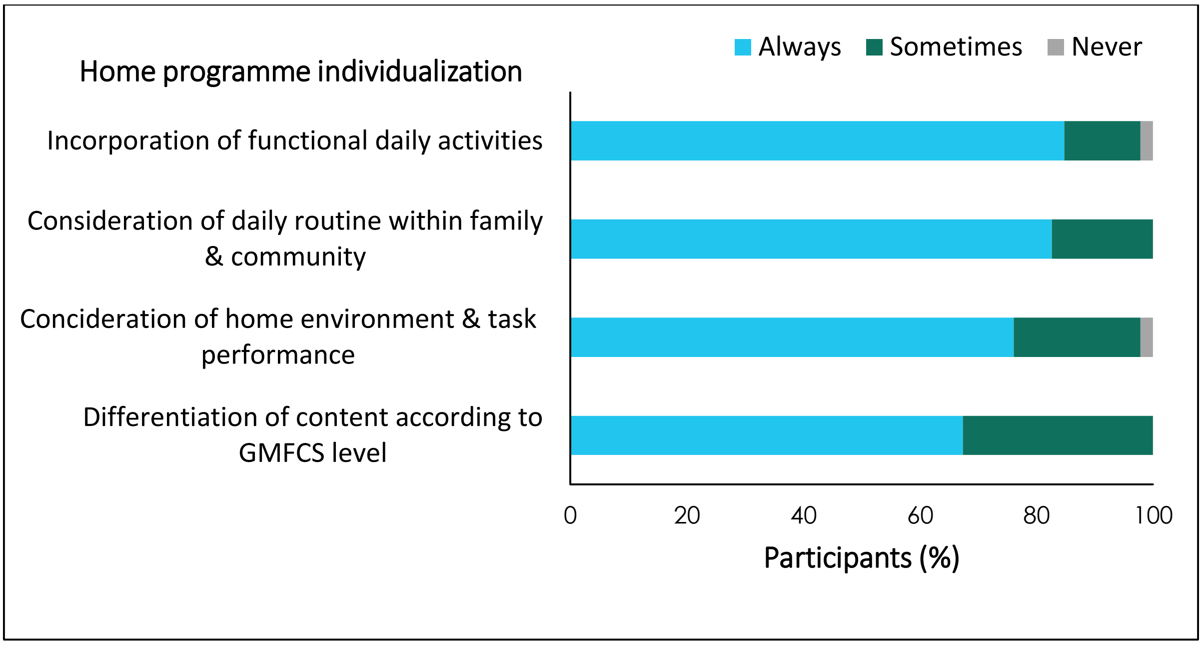


Figure 4.15 Percentage of participants, across the service delivery settings, that described if home programmes were individualized according to daily activities, routines, context and the child's abilities. Data from all settings were combined (n = 46 participants).

4.2.3.4 Home programme duration and frequency

The majority of participants indicated no specific time frame for home programmes, but rather programmes were part of daily activities within daily routines (63%) and were thus performed everyday (61%) (Figure 4.16).

Other categories included in the question: 1-2 times/week; 30min/day and 60min/day, did not receive any responses. Relevant comments included the fact that the length and duration of the programme depended on the routine of the family, the severity of the child's disability and what was realistic and manageable for the caregiver. The participants were able to indicate more than one response and two school participants did not complete this question.

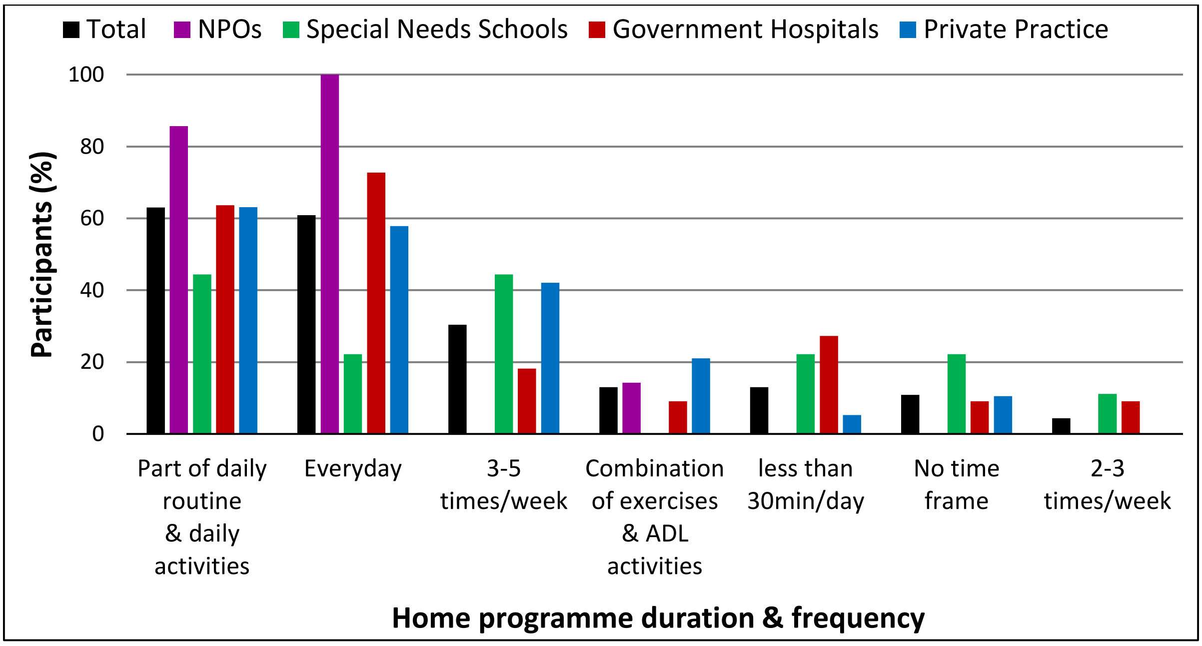


Figure 4.16 Percentage of participants, across the service delivery settings, that described home programme duration and frequency as consisting of each of the presented length and/or time frames (n = 46 participants).

4.2.3.5 Home programme explanation

Within all the service delivery settings, most participants used verbal explanation and demonstration (n = 40; 87 %) or pictures and written explanation (n = 28; 61%) to explain home programmes (Figure 4.17).

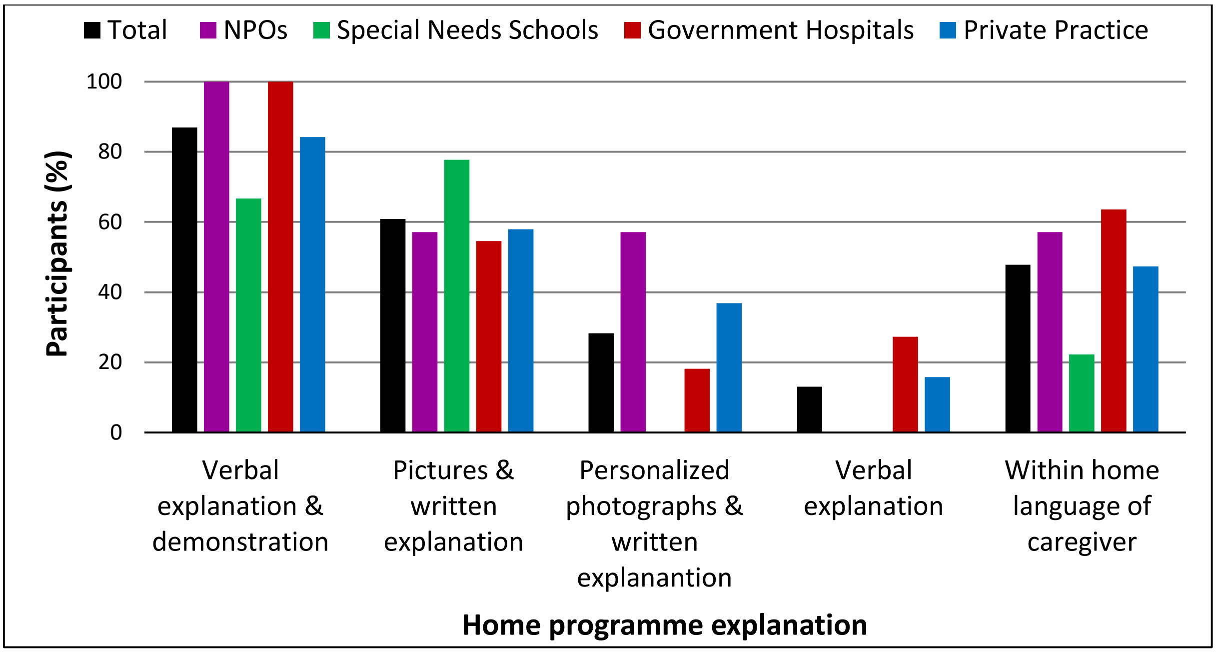


Figure 4.17 Percentage of participants, across the service delivery settings, that described home programme explanations as consisting of each of the presented methods (n = 46 participants).

Four respondents (9%), indicated ‘other’, which were collectively categorized as: video recording of the therapist and child; parental/caregiver practise of the home programme activities or the use of communication through emails or text messages. Seven percent of participants indicated the use of all the available categories. Almost half the participants (n = 22; 48 %) placed written explanation of home programmes in the home language of the parent/caregiver or used an interpreter if a difference in language existed. Forty one percent ‘sometimes’ ensured the home language of the parent/caregiver was used.

Comments from participants indicated a greater use of gestures, demonstration and simple pictures to account for language differences and difficulties. This was less prominent for private practitioners where few language barriers were reported. The participants were able to indicate more than one response and two school participants did not complete this question.

4.2.4 Phase 4: Supporting the programme implementation

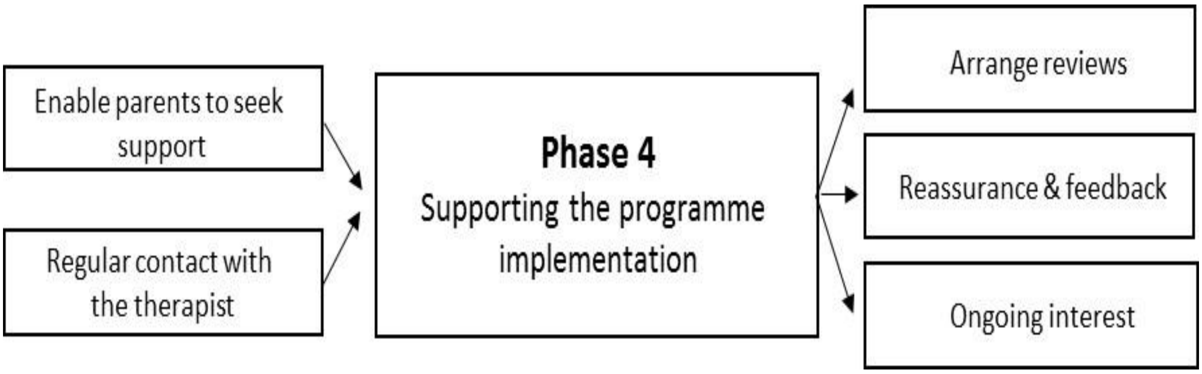


Figure 4.18 Phase 4 of the 'model home programme approach', modified from Novak & Cusick (2006).

4.2.4.1 Home programme purpose and description related to supporting the programme implementation

The final theme derived from the open ended questions of home programme purpose and description was ***supporting home programme implementation*** (Appendix J). This was described as ensuring carry over at home and is explained under the following headings:

- Extension of therapy into the home environment
- Daily care of the child with CP
- Prevention of further disability

Extension of therapy into the home environment

Almost half of participants (48%), regarded the purpose of home programmes as a continuation of therapy where skills learnt in therapy were carried over into the home environment. Participants, particularly those in NPOs (71%) and hospitals (36%), used home programmes to substitute or reinforce therapy because of limited treatment time and contact with parents (Figure 4.19).

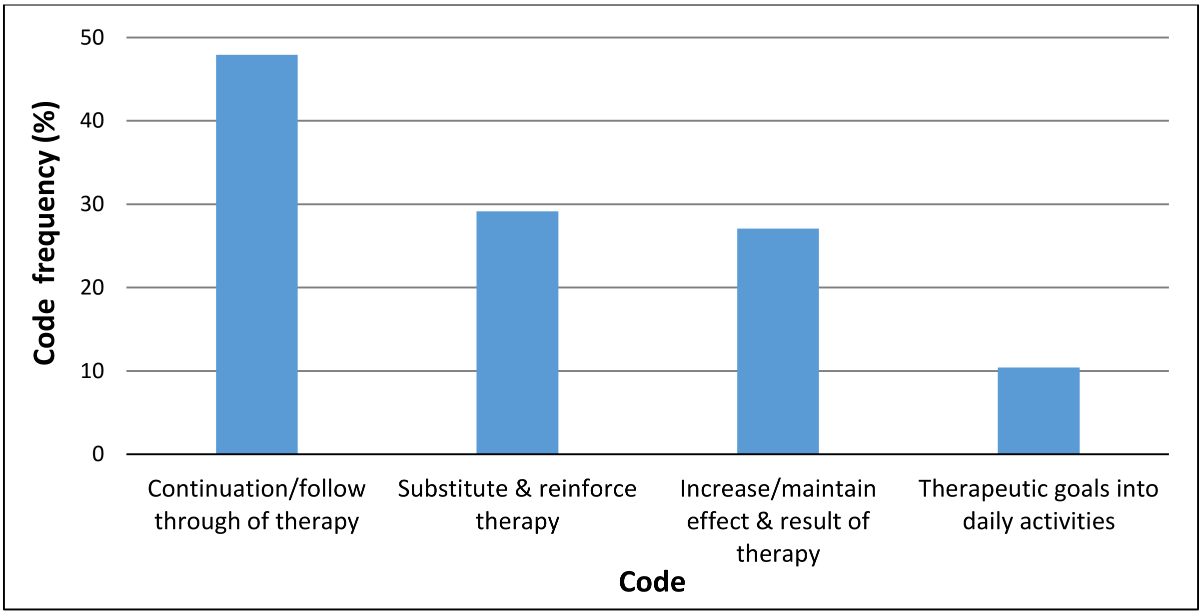


Figure 4.19 Code frequency of participant responses regarding the extension of therapy into the home environment as part of home programme support. Data from all settings were combined (n = 48 participants).

Daily care of the child with Cerebral Palsy

Participants valued daily input into the child's life through appropriate handling and positioning during activities of daily living, including therapeutic play (38%). Thirty three percent explained how exercises should be specific to the child's needs and form part of everyday life, the family routine or a way of life for the child with CP and the family (Figure 4.20).

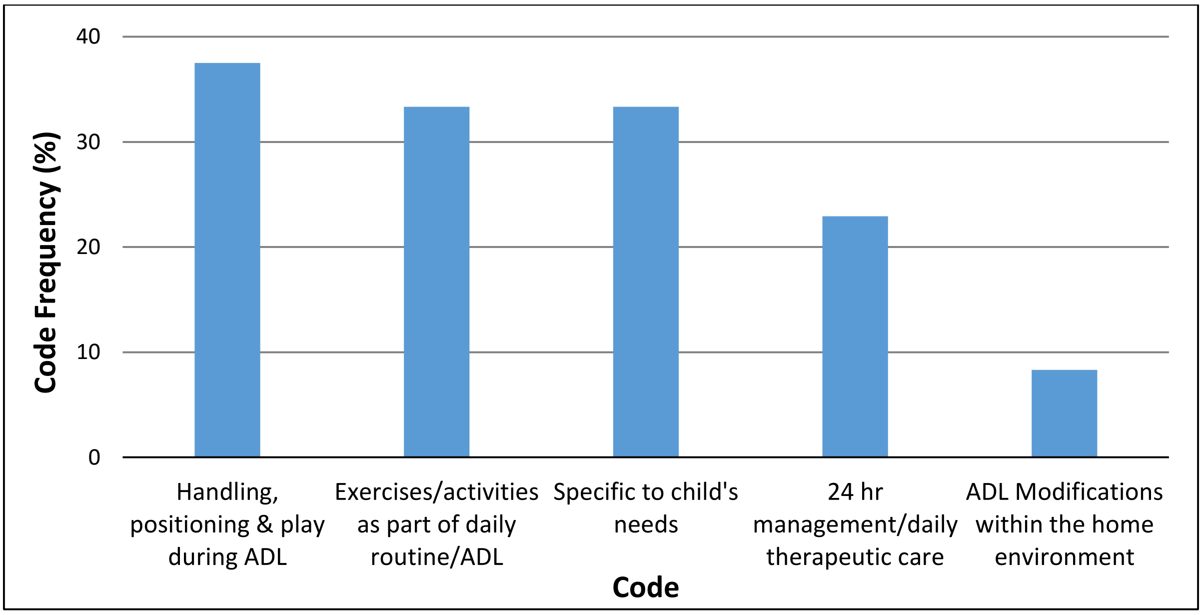


Figure 4.20 Code frequency of participant responses regarding daily care of the child with cerebral palsy as part of home programme support. Data from all settings were combined (n = 48 participants).

Prevention of further disability

The importance of daily input and correct handling of the child with CP was further emphasised by participants to prevent and minimize secondary impairments (13%) or complications (10%) (Figure 4.21).

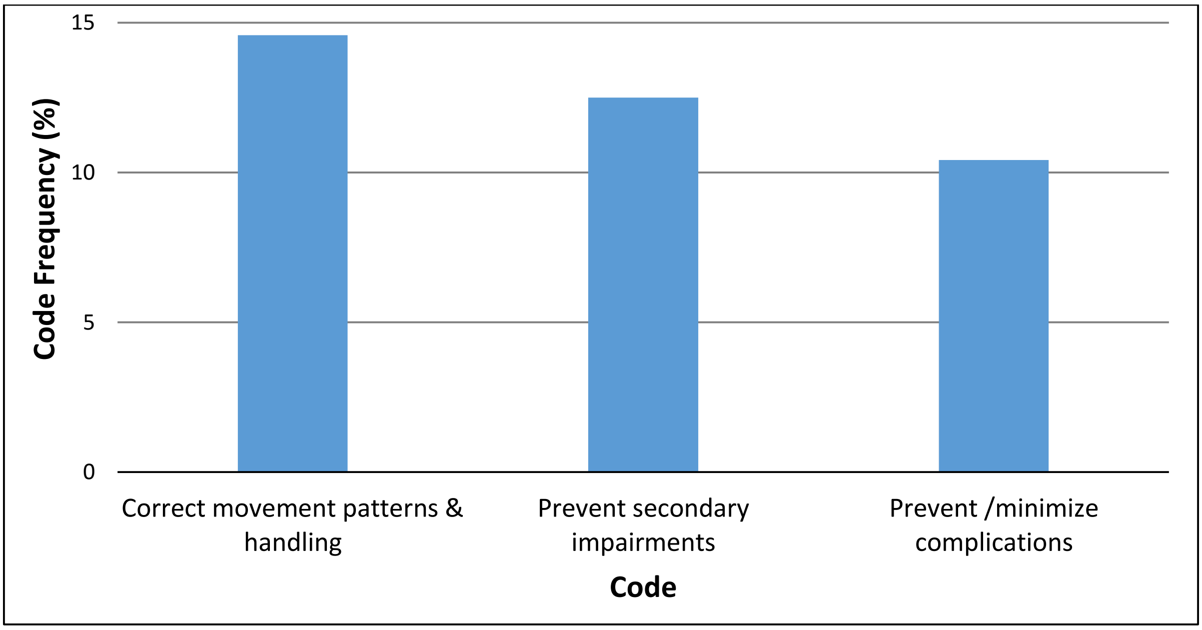


Figure 4.21 Code frequency of participant responses regarding the prevention of further disability as part of home programme support. Data from all settings were combined (n = 48 participants).

4.2.5 Phase 5: Evaluating the outcomes

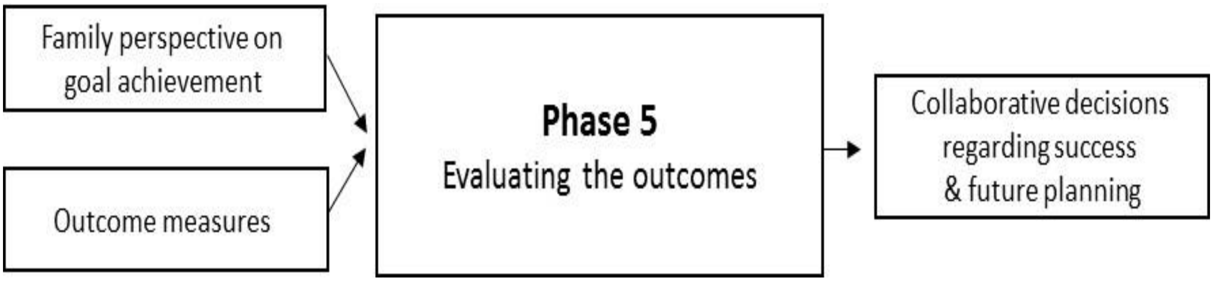


Figure 4.22 Phase 5 of the ‘model home programme approach’, modified from Novak & Cusick (2006).

4.2.5.1 Home programme evaluation

The majority of participants within all service delivery settings considered feedback from the caregiver as the most important form of home programme evaluation, followed by visible improvements of the child in functional activities as observed by the participant and the caregiver. Only eight participants (17%) indicated the use of goal attainment scaling (GAS) (Kiresuk & Sherman, 1968). Although the category 'other' was included in the question, there were no responses i.e., no other standardized measures were indicated. Participants were able to indicate more than one response and two school participants did not complete this question (Figure 4.23).

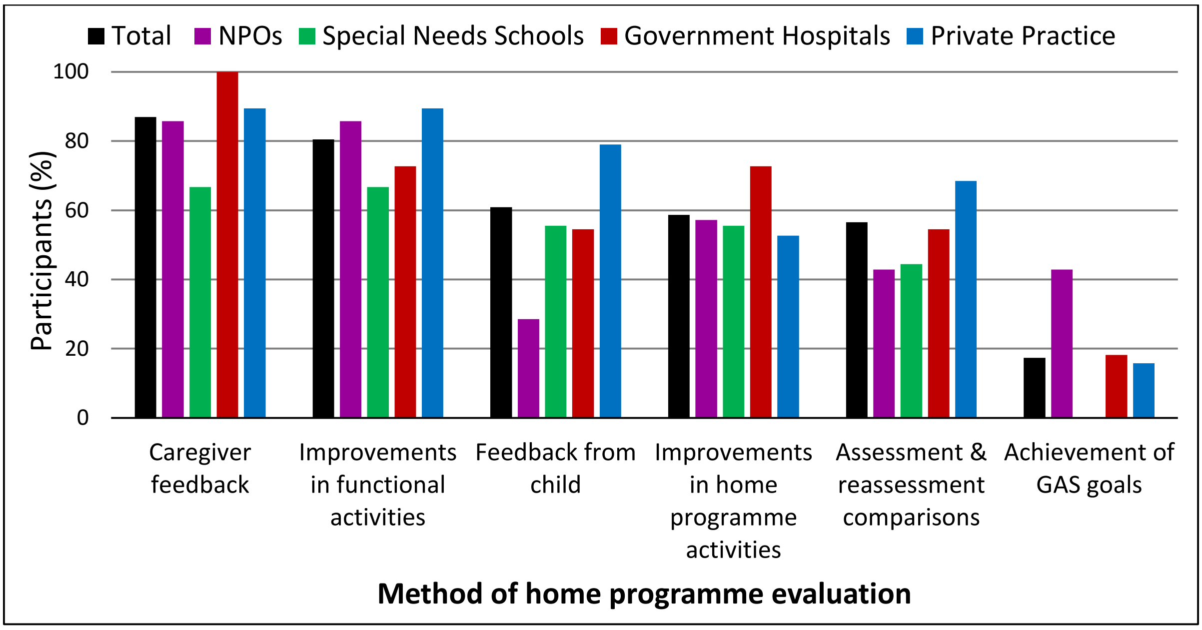


Figure 4.23 Percentage of participants, across the service delivery settings, that described home programme evaluation as consisting of each of the presented methods (n = 46 participants).

4.3 Summary

Part 1 of this study sought to understand how participants in South Africa design and implement home programmes, and how similar or different this was compared to the Novak and Cusick model. Part 1 places a particular emphasis on home programme purpose and descriptions to establish a greater understanding of home programme content. The model home programme approach by Novak and Cusick (2006) was used as a basis to describe and compare current practice of home programmes for children with CP by these participants (Novak & Cusick, 2006).

According to the model, home programmes should incorporate a family centred approach and begin with forming a relationship with parents/caregivers. In this study, therapists working in NPOs placed greater emphasis on family centred home programmes that were parent initiated as compared to therapists working in other settings. Home programmes were especially more child centred and less individualized by school based participants in the study. Similarly, goals set by school based therapists were according to an assessment of the child rather than in partnership with the family. Participants in government hospitals also placed a greater emphasis on child assessment with regards to goal setting while those in private practice, and especially NPOs, seemed to have greater collaborations with the parent/caregiver.

Therapists working in NPOs as well as private practitioners largely described the content of home programmes as activities incorporated into daily living. In addition to this, the purpose and description of home programmes was similar across service delivery settings and was described as a means to meet the individual needs of the child, improve performance skills and participation. This was predominantly through stretching exercises, positioning and stimulation to improve function and independence.

Participants related supporting the implementation of home programmes being that of extending therapy into the home environment and providing daily care of the child with CP. The substitution or reinforcement of therapy was especially emphasised by participants in NPOs and hospitals because of limited treatment time and contact with parents. Home programmes were evaluated mainly through parental feedback with minimal use of standardized measures by participants in all settings. The participants agreed that home programmes were more likely to be implemented when there is an improvement in the child’s functioning and daily benefit but these were subjectively measured.

Greater detail and understanding of the above results are presented in Part 2 of this study.

PART 2: QUALITATIVE INTERVIEWS

INTRODUCTION

The perceptions and experience of 15 therapists from Part 1 regarding home programmes for children with CP were explored in greater detail. These data were analysed using a deductive content analysis based on *a priori* themes from the phases in the ‘model home programme’ developed by Novak and Cusick (2006) and further compared to existing knowledge regarding home programmes for children with CP.

This section first provides details about the demographics, context and experience of the participants interviewed, followed by a greater exploration of home programme design, content and implementation by this sample group.

4.4 DEMOGRAPHICS, CONTEXT, QUALIFICATIONS AND WORK EXPERIENCE

4.4.1. Location and work environment

Participants were located in five different provinces of South Africa namely: Kwazulu-Natal, Eastern Cape, Western Cape, Free State and Gauteng. A brief contextual background of the particular setting of each participant is provided.

4.4.1.1 Non-profit organisations

Participants working within NPOs serviced low resourced areas and provided either individual or group therapy, depending on their resources and client load. Two participants worked within care centres where their main objective was to educate and assist caregivers to look after and care for the children. The location of therapy varied from been adjacent to government hospitals to low resourced, rural areas within three different provinces (Table 4.5).

Table 4.5 Location and context of the participants that worked within non-profit organisations.

Therapist code	Location	Description of setting
9	KwaZulu-Natal	- Organization located adjacent to government hospital - Children seen monthly with parent/caregiver - Mostly seen in group sessions with therapist and assistant (both able to speak Zulu) - Final year speech therapy students 1/week with clinical supervisor
12	Eastern Cape	- Worked for two NPOs - One consisted of block therapy to low resourced areas every few months with a team of therapists - Based at government hospital or clinic and certain children with their parent/caregiver and/or family were invited for therapy - Other NPO based within city but therapist travelled to two low resourced areas every 3 months and provided services to children and their caregivers within a care centre - Worked with two occupational therapists (OT's) within one centre and one OT at other centre, when possible
28	Western Cape	- Located within government hospital but funded and run by CP association - Good relationship with hospital (Paediatrician visits once/week) - Total of 12 therapists that worked part-time (physiotherapist (PT); OT & speech therapist (ST)) - Two social workers & one interpreter - Children and parent/caregiver seen monthly for individual therapy with one or more therapists from different therapies (depending on needs and priorities)
44	Eastern Cape	- Worked for CP association - Provided services to four care centres and two residential centres in low resourced areas - Includes management, provision of equipment and training the caregivers - Some individual therapy and home visits but focus was mainly on centre 'as a whole' - Parent contact possible but services were mainly to caregivers at the centres

4.4.1.2 Schools

School participants were all located within the Western Cape. Two of the three worked within communities where families were either from low resourced areas or had greater resources, including medical aids. One school was located in a poorly resourced area. Children were seen either for individual or group therapy. Parent contact was maintained through contact books, telephone, email or arranged appointments (Table 4.6).

Table 4.6 Location and context of the participants that worked in special needs schools.

Therapist code	Location	Description of setting
5	Western Cape	- Mixture of children from poorly resourced families to well-resourced families - Children with physical disabilities and/or learning disabilities - Joint sessions with other disciplines when necessary - Regular contact and access to other disciplines - Client load of about 50 children, seen individually, in groups or regular follow up
34	Western Cape	- Semi-urban setting (low economic status) - Limited resources - Most children from very poor home conditions, poor community - Learners with physical disabilities and/or learning difficulties - Gross motor groups, individual therapy or in small groups of two or three
14	Western Cape	- Mixture of children from poorly resourced families to well-resourced families - Children with physical disabilities and/or learning disabilities - Children seen individually 2 sessions 2x/week - A lot of communication with multidisciplinary team (MDT), occasional joint sessions

4.4.1.3 Hospitals

All hospital participants provided therapy to children and families from low resourced areas. Hospital-based therapy generally comprised individual sessions with the child and parent/caregiver with or without members of the multidisciplinary team (MDT), mostly once or twice a month (Table 4.7).

Table 4.7 Location and context of the participants that worked in government hospitals.

Therapist code	Location	Description of setting
40	Free State	- Mostly families from poorly resourced areas - Child and caregiver seen 1/week; 2/month or 1/month depending on priorities and needs - Individual sessions - Worked within MDT when possible but usually not due to time constraints and staff shortages
1	KwaZulu-Natal	- Mostly families from poorly resourced areas - Three clinics for children with CP a month - Children were seen 1/month (high client load). - Joint sessions with PT and OT; sometimes ST if community service therapist for the year
29	Eastern Cape	- Mostly families from poorly resourced areas - Children seen individually once or twice a month with OT, PT and ST (joint session)

4.4.1.4 Private practice

The majority of private practitioners worked within Gauteng and provided services to well-resourced areas and families who had medical aid cover. Therapy was on an individual basis with the child's parent/caregiver. Contact with other members of the MDT was arranged if applicable and necessary (Table 4.8).

Table 4.8 Location and context of participants that worked as private practitioners.

Therapist code	Location	Description of setting
46	Western Cape	- Sole practice within home of therapist - Children seen individually with parent/caregiver - Joint sessions with other team members arranged if necessary
2	Southern Gauteng	- Sole Practice - Children seen 2x per week, 2x/month, during holidays or post botox (depending on needs and medical aid funds) - Individual session with child and parent/caregiver - No joint sessions with MDT but contact and discussion possible
37	Northern Gauteng	- Individual session with child and parent/caregiver - Able to work within MDT if/ when applicable
21	Southern Gauteng	- Paediatric private practice with two other therapists (PT) - Individual session with child and parent/caregiver - Able to have joint sessions with OT or ST if necessary - Located in affluent area of Gauteng
32	Southern Gauteng	- Part of private practice focusing on neurology - Only therapist in practice working with paediatrics - Individual session with child and parent/caregiver - Communication with MDT if necessary

4.4.2 Additional training and years of experience

Three out of the four participants from NPOs were physiotherapists with more than 20 years of experience working with children with CP, and more than four years within this particular setting. The majority of these participants had completed advanced NDT courses and additional training relevant to the treatment of children with CP. A limited number of therapists from special needs schools volunteered to participate in Part 2 of the study, resulting in only one out of the three school based participants being an NDT certified therapist. Although not all of these partcipants met the inclusion criteria, their input was deemed valuable given the lack of respondants. All three of these therapists had worked for at least three years with children with CP, and had a minimum of two years of experience working within a special needs school.

Hospital participants were mainly physiotherapists with more than four years of experience working with children with CP and at least four years of experience within this setting. One participant, an occupational therapist, had 28 years of experience both working with children with CP and within government hospitals. Private practitioners were all physiotherapists with additional NDT and other training. Three of these five participants had more than 30 years' experience working with children with CP (Table 4.9 & Appendix K).

Table 4.9 Qualifications and work experience of the participants.

Therapist	**Qualification (yrs.)** **NDT (yrs.)**	**Additional training**	**Experience (yrs.)**
NPOs			
9	-Physiotherapist (1985) -Basic NDT (1988)	-NDT Baby Course (1989) -Advanced NDT (2002)	23
12	-Physiotherapist (1975) -Basic NDT (1977)		39
28	-Physiotherapist (1976) -Basic NDT (1995)	-Subtle Problems with Movement and Posture (1996) -Advanced NDT (1997; 2004; 2006; 2008) -Basic & Intermediate Seating Course (2004)	36
44	-Occupational therapist (2005) -Basic NDT (2011)	-Advanced NDT (2013) -Masters in Early Childhood Intervention (2007) -Basic & Intermediate Seating Course (2012; 2013)	6
Special Needs Schools			
5	-Physiotherapist (2007) -Basic NDT (2010)	-Advanced NDT (2012) -Basic & Intermediate seating Course (2014)	5,5
34	-Occupational therapist (2010) -No NDT	-Introduction to the Assessment & Treatment of CP (1 week; SANDTA; 2014) -Basic Seating Course (2014)	4
14	-Physiotherapist (2010) -No NDT	Introduction to the Assessment & Treatment of CP (1 week; SANDTA; 2011)	3
Government Hospitals			
40	-Occupational therapist (1986) -Basic NDT (2003)	-Sensory Integration (2000)	28
1	-Physiotherapist (2010) -Basic NDT (2014)		4,5
29	-Physiotherapist (2009) -Basic NDT (2013)	-Intermediate Seating Course (2012)	5,5
Private Practice			
46	-Physiotherapist (1978) -Basic NDT (1981)	-Baby NDT (1988, 2002, 2000) -Advanced NDT	37
2	-Physiotherapist (1981) -Basic NDT (1983)	-Masters in Physiotherapy (2006) -Advanced NDT & NDT courses (1990; 1995; 1996; 2000; 2004; 2007; 2009; 2011; 2013)	33
37	-Physiotherapist (1982) -Basic NDT (1984)	-Baby NDT (2012)	31
21	-Physiotherapist (2003) -Basic NDT (2010)	-Advanced NDT (2013)	6,5
32	-Physiotherapist (2009) -Basic NDT (2012)	-Advanced NDT (2014) -Advanced NDT baby course (2014)	Approx. 5

4.5 DESIGN, CONTENT AND IMPLEMENTATION OF HOME PROGRAMMES

The participants shared their experiences regarding home programmes for children with CP related to their particular service delivery setting. The five phases of the model home programme (Novak & Cusick, 2006) formed the basis for the themes and categories while the subcategories and codes were developed according to the data obtained from the participants. These are collectively presented in Appendix L and presented according to themes (phases of the Novak and Cusick (2006) model) below. Similarities and differences across the four service delivery settings are highlighted within each theme. Quotes from participants will be indicated subsequent to the explanation of each code and these are specified according to participant number and setting. The abbreviation for each setting will be used i.e. NPO: Non-profit Organization; SHS: Special Needs School; GH: Government Hospital and PP: Private Practice.

4.5.1 Establishing a collaborative relationship with the child's parent/caregiver

Questions pertaining to this theme sought to understand how participants viewed and described a family centred service and how easy or difficult this was to implement in their particular service delivery setting in relation to home programmes. Relationships and perceived roles between participants and parents were explored, as well as any challenges that might exist (Table 4.10).

Table 4.10 The categories, subcategories and codes of Theme 1: Establishing a collaborative relationship with the child’s parent/caregiver.

Themes:	**Category:**	**Subcategory:**	**Code:**
Establishing a collaborative relationship with the child’s parent/caregiver	Therapists attitude towards a family centred approach	Involving the family/caregivers	- Not just about the child - Family/caregivers as active partners
		Parental buy-in	- Perceived level of motivation & commitment - Therapy attendance & involvement
		Understanding the effect of the family context & resources	- Social dynamics & support - Resource constraints - The value of home visits - Physical environment - Cultural differences
	Personal factors affecting relationships in therapy	Effective relationships between all role players	- Effective communication (language) - Taking time to establish a relationship of trust & understanding - The emotional state of primary caregiver - Freedom to share hopes, problems & to ask questions - Formal / informal support groups
	Define roles & expectations	Parental expectations about therapy & home programmes	- Parental insight & understanding - Perceived value of therapy & home programmes
		Encourage caregiver competency	- Parents as experts - Parents as part of the team
		Therapist as technical expert	- Facilitate change - Knowledge, experience & maturity of the therapist
	External factors affecting relationships in therapy	Therapy based resource constraints	- Limited time with child & caregiver (high client load) - Staff shortage (therapists) & changes (employed caregivers & therapists) - Physical environment of therapy location

The categories, subcategories and codes are described in the text below.

4.5.1.1 Therapist's attitude towards a family centred approach

Involving the family/caregivers

Therapists from all four service delivery settings agreed that home programmes were **not just about the child**, but needed to involve and include the family as *'part of the team'* (34, SNS [participant number, setting]). This was because caregivers and families were the ones carrying out the home programme and had a greater influence on the child's occupational performance. Participants welcomed family attendance at therapy when possible, or at least considered family members who were involved in looking after the child when formulating home programmes.

> *"Not focusing only on the child…but looking at the child within his family and within his setup and involving anyone of the family that you can, the mom, the dad the sister or whatever, a granny, anyone that you can involve them and…assist the whole family that has to look after the child, not only looking at the child."* (29, GH)

> *"…if they (the family) all want to come, they can all come…you will have situations where there will be four people around the mat. So anybody that has any input into that child's life must come."* (28, NPO)

Participants therefore acknowledged the importance of **family/caregivers as active partners** and believed this type of involvement was dependent on the parent/caregiver's concern, understanding and motivation, as well as on the amount of responsibility that the therapist gave to parents/caregivers. Participants found this to be dependent on individuals.

Private Practitioners and some school therapists had conflicting remarks regarding a partnership relationship with the family and acknowledged that although it made a big impact in terms of home programmes, it tended to be neglected in this sector. Participants in this group expected more involvement from parents/caregivers in taking responsibility for the child's therapy because as parents, they had initiated the therapy process. Some participants felt that the parents/caregivers and therapist were on an *'equal footing'* and there appeared to be less of the '*top down approach'* (21, PP), but that parents/caregivers might not feel the need to be as involved because they were paying the therapist and may not want to share the responsibility of therapy and home programmes.

> *"They come to you for help, so they're actually expecting help, so they're open. It is the exception that I don't find a parent that's not willing to cooperate…some of them are excellent; some of them are not so excellent…"* (37, PP)

> *"I think in private what happens is people have a lot more money and so they're happy to spend money and say 'okay well you're responsible to look after my child and to make him better.'"* (32, PP)

Parental buy-in

Participants felt their ability to incorporate a family centred approach was determined by the parents/caregiver's **level of motivation and commitment** to the therapy process and to home programmes. Within all settings, this was attributed to the personality of the parent/caregiver, how receptive they were or if *'they wanted to make a difference'* (28, NPO). Underlying reasons such as the *'burden of care'* (9, NPO) over many years and also the severity of the child's CP, were factors believed to affect the level of parental/caregiver motivation. Views from participants in all settings ranged from motivated and dedicated parents/caregivers to those that were *'content to do nothing'* (29, GH), which influenced the content and length of home programme activities.

> *"My experience is that these moms are compassionate and concerned and involved to a degree we can't even begin to imagine and that the majority of the moms will do absolutely whatever it takes to help their children so I don't think it is necessarily all that difficult to get buy-in from the family."* (9, NPO)
>
> *"I'd say the caregiver (is) not always … as caring and dedicated as one would hope for them to be."* (29, GH)

Within private practice, there was a perception that parents had greater control within the therapy process and were inclined to want to go elsewhere or want therapy changed if they didn't like what was being done or what they were told. This affected both the relationship with the therapist and the effectiveness of the home programme and presented an ethical dilemma for the therapist.

> *"…if you are not friendly, if you are not supportive of them (the parents/caregivers), even if you don't agree with what they're saying…you've got to be their friend because if you're not they're going to dump you so no matter what your personal feelings are about the way they're dealing with it or what they're doing…if they don't like me and they don't want/like what I say,*

> *they won't return so I'll lose them so if I want to keep them I have to buy into the relationship with them."* (2, PP)

Participants also recognised the need to respect the parents/caregiver's preferred level of involvement, to adjust their expectations and to acknowledge that they are doing the best they can to help their child.

> *"…you must never think a parent doesn't want to help their child because each parent does what they can or each parent loves their child extremely. So you can't really say that this parent isn't giving all she (can)… because a parent will die for his child."* (34, SNS)

In addition to this, the impact of **therapy attendance and involvement** was seen as a barrier in NPOs, schools and hospitals and a facilitator in private practice. Those working in NPOs, schools and hospitals all expressed difficulties regarding a lack of therapy attendance due to factors such as low income that resulted in transport difficulties, particularly if travel distances were long. In these cases, the appropriate application of the home programmes became more important because the child received therapy infrequently. The motivation and involvement of the parents/caregivers was therefore difficult to monitor and a family centred service within home programmes difficult to implement.

> *"Some have transport problems, they don't have money to come, so it is quite difficult to have a true family centred approach in the model that we are working with."* (44, NPO)

Transport issues and a lack of resources did not affect therapy attendance and involvement in private practice, where therapy was mostly regular and frequent, apart from when medical aids only approved a few sessions.

However, a lack of caregiver consistency was reported by participants in all settings, which was attributed to busy parents who send other caregivers with the child. In private practice it was usually either the parent or a consistent other caregiver, whereas in other settings, particularly government hospitals, children had multiple caregivers, and therapists were often unsure who would arrive with the child. A lack of transference of skills or carryover of the home programme would then occur because primary caregivers rarely attended therapy sessions and a *'breakdown in communication'* (1, GH) between caregivers meant the home programme was not carried out.

> *"…busy moms and sometimes the moms don't come (to therapy). Then there's a caregiver that I actually work through and the caregiver can tell the mom what to do, but the mom didn't hear that from me first hand. Then the compliance is not that good."* (37, PP)

> *"What often happens, which makes it difficult, the child lives in a house with different carers, there's a granny that's maybe too old (and) they can't come to the hospital and there's an aunt and another aunt and a niece…multiple people looking after the child and then different people bring them to your session."* (29, GH)

Within special needs schools, limited contact with the families and an extra effort required for both the therapist and the parents/caregivers to arrange appointments to discuss and explain home programmes was also problematic. Therapy occurred at school and home programmes were sent home with little direct communication because parents/caregivers did not attend every therapy session.

> *"…it needs to be a conscious effort to meet up with the parent. It doesn't really happen that easily…I would actually only see the parent if I would make a specific appointment with them…"* (14, SNS)

Understanding the effect of the family context and resources

Social dynamics and support were important considerations by participants in all settings. Participants acknowledged the need to understand *'how the family operates'* (12, NPO), and what supports were available to them with the view that those with better home circumstances and a greater support system were more receptive to home programmes and found them easier to implement.

> *"…you do need to know where they stay and who they're staying with, who looks after them, how much time have you got with them, what would you like to do, how easy it is, how well do they sleep how easy it is to work with them in the day because if their home situation is really difficult and they're not sleeping well and the kids very sick and they've got to work, it really does change your home programme."* (2, PP)

Within NPOs and government hospitals, a range of social issues were of concern, including the age of those expected to care for the children (e.g. very young mothers and grandmothers), the death of primary caregivers, issues with social grants, and moving between provinces. The health of primary caregivers, such as grandmothers with diabetes or arthritis, meant that home programmes were physically difficult for them to implement. Other responsibilities of caregivers and lack of time to perform the home programme were also a concern. Participants realised that home programmes were not always a priority when other social issues or responsibilities took precedence. Similarly, private practitioners considered the impact of busy mothers who had work, other children to care for and additional responsibilities that needed to be considered. There was a need to understand these circumstances and adapt home programmes accordingly.

> *"… (This is a) family I spent hours and hours and hours with and just I think went out the other ear because their social dynamics were so bad."* (9, NPO)

> *"I also think who's implementing the home programme is a big thing. Sometimes, a lot of our kids are being looked after by granny and granny is elderly and granny can't do the things that we want her to do and that limits your home programme majorly."* (28, NPO)

> *"…you've still got to have a life and you've still got to have other kids and you've still got to work…"* (2, PP)

Similarly, participants in NPOs, hospitals and schools, regarded **resource constraints** as a hindrance to home programme implementation and realised that if families were not coping financially, the home programme would be of less importance.

> *"…the last thing on their mind is to do a home programme when they can't even pack a lunch or they can't even afford new socks for the child."* (14, SNS)

In contrast, family support and resources were perceived to be better in private practice and, in some cases, schools, especially when parents/caregivers could afford additional help, such as a private facilitator or nanny/au pair. This provided a greater amount of individual attention for the child with CP, and therefore more time was available for home programmes.

> *"Well things like the family situation plays a very big role…does the mother work? Do they have an Au pair or a nanny?..."* (46, PP)

> *"…some of the kids had fulltime facilitators and they were wonderful because then they came to school and you could work with them and show them stretches and show them exercises and follow up with them on a weekly or daily basis and you could help them to do stuff in the classroom. The facilitators were always great and we worked with them quite a lot."* (5, SNS)

Although resources were more readily available in private practice, one participant expressed the difficulties faced by single mothers.

> *"Coping with things like finances, resources, bringing their child (to therapy), having transport, having time to get off from work is really a big issue with me and also having time to spend with their child…there's a lot of problems with the single mothers."* (37, PP)

In order to fully understand the family context and resources available, **home visits** were valued by all participants and provided greater insight into the home environment, the family routine, time and resources available for home programme activities. Private practitioners were able to include a home visit as part of therapy. Those in NPOs either liaised with social workers, or were able to perform individual home visits themselves.

> *"…because you have no idea when they come into a clinic no matter how well dressed they are, and usually they coming into town so they put on their Sunday best. You have no idea unless you visit the home."* (12, NPO)

> *"Yes, always they (home visits) are the best…because then you can use their couch you can see what they've got and your therapy session is a million times better."* (2, PP)

Hospital and school participants reported that home visits were difficult to organise. They described resource constraints within their organizations, such as a lack of transportation, as problematic. Home visits were occasionally provided, but required organization and a clear motivating reason, e.g. an assessment for equipment allocation.

> *"Previously home visits were done more regularly and more effectively, I think, when there were more funds available and the systems in place, but at the moment, not so much."* (34, SNS)

In addition, only a third of participants, and none within special needs schools, acknowledged the importance of understanding the **physical environment** of the child and the family. Those in NPOs recognised overcrowding and space constraints, which impacted the activities given for home programmes and their implementation.

> *"It's no good giving him all sorts of fancy things to do if they live in a little hut… it's basically knowing what kind of place…where the child lives and who's in the home with them."* (28, NPO)

Some participants viewed **cultural differences** as a challenge and linked this to limited support provided to primary caregivers in poorly resourced areas where the parent/caregiver was expected to look after the children as well as perform household duties, thereby being unable to cope with the extra burden of a home programme. It then became even more important to educate the whole family regarding the value and importance of therapy and of implementing the home programme.

> *"…and the husband sits outside and smokes or drinks or something…and I've said, 'this is where you need to decide, do you want the best for your grandchild or does your culture come first or your traditions? Which/what's more important? This child's life, for this child to be happy and to feel like he's part of the family or for granny to have to do everything, which she cannot do because she's a human being? And so your child will get worse and worse.' And then they just smile or laugh. So yes, the culture is a huge challenge."*(12, NPO)

Other comments related to the cultural differences between therapists and parents/caregivers and the barriers these could create in terms of open communication, mutual respect and understanding. These cultural issues were both race and gender related, and participants believed they affected whether parents/caregivers were willing to take part in the process or not. Comments demonstrated the lack of partnership based relationships with families.

> *"…there are definitely instances where a younger black lady wouldn't really respect a young white girl like me so definitely the age in their culture makes a difference."* (29, GH)

> *"…the man is absolutely the head and he doesn't have to listen to women and here there's two white women coming and in and trying to tell him what to do so that has been a learning curve for me as well, how to negotiate that…"* (44, NPO)

Despite these comments, participants also expressed the need to understand different cultures, respect them and provide education regarding the importance of home programmes where culture or traditions can affect involvement. Cultural differences between therapists and parents/caregivers were not as marked in private practice because *'everyone tends to be more similar'* (21, PP).

4.5.1.2 Personal factors affecting relationships in therapy

All participants felt that it was important to establish an effective relationship with the parent/caregiver and family in order for therapy and home programmes to be successful. Personal factors affected this relationship and presented challenges, but this was commented on less by the school participants who rarely saw the parents/caregivers and therefore could not take these factors into account.

Effective relationships between all role players

Language barriers meant that **effective communication** was a challenge especially in NPOs and hospitals. This not only affected the depth of the relationship and the understanding of emotional issues experienced by parents/caregivers, but also the ability to form partnership based goals for home programmes and to explain home programme activities. Translators were both valued and necessary to all therapists in these settings and often formed a link, not only between different languages, but also between different cultures.

> *"I won't even try and talk to a mother who doesn't understand English properly unless I had a translator."* (12, NPO)

> *"…we've got our wonderful interpreter, who's so much more than an interpreter and she often gets the story before we do and she's been there for years and she knows exactly what we're looking for."* (28, NPO)

Language barriers were less problematic in schools and were only present with a few parents/caregivers in private practice.

Taking time to establish a relationship of trust and understanding was valued by all participants, but often took more time in settings where cultural and language barriers existed. The participants related effective relationships with parents/caregivers with mutual respect and agreement and for parents to trust them, realise they care and for parents/caregivers to be *'less sceptical'* (29, GH). Comments also related to the relationship that usually developed over many years due to the nature of CP, and that *'you walk a mile with the child'* (34, SNS), which was especially noted by participants in schools. This long term relationship facilitated trust and understanding, but the participants acknowledged that this takes time and thus the value parents/caregivers place on home programmes is often gradual.

> *"I think it's a long road in terms of establishing trust and establishing credibility if you really want to bring about change…"* (9, NPO)

> *"…they're getting to know us and they start to realise now that we're not there to tell them that they're doing everything wrong…we're actually there to try and help them but it is difficult for them if we just come in there and they don't know who we are…"* (44, NPO)

The **emotional state of the primary caregiver** was also believed to impact the relationship between the therapist and parent/caregiver and participation in home programmes. This was considered by participants in NPOs and hospitals, where they acknowledged that parents/caregivers can feel stressed, tired, depressed, overwhelmed or anxious. This they related to both the parents/caregivers understanding and acceptance of their child's condition as well as the impact of their home circumstances and relevant social issues. Again, home programmes become less important in light of poor insight and understanding, and poor emotional wellbeing.

> *"I think a lot of parents of kids with CP, it takes a long time for them…to understand the whole thing and often they're so overwhelmed that it takes them a good few sessions to actually buy in. And you just have to be very patient and just repeat everything…They often don't actually realise the full implication of what cerebral palsy is for a long time."* (28, NPO)

In this way, it was important to create an environment where parents/caregivers had the **freedom to share hopes and problems, and to ask questions**. Participants within NPOs and private practitioners felt that mothers who were coping could better *'help their child in the long term'* (28, NPO), and therefore be better equipped to carry out home programmes. There was only one comment related to this code from a hospital participant and one from a school, where participants rarely see parents.

> *"…they're not coping…and in fact then the treatment isn't that important. It's far more important to talk to that mom and try and find out how you can help her in some other way…why she's feeling so down and, yes, what the story is. Whether there's social stories…then you just talk through that…to get his mother back on board. So we have lots of tears and you do lots of talking."* (28, NGO)

Formal and informal support groups were encouraged by participants in NPOs, hospitals and private practice. These were either as an arranged parent meeting, or strategically booking similar children for therapy *'so that the parents meet each other in the waiting room'* (21, PP). The participants believed that parents would cope better and gain greater insight and support from those who are in a similar situation. This was related to providing a *'holistic kind of care'* (9, NPO).

> *"I actually think through stories that they tell, obviously if it's positive stories, you know they actually believe each other more and take it more to heart because they know that the other mom is in the same situation as them."* (29, GH)

4.5.1.3 Define roles and expectations

Parental expectations about therapy and home programmes

Parental insight and understanding was a factor that affected parental expectations about therapy and home programmes for participants in all settings. This was because *'home programmes only work when the parents understand what they're doing and why they do it'* (40, GH). The participants also linked this to the motivational level of the parent/caregiver, whether they understand the consequences of what they do and that home programmes can *'make the world of difference'* (21, PP). Closely related to this was the **perceived value of therapy and home programmes**. The participants recognised that parents/caregivers often first needed to appreciate the effects of a home programme before they understood the importance.

> *"…they've (parents) have got to buy into the whole programme. They've got to understand why they're doing all these things and what the importance is and if they don't, then you've kind of lost them before you start."* (28, NPO)

> *"(Parents need to be)...interested… convinced that it needs to be done and I've also got to show them that it's of value. If they don't see the value in it they're not going to do it…and they also need to see that it makes a difference…"* (2, PP)

Role clarification was also an important aspect as participants felt that parents often believed that the therapists were there to *'fix their child'* (32, PP), which impacted their level of involvement and responsibility. This was especially prevalent in private practice.

> *"In the beginning I've got to explain what my role is, where I can help them because they often feel like I'm the one that can wave the magic wand, I'm the one that can fix the child. I've got to explain to them that I'm not the magic person, I'm the one who can guide them to make it easier to help the child but I'm not the one who can solve the problems."* (2, PP)

Encourage caregiver competency

The participants acknowledged **parents as experts** in their knowledge and understanding of their child. Providing respect, listening to suggestions, *'not talking down on them'* (29, GH) and empowering them were ways in which they encouraged partnership-based relationships and parental competency.

> *"I'm not the expert, I'm the one who can give advice, but they're the ones who are 24/7 with the child. They know their child the best…"* (2, PP)

> *"…perhaps one of the biggest things we try and do is empower the moms to understand that they really are the ones who make the biggest impact on their children's lives and if they can take that on board that's half the battle won."* (9, NPO)

Similarly, participants in all settings valued **parents as part of the team**, but acknowledged that this was not always the reality. In private practice, this was dependant on individual parents/caregivers and their level of active involvement. In other settings, parents/caregivers feelings of empowerment, the effort participants placed in *'making them aware that they are just as much part of the team'* (14, SNS) as the therapist, and showing them *'a bit more respect'* (1, GH) were more prominent factors. In these settings, where parents were usually from lower socioeconomic circumstances, participants felt it was important to make them feel more secure and confident, and to provide reassurance regarding their role as the parent, which they believed would improve cooperation and home programme involvement.

> *"…we'd love it to be parent and therapist equal, but often they come and see us as the therapist and they are looking up to us… but most of the folk that we get are so disempowered anyway that they definitely come looking for help and advice from us."* (28, NPO)

> *"…they can feel insecure quite quickly and then you don't get the corporation that you want. So to make them feel empowered and to make them feel capable of doing the home programme, I think it is important and to make them feel that you know they're doing their best and these are just guidelines to help them or assist them."* (34, SNS)

Therapist as 'technical expert'

The participants identified with the role of educator and agent to **facilitate change**. This was related to identifying and facilitating additional intervention needs, but especially with helping parents/caregivers and making their lives easier.

> *"…but I can't be them at home, I can't live in their home. I'm willing to share what I can in terms of skills education and knowledge, support, understanding, empathy, I'm willing to share whatever I can to make their lives easier (including) the family and to enable that young person or child to reach their full potential…"* (12, NPO)

The **knowledge, experience and maturity of the therapist** was a factor believed to influence the approach to therapy and home programmes. Participants in NPOs, hospitals and private practice denoted a greater understanding of parents/caregivers and a more family centred approach that accompanied experience and maturity. The participants explained how they were less judgemental and dictatorial, that they placed more realistic expectations on parents/caregivers and were more understanding of cultural differences – characteristics and skills they acquired through experience.

> *"You know, initially, years and years and years ago it was more therapist-child, but now I'm involving the parents so much more."* (37, PP)

> *"Especially when I was a community service therapist, I had this little therapy ego…and the moms would have an attitude regarding my attitude and when I dropped it and when I started to speak more Zulu, understand their culture…understand why they were doing it and appreciate who they were and for what they were trying to do, even if it was minimal."* (1, GH)

The lack of knowledge and experience of community service therapists (newly qualified therapists who provide a year of service to government hospitals/clinics as per government policy (Reid, 2002)), as well as the high staff turnover and therefore poor continuity of therapy and skill development in hospitals, was also highlighted.

> *"I think that is one of the weaknesses often in a state service that a lot of CP's are being left to community service therapists who are the least equipped to cope with the huge demands and the whole picture."* (9, NPO)

> *"…and I can fully understand because I sit there sometimes and listen to these young therapists some of whom are community service therapists and some of*

> *whom have actually been qualified for a few years totally immersed in the child and ignoring the mother or granny, not trying to find out anything about what makes them tick at home and just kind of rattling off and telling them things they've got to do at home which are totally impossible, impractical and irrelevant to this child…"* (12, NPO)

4.5.1.4 External factors affecting relationships in therapy

Therapy based resource constraints

Limited time with the child and the caregiver due to high client loads was a prominent problem expressed by participants in NPOs, hospitals and schools. According to participants, this heightened the importance of implementing a family centred approach to make a greater impact, but also made a family centred approach difficult due to limited time with the child and family. This was especially expressed within schools, where therapists have other responsibilities such as transcribing for exams, and within hospitals where therapists have inpatients to treat amongst other duties. Because of these constraints, home programmes became more general and less individualized, or certain children received higher priority. This was especially noted by participants in care centres and schools.

> *"In our situation we can only see a child once a month 8 or 9 times out of 10 and we never going to make a dramatic change if the family is not on board."* (9, NPO)

> *"…it's very time consuming, you only get maybe once a week a few hours that you can actually see a parent. So it is very time-limited."* (34, SNS)

These were not concerns for private practitioners where therapists were able to have *'one on one'* (21, PP) sessions continuously and frequently.

> *"Time is not an issue. I make hour appointments and I usually use all the time up. Sometimes more. So I make use of that, but by an hour, the home programme is written down, the next appointment is made and everything is sort of okay, yes."* (37, PP)

In addition to this, **staff shortages** were common constraints for participants in NPOs, hospitals and schools. Participants in NPOs also struggled with **staff changes**. This again related to the degree of home programme individualization and the time needed to explain and support home programmes. Staff changes related to the continual need to re-educate new staff members, not only because this takes time, but also because home programmes tend to focus on the same thing *'year after year, and so never progress'* (9, NPO). This was also true of community service therapists in hospitals, who tended to change yearly. There were no comments from private practitioners regarding these difficulties.

> *"…we have about…probably more than 100 children and we are 1½ therapists, my colleague works part time…"* (44, NPO)

> *"…and also the turnover of that staff is huge because they are paid very, very little for very long hours…"*(12, NPO)

The **physical environment of the therapy location** was a challenge for one participant working within an NPO, where limited space and overcrowding was not always conducive to building relationships with parents/caregivers and therefore formulating and discussing home programmes. In contrast to this, a school based participant explained the positive aspects of working within *'a structured environment'* (14) where equipment and a multidisciplinary team were readily available.

4.5.2 Collaborative goal setting

The second theme sought to understand how participants approach the goal setting process. Questions related to if and how parents/caregivers were involved in this process and if their individual needs were taken into account. The assessment procedure and formalized goal setting methods were investigated (Table 4.11).

Table 4.11 The categories, subcategories and codes of Theme 2: Collaborative goal setting.

Collaborative goal setting	Identify goal areas (ask the ‘miracle’ question)	Family & caregiver needs & priorities	- What is the most important (first things first) - Find out their needs
		Parents as primary decision makers	- Enhance the capacity of parents (increase knowledge & skill) - Family vs therapist initiated goals
	Comprehensive assessment	Therapist & parent perspectives of child & family needs	- Individual assessment of the child - Assets & competencies - Goal areas identified (by the therapist)
		Technical information to parents	- Understanding their child’s condition - Realistic goals & solutions
		Working together (with other team members)	- Support / lack of support from hospitals, clinics, schools & other - The need for a multidisciplinary team
	Lack of formalized goal setting procedures	Observable outcomes only	- Lack of standardized measures

The categories, subcategories and codes are described in the text below.

4.5.2.1 Identify goal areas (‘ask the miracle question’)

This related to identifying ‘areas of potential change and what families already had in place’, i.e. their assets and competencies (Novak & Cusick, 2006).

Family and caregiver needs and priorities

Comments from all settings revealed that participants valued **what was the most important (first things first)** for parents/caregivers and **finding out their needs** and concerns in formulating the goals for a home programme**.** This was especially so for participants in NPOs and private practitioners who sought to find out the priorities of the family, what made *‘their lives easier’* (12, NPO) and what they would like their child to be able to do. This was also regarded as a part of building a relationship with the parent/caregiver.

Due to the limited contact time with parents/caregivers in schools, participants tended to discuss the priorities of the parents/caregivers for home programme goal formulation only periodically, even yearly, and rather met as a team with other disciplines to formulate an *'individual education plan'* (5, SNS). Often, the multidisciplinary team then decided on what goals were appropriate and parents were involved more when the child had less cognitive potential and the 'plan' was less academically driven. Despite this, and as far as possible, therapists sought to understand what problems families had at home and acknowledged that these were *'sometimes quite different than what (I) thought'* (34, SNS).

Comments from participants in NPOs, schools and private practice indicated that finding out the needs and concerns of the caregiver and family would increase parental/caregiver involvement and cooperation in home programmes. There was only one comment from a hospital participant that implied that little time was spent finding out the needs, priorities and assets of the family by therapists in this setting, and that home programme goals were more therapist driven.

> *"…we started with the caregiver interviews first before we did anything else so that they get to know us and we could hear what their needs were…"* (44, NPO)

> *"And the moment you can address…a priority problem to make their (parents) life easier and the child's life easier, they (parents) are more cooperative."* (34, SNS)

Parents as primary decision makers

The process of parents as primary decision makers was a challenge for therapists in all settings because *'parents don't always know what they want'* (28, NPO). Comments related to the importance of educating and empowering parents/caregivers, i.e. **enhancing the capacity of parents (increase knowledge and skill)**, and how important this was to the process of goal setting. This was described as a timeous process with decisions often beginning as led and initiated by therapists. Participants in NPOs and private practice related to a supportive and advisory role, with the primary aim of parental/caregiver empowerment in the form of providing ideas, guidance and advice. In private practice, realistic expectations and role clarification, especially of the therapist, continued to be important. School participants also commented on the need to provide parents/caregivers '*tools'* to help their child and related this to *'giving them* *the responsibility'* (34, SNS). Parental/caregiver ability to assist their child in school related tasks was also correlated to their level of education.

> *"…the first few appointments they often don't know and then eventually after a year or two they'll start coming with ideas, but initially they're often very overwhelmed by the whole story."* (28, NPO)

> *"…the parents aren't that educated or…they don't know how to stimulate children. They don't know how to support children in school (because) they don't have the knowledge themselves…you send the homework but the parent…can't do it, how must the parent help the child?"* (34, SNS)

There were mixed views regarding **family versus therapist initiated goals** from participants within all settings. The participants acknowledged that parents are *'just as important as the therapist in making decisions'* (44, NPO) and that home programmes with parent initiated goals were more meaningful and more *'likely to get done'* (32, PP), but goals still tended to be more therapist directed. This was because parents/caregivers were often unrealistic in terms of goal setting and tended to make general goals rather than specific, attainable, short term goals and needed guidance and education to assist parents through the process. Goals appeared more therapist directed in settings where there was greater contact with the multidisciplinary team, especially in schools where goals were also more academically driven than parent initiated.

> *"I think it definitely is more therapist directed…. because the parents goals are maybe not always appropriate or a lot of them didn't know what they wanted or they didn't know what their goals were...*" (5, SNS)

> *"I think so (goals are school related) because at the end I think your big aim, your big goal is to help the child to function at school, in the classroom."* (34, SNS)

4.5.2.2 Comprehensive assessment

Therapist and parent/caregiver perspectives about child and family needs

Participants in all settings performed an **individual assessment of the child**. This was in the form of observations, handling, classification systems, videos and obtaining information from parents/caregivers. There was a lack of formalised and standardised assessment procedures within all settings. Within schools, this appeared to be more of a child-centred assessment than an attempt to find out what the needs of the family were, and was performed and discussed with the multidisciplinary team. The participants highlighted an advantage within this setting, in that children are seen *'daily, in the school environment in the classroom and on the playground'* (34, SNS). This gave therapists *'a good idea of how the child functions in a few areas'* (5; SNS). An individual assessment of the child was most collaborative within private practice.

> *"…more through talking…no thorough assessment no…"* (2, PP)

> *"…my assessment often isn't an exact 1 hour when you first begin so… you kind of get the basics…I've chatted to the family and kind of found out a little bit about what their daily routine is and then looking at the child and then trying to work out how it both works together and then once I have got in my head where my goal would be then I try bring that back to their daily routine and get a little bit more detail about how they could fit it in."* (32, PP)

Few comments emerged from questions related to therapists trying to find out what the **assets and competencies** of the child and family were. Where they were recorded, they were mostly from participants in private practice and stated the value of identifying the child's strengths and of showing the parents/caregivers areas of potential change.

> *"…it's easier for a therapist to look at deficits and work out what are you missing, what range are you missing, … what play are you missing, what participation and everything you're missing, but actually then that just bombards the parents a bit more so often the question I ask the parents is 'what can your child nearly do' …and getting them towards function…"* (32, PP)

Specific **outcomes identified** were largely **therapist directed**. Corrective positioning and seating were most frequently mentioned, followed by improving function, participation and development in activities of daily living, particularly feeding. Stretching exercises and maintaining range of movement were aims frequently mentioned by private practitioners.

> *"I mean the ultimate goal is to improve function, if it's not so to improve their range so they have the function, to improve the muscle strength so that they can maintain…(what) they're doing or improve in what they're doing and then positioning so they have the most advantage of their abilities or their capabilities."* (46, PP)

Technical information to parents

All participants from all settings identified with the role of an educator and valued the importance of parent/caregiver **understanding of their child's condition**.

Frequently mentioned by participants in NPO's and hospitals was the Hambisela Programme. This is unique to South Africa and provides information and practical guidelines regarding CP (Hambisela Training Program for Parents and Carers of children with Cerebral Palsy, http://positiveparentingtips.net/wp/?p=5968).

> *"…the most important thing of a home programme is to teach a parent to deal with their Cerebral Palsy child and understand the child's situation…"* (46, PP)
>
> *"It is for the parents (the 'Hambisela' programme), it's not for the children. You teach the parents everything about CP. And into seven sessions everything is worked out and the parents really learn a lot and they enjoy it a lot."* (40, GH)

Enabling parents to identify **realistic goals and solutions** was linked to educating the parent/caregiver. Participants in all settings felt that families were often unrealistic in terms of goals and wanted their child to *'walk and talk'* (12, NPO) without a clear understanding of the long term impact of CP. Participants valued family education to develop more realistic solutions and expectations of therapy and home programmes. The interpersonal skills of the therapist were important factors in helping parents/caregivers understand the value of small changes.

> *"…you will ask the carer or the granny or the parent 'what do you want, how do you want me to help you with your child' and sadly in many instances they are totally unrealistic (and it)…takes time not to dash their hopes… you then have to kind of back track and…that all takes time as well…"* (12, NPO)

Working together with other team members

Collaboration with other team members was mentioned in a broader sense regarding **support or lack of support from hospitals, clinics, schools and other**. This was more prominent for participants within NPOs who work with other outreach clinics, referral hospitals and other NPOs. Participants within this setting also valued educating and empowering less experienced therapists within these collaborations. Private practitioners were open to collaborations, especially with the treating doctor or with school teachers, but this was dependant whether these individuals were willing to maintain contact and work together. When possible, these collaborations ensured that the same goals where carried over within therapy and home programmes.

> *"They are also still involved with the clinics and the hospitals some of them still go for therapy there as well so our involvement doesn't replace that, we sort of work together."* (44, NPO)

> *"I think it's very important for them to realise that everything the child does how they do it and all the role players should understand what is conducive to the situation and what is not."* (46, PP)

The need for a multidisciplinary team which included OT, PT and ST varied within all the settings. Those working within NPOs were either the only therapist, had some contact with other team members (although often not all of the disciplines), or were able to work with regular contact and discussion. Hospital participants reported having joint sessions with other therapists, but this was also dependant on time, client load and other responsibilities. Many comments emerged from school participants who had easy access to other team members and regular collaboration with regards to goal formulation and home programmes. Additional effort was required for private practitioners because they were not always *'in the same building'* (2, PP) and the relationship was *'not always spontaneous'* (2, PP). Also mentioned by this group was the fact that medical aids don't always pay for all three therapies. Despite this, participants valued collaboration so that team members were *'on the same page'* and did not *'overwhelm parents'* (21, PP) when giving home programme activities.

> *"There is opportunity to work closely with the speech therapist or occupational therapist if we have a child that we feel will benefit from a joint session and then (we make) telephonic contact at least (and) make sure we are on the same page with regards to goals and things (because)…if one therapist is saying one thing and another therapist says a completely different thing it can be very overwhelming for parents…"* (21, PP)

4.5.2.3 Lack of formalized goal setting procedures

Observable outcomes only

A **lack of standardized measures** for goal setting was dependant on individual therapists and not the setting. Specific, Measurable, Achievable, Realistic/relevant and Timed (SMART) (Bovend'Eerdt et al., 2009) goals or Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968) were sometimes used and no other formalized goal setting procedures were mentioned.

> *“Mainly (use goal attainment scales in therapy) and then through therapy you can see maybe if there has been a follow through from the home programme on to that.”* (1, GH)

> *“SMART goals I try to use…my SMART goals I want (them) to be very specific.”* (37, PP)

4.5.3 Constructing the home programme

The third theme relates to the design of the home programme - what ‘supports, tasks or activities’ were included (Novak & Cusick, 2006). (Table 4.12).

Table 4.12 The categories, subcategories and codes of Theme 3: Constructing the home programme

Constructing the home programme	Embedded within everyday activities	Incorporated into ADL & part of daily routine	- Not a separate exercise regime (not something extra) - Part of normal life (part of the child & family routine) - Therapeutic caregiving
		Supports (adaptive equipment & assistive devices)	- An adjunct to home programmes - Low cost equipment (within the resources of the family) - Availability & funds
	‘Home exercise programme’	Tasks, activities & exercises	- Mobilization & positioning - Stimulation and activities - Separate exercises e.g. stretching, ROM etc.
	Child & family preferences (pleasing for the parent; not stressful for the child)	Active engagement and participation of the child	- The child is part of the family - Using play & making it fun - Child specific - Active movement & involvement
		Realistic expectations upon parents/ caregivers	- Understand competing responsibilities - Appropriate & manageable (do not overwhelm)
		Home programme dissemination to parent/caregiver or child	- Ensure clear understanding - Verbal explanation & demonstration - Written information & pictures/ photographs

Themes are based on participants responses as to if and how these were implemented into the family routine and if and how the preferences of the family were considered. Questions regarding how home programmes were explained and/or demonstrated were included. The categories, subcategories and codes are described in the text below.

4.5.3.1 Embedded within everyday activities

Incorporated into ADL & part of daily routines

Participants from all settings valued home programmes that were **not separate exercise regimes (not something extra)** and that formed **part of normal life**, i.e. were **part of the child and family routine.** This was regarded as more functional, realistic and easier for parents to implement. Participants in NPOs likened this to a more family centred approach and that children should not be *'therapized'* (12, NPO) and separated from the family for a certain period of time to perform a home programme. The emphasis, from participants in all settings, lay in providing ideas and practical guidelines on how to perform daily tasks that were more natural, rather than separate exercises. This was defined as **therapeutic caregiving** and was described as a way of handling and positioning the child during everyday activities, using activities that they were already doing, and making these therapeutic, functional and *'better'* (44, NPO). The importance of explaining handling principles to parents/caregivers, and why they were doing certain activities in a particular way was highlighted.

> *"It (the home programme) must be incorporated into their playtime their meal time their bath time because that's how we really live and parent's lives are…"* (12, NPO)
>
> *"…that's again why we try to go to the therapeutic care giving so it might take a little bit longer to feed them but if you're doing it in this way it is a therapeutic way."* (44, NPO)

Despite this, some school and hospital participants, and especially private practitioners, still mentioned a *'therapeutic component'* (1, GH), which implied separate activities or an exercise regime.

> *"…more how they can incorporate therapeutic activities into their program where the actual one on one time is more the stretches or the positioning but then lots of ideas of what to do at home."* (14, SNS)
>
> *"The home programme is my 5 or 4 exercises and then activities of daily living, it depends on how old the child is."* (46, PP)

Supports (adaptive equipment & assistive devices)

Adaptive equipment was regarded as **an adjunct to home programmes**, especially to enhance corrective positioning. Participants in NPOs and hospitals placed a greater emphasis on the use of equipment and believed these made home programmes easier for parents to implement and improved their success because they provided encouragement and motivation. **Low cost equipment within the resources of the family** was also important. These were often homemade and therapists were required to be innovative and use what families already had in their homes. This was more sustainable and realistic due to resource limitations, in both poorly resourced families and service delivery settings.

> *"It makes a huge difference. When we had the buggies, you could see the parents' reaction when they received something. It really motivates them and it makes them just feel 'okay, somebody is trying to help me.'"* (40, GH)
>
> *"I think you've got to be as innovative as you can but you know you don't have to have a plastic chair that costs R120 you can sit on a tree stump you can sit on a dish you can sit on an upturned pot and we really push for that."* (9, NPO)

In contrast, private practitioners tried to stay away from *'fancy equipment'* (2, PP) that may take the place of the home programme and/or active movement of the child. Cost was less important, but therapists continued to encourage parents/caregiver to use what they had and to focus on the goals and not the equipment. Equipment for school therapists was dependent on the needs of the child and the willingness of the family to incorporate the equipment or device into their daily routine.

> *"…you don't have to have that equipment for the basics, so the kid who doesn't have the equipment and the kid who has the equipment - it doesn't matter because the kid's got to do it whether he's got the equipment or not, the equipment's not going to suddenly make it happen."* (2, PP)
>
> *"It's also about building it into routine and if it's not, if the parents haven't made the effort to put it into routine it's not going to happen (the equipment won't be used)…"* (5, SNS)

Availability & funds was an important factor for participants in NPOs, schools and hospitals. Those in NPOs were able to generate their own funds or work with government hospitals and other organizations to provide equipment for children and their families.

> *"We're lucky because we've got a huge amount of equipment, but you know it hasn't come from the sky, we've worked really, really hard to get the funding to buy the equipment because obviously we're a small NPO and the moms aren't paying anything … so it's been a lot of marketing…"* (9, NPO)

This was not always possible for hospital and school participants where the availability of funds varied from year to year.

> *"That's a problem. In the past we were lucky to get around five or six buggies every year, but the last two years, no."* (40, GH)

This was not a concern for private practitioners. Even though equipment was not always emphasised, simple activities that required a device or tool within the home programme were easier to obtain due to a greater availability of resources.

> *"I think people genuinely have a little bit more resources, so I think if you then say 'okay I want you to play with a ball in a specific way…okay I actually have a ball', so that's helpful."* (32, PP)

4.5.3.2 Home exercise programme

Tasks, activities & exercises

Activities that were described by participants related to specific goal areas that were identified. There were also significantly more comments and details from school participants than from the other settings in terms of these activities. This correlated to a greater amount of individual therapy time with the children.

Mobilization & positioning was described as important within all service delivery settings. Participants gave examples of optimal positions, the facilitation of movement and the importance of active mobilization within the home programme.

> *"…we just want to get everyone sorted out, get their positioning programme, take pictures and put it up for the caregivers. Give them guidelines on how long they must stand for and sit in a chair, and how they can lie..."* (44, NPO)

> *"Okay, then prone toys at the sides for pushing up and start moving. Transitions, I tell them to help your child up, not to pick the child up. And then sit, put toys at the sides so they can go over to crawl…."* (40, GH)

Stimulation and activities had to do with specific aims such as improving hand function, visual perceptual stimulation, gross motor skills development and play. School participants described gross motor or perceptual exercises that were given to children to complete during school holidays. There were no comments related to specific stimulatory activities from private practitioners.

> *"…depending if it is a physical need or perceptual need or a thing like that, if it is just something to keep them on par through the holidays you focus on (that)…"* (34, SNS)

In spite of comments regarding embedding home programme activities within daily routines, participants in all settings described **separate exercises such as specific stretches** to maintain range of movement, which they referred to as *'the conventional home programme'* (44, NPO). This was especially important post-surgery, and was a greater characteristic of home programmes within private practice. School participants and private practitioners also encouraged children to be more involved and take some responsibility for the *'home exercise programme'* (14, SNS), especially those with greater cognitive ability and awareness.

> *"I think I like to do a bit of ADL because that's what the kid's parents need, but I also want my part, and my part is the specific part… and if there's a parent that is really quite motivated, or they've got time, I give them more specifics…. probably more boring…"* (2, PP)

> *"For the older kids, the more cognitively abled kids, I really focused on giving them and trying to get them to take responsibility for their bodies, which is not always easy because they don't like to do stretches and they don't always remember…"* (5, SNS)

Two participants felt that parents/caregivers preferred a list rather than activities incorporated into their daily routine and that this increased home programme implementation. This was also correlated to the level of understanding of the parent/caregiver and the risk that they may *'not add it to the normal routine if it's not a specific thing that they must do'* (29, GH).

> *"I found that most of my parents ask specifically for something more concrete in the sense that they want to see, okay, I placed the child like this, I put my hand there and that's the hand stretch, tick, and then this stretch…they want more structure…"* (14, SNS)

4.5.3.3 Child & family preferences - pleasing for the parent; not stressful for the child

Active engagement and participation of the child

Participants from all settings valued the inclusion of **the child as part of the family**, and that part of a home programme was *'teaching the family how to incorporate the child'* (46, PP) and spending time together. This was emphasised especially by participants in NPOs, where therapy and life was not viewed as two separate entities. Private practitioners considered the need to help parents/caregivers *'enjoy their child'* (37, PP) by encouraging parent-child interaction. Family involvement, such as siblings being part of home programmes, was encouraged. There were few comments from school participants and less so from those in hospitals.

> *"I think that how we try and talk to the moms is that we want to try and get the child up and about and as much part of the family as they can."* (9, NPO)

> *"We don't see this child necessarily as a functional little human being that must fulfil his little role in the family and in society, and I actually think that is our biggest role - to help the parents to see how this child is going to fulfil his role in the family and society with his disability…I've realised that parents see physio and OT and then there's my child's life."* (46, PP)

Another form of engagement and active participation of the child was **using play and making it fun.** This was regarded highly by the majority of participants from all service delivery settings, not only because it was how '*a child learns'* (9, NPO), but also because it takes away the burden and the guilt experienced by parents. It was viewed as more enjoyable for the child and more likely to be implemented if home programme activities were within their interests and play was made therapeutic. Exercises and play were regarded as interchangeable.

> *"I think being fun for the child and the parent… (to) enjoy doing it…making it fun and nice to do."* (29, GH)

> *"…but (for) your younger kids, there's so much time that you spend on the floor and in playtime and exercises can be done during that time, so that it doesn't necessarily feel like 'oh this is exercise time', it's playtime, but we're playing in the right way rather than…just any old way."* (21, PP)

In addition, participants acknowledged that home programmes were unique to the individual child and should be **child specific** depending on their needs, their abilities and the *'severity of their condition'* (46, PP).

> *"The trouble is with CP everything is so different. Although you do have things that you do often, but…it depends on the child."* (28, NPO)

Active movement and involvement of the child within home programmes was regarded as more functional, therapeutic and meaningful by participants in all service delivery settings. This was linked to parental insight and understanding and a need to educate parents *'not to do everything for the child'*, but to *'let them try'* (28, NPO). Involvement of the child was related to their own understanding and *'ability to take responsibility for themselves'* (5, SNS).

> *"…then if I want stretches, then I'm trying to do play through a different position that would get that stretch because as soon as it's functional and more meaningful for the child, your brain assimilates it more anyway than someone just stretching you."* (32, PP)

> *"…she mustn't do it all for the child. That's one thing that we advocate a lot. Don't do everything for your child. She or he must try and do it."* (28, NPO)

> *"…a child with a problem must have insight into their problem eventually and must understand why they're doing things, not when they're 2 years old, but when they're surely 10, they must start understanding why…"* (46, PP)

Realistic expectations upon parents/ caregivers

Understanding competing responsibilities of parents/caregivers and families was an important factor for all participants. Time constraints were most frequently mentioned across all service delivery settings with similar reasons. These ranged from young mothers or grandmothers who had '*to do everything'* (28, NPO), including looking after other children, cooking and cleaning for the *'whole family and extended family'* (9, NPO), or single parents with little family support or assistance. This was prominent in NPOs, schools and hospitals, especially in care centres within NPOs where there were many children, a shortage of caregivers and even less time for home programmes. Busy parents who had other children to take care of, was also a factor for private practitioners. Time constraints due to working parents was more prominent in this setting, as well as taking other children to sports and additional activities. In schools, the academic load was classified as an added concern *'on top of the physical needs'* of the child (14, SNS).

In all settings, participants acknowledged the need to be realistic in terms of what they expected of families. The importance of understanding the family dynamics and the inclusion of family and child priorities was once again highlighted. This was related to the specific needs of the child and the severity of their condition in that certain activities of daily living already took increased time and would therefore be a greater priority than a separate set of exercises prescribed as a home programme.

> *"You know a lot of these moms are the young 'Makoti' and the bride at home. They don't have 6/7 hours to dedicate to that child… we need to be reasonable in terms of what we expect from them."* (9, NPO)
>
> *"I think the time constraint and the busyness of life is the biggest problem that I've seen parents are faced with home programmes."* (14, SNS)
>
> *"If you have a child with cerebral palsy and it's taking you an hour to feed them, feeding them is going to be a lot more important than doing a couple of ankle stretches in terms of your day and the priority of your time, so again it depends on the severity of the child…"* (5, SNS)

Similarly, **appropriate and manageable** home programmes that were **not overwhelming** and did not cause additional guilt or place undue pressure on parents, was an important consideration and highlighted by several comments from each participant in all service delivery settings. Simple, short and uncomplicated programmes that were easily understood were important. Participants also felt that parents/caregivers should not be expected to be therapists because *'their first job is to be the mother.'* (2, PP)

> *"If the thing you get is too complicated or too long, and it's going to take a lot of time then you're not going to do it. I don't think it matters how educated you are or…if you can read that language. I don't think that matters, it's a general thing."* (44, NPO)
>
> *"…but 'I don't want to make you feel too bad that you've got to do all these things'… because sometimes you can overload them (the parents) and they feel guilty… they mustn't feel guilty that they haven't done what I want, so you have to take the whole family into consideration."* (2, PP)

> *"It (their role) doesn't have to be as a therapist because that's not fair on a parent to be a therapist as well…"* (32, PP)

Home programme dissemination to parent/caregiver or child

Participants from all settings **ensured a clear understanding** of home programmes by using either **verbal explanation and demonstration** or **written information and pictures/photographs.** This was in accordance to parent/family preferences and therefore varied, not necessarily according to service delivery setting, but with individual children and their families. For participants working in NPOs and hospitals, language barriers were considered. Participants made use of a translator to explain and/or translate the written home programme, or they expressed a greater use of demonstration or pictures to aid explanation. These were sometimes listed as difficulties in private practice and schools, but were less frequent in these settings. Private practitioners also described the benefits and use of technology such as 'whatsapp' or parents/caregivers taking videos of the participant performing the exercise with their child. When describing the nature of home programme dissemination private practitioners frequently referred to a set of exercises.

> *"If a video works for them, if a drawn diagram works for them, or if a photograph works for them, it's really actually having a look at where that family is at."* (21, PP)

4.5.4 Supporting the programme implementation

The fourth theme, **supporting the programme implementation,** ensures adequate follow up with parents/caregivers and families to ensure the home programme is 'meeting the needs of the family' and is also 'practical and feasible' (Novak & Cusick, 2006). Participants were asked how they support families in this regard. Regular communication and the possible challenges therein were explored (Table 4.13).

Table 4.13 The categories, subcategories and codes of Theme 4: Supporting the programme implementation

Supporting the programme implementation	Parental support & assistance	Enable parents to seek support	- Contact & communication - Positive reinforcement & ongoing interest - Support groups
		Arrange reviews	- Review parent & child performance - Feedback & questions

The categories, subcategories and codes are described in the text below.

4.5.4.1 Parental support and assistance

Enable parents to seek support

Regular **contact and communication** in order to support home programmes was easier in some settings than in others. Whatsapp, text messages and/or telephonic contact was sometimes used in NPOs, but this was more challenging for therapists working within care centres because employed caregivers were *'less likely to use their own phones to phone about a child that's not theirs, and it's just their job'* (12, NPO). In schools, effort was required to make contact with the parents/caregivers because they did not typically accompany the child to therapy. Contact was mainly through the child's contact/homework book, telephonically or through email. There was greater use and availability of technology in private practice, such as Whatsapp and emails. Contact and communication was easier in this setting because language barriers were less problematic and contact time was more regular. There were no comments regarding the use of contact and communication from hospital participants.

> *"…it is difficult to always find time, but we always try to contact them, especially telephonically or writing notes in homework books."* (5, SNS)

> *"… (if they don't understand or are struggling with something in the home programme)…they just wait till they come again."* (46, PP)

> *"Yes technology has made it much easier...you know and emails too… I can email them…"* (46, PP)

Positive reinforcement and ongoing interest was a method used by participants from all settings. They agreed that it was important to continue to empower parents/caregivers, to provide encouragement and motivation, and to create awareness of the importance and significance of small changes. This was less frequently implemented by school participants.

> *"Just trying to get them to buy into it, trying to sort of show them if they do it what happens and then what the benefits are, and if you see an improvement then to really praise them for the fact that your child can now do this because you have been doing the exercises with them…obviously giving praise and always motivating and encouraging them."* (29, GH)

Participants from NPOs and hospitals used **support groups** as a form of supporting home programme implementation, especially when parents could talk through the impact and benefits of home programmes and learn from each other.

> *"…they talk about what their child couldn't do and what they can do now, and then they often ask, 'okay, but do you know why, what did you do?' And then they'll say, 'they did the exercises every day'…"* (29, GH)

Arrange reviews

Participants in all settings **reviewed parent and child performance** to establish if they were doing the home programme, how it was going and if they were doing it correctly. In schools, this was mainly through asking the child and then arranging a meeting with the parents if necessary. In hospitals, reviews were important to ensure parents understood the home programme. The *'hand over process'* (1, GH) and allowing parents/caregivers opportunity to practice was also valued due to less frequent therapy sessions. The frequency of therapy in private practice allowed for regular parental reviews, which made it easier to modify home programmes and ensure parents were coping with the exercises/activities.

> *"That way I could monitor if the carer was actually interested, because sometimes they would come back and it just didn't look like they even knew what they were doing, so this was also a good way for me to know, okay, back to the drawing board. I need to educate this mom a bit more, or I need to change the exercise. It might be too hard for her to understand."* (1, GH)
>
> *"I give them things to do and so forth, especially when they start with me. I do a lot of that, but as they grow: 'change that, change that, don't do that anymore, are you coping with that? Are you not coping with that? Let's try and change it'."* (37, PP)

Feedback and questions were encouraged by participants in all service delivery settings. School participants found this to be minimal and usually when they were *'struggling'* or if they were *'unsure about something'* (5, SNS). Participants sought to find out if parents/caregivers were coping with the home programme and if they understood it.

> *"One of the 1st things I always ask when they come in is, 'do you have any questions to ask me right now? …is there something that you were taught last time that you can't get right? Please ask.' And actually, they very seldom do ask, but sometimes they do and usually they're very relevant things…and it can make such a difference…"* (12, NPO)

> *"…usually what I do is chat to them about how it's going, if they've had any difficulties…and say, 'well did it work and how can we make it easier?' So generally, just getting feedback every time..."* (21, PP)

4.5.5 Evaluating the outcomes

The final theme, **evaluating the outcomes,** relates to ensuring the goals of the home programme are being met and that progress is being made (Table 4.14)

Table 4.14 The categories, subcategories and codes of Theme 5: Evaluating the outcomes

Evaluating the outcomes	Home programme outcomes	Change noticed	- Therapists observations of goal achievement - Increased caregiver involvement & competency
		Measuring outcomes	- Non-use of standardized measures & documentation - Informal progress assessments

Interview questions focused on evidence of home programme effectiveness and outcome measures used. The categories, subcategories and codes are described in the text below.

4.5.5.1 Home programme outcomes

Change noticed

The changes in a child's improvement were mainly due to **therapist's observations of goal achievement**. This was demonstrated by visible improvements in the child's function, greater participation or *'slowing down the* *progression of the deformities'* (12, NPO) and was expressed by participants from all settings. This was through clinical observations, reassessment, parental reports and *'happy families'* (9, NPO).

> *"Because we can see change when the kids come back. They've often improved and they're doing other things and mom's thrilled with what they're doing…"* (28, NPO)

Participants also measured outcomes by an **increase in caregiver involvement and competency.** In NPOs, hospitals and private practice, this was related to a change in the parent/caregiver's attitude, their level of involvement and commitment i.e. if they were carrying out the home programme. There were no comments from school participants.

> *"…even the other carers, who really were doing nothing, are actually now looking at those photographs and trying their best to reproduce the photographs…"*(12, NPO)

> *"…and also I think in the attitudes…they would be much more involved and that's not really something that you can measure…"* (44, NPO)

Measuring outcomes

Non-use of standardized measures and documentation was prominent in all service delivery settings, by their comments and also lack of comments for these questions. This was attributed to limited time, resources and also a lack of *'a good measurement to test effectiveness'* (44, NPO). There were no comments regarding measurement tools from hospital participants. One private practitioner sometimes took videos to measure progress. Generally, measurement was through handling and observation.

> *"You know, my time is so limited when I'm there, I don't believe it's justified to do any fancy standardised things because that's not what's going to make a difference."* (12, NPO)

> *"I'm trying to compile something that we could measure the effectiveness because that is a big gap for me at the moment…I don't really know how to measure it empirically…I can see that it's working, but it's not really enough."* (44, NPO)

> *"I don't think it's always possible to have evidence of everything you do, but I think if we check ourselves all the time that we are doing what we think we're doing, then we're on the right track."* (46, PP)

Participants performed **informal progress assessments** by recording findings in their own therapy notes and patient files.

> *"It's not measurable, I don't measure that (the home programme), but I definitely record that. I assess them (the children) again through all the functional things, see if there are things that they can do now which they couldn't do."* (46, PP)

> *"…I do do that (write progress notes) but it's …I think us as therapists are shocking with them, but I can generally remember what the child was like the week before."* (21, PP)

4.6 Summary

The most prominent finding of Part 2 of this study was that the first phase of forming a collaborative partnership based relationship with parents/caregivers when introducing home programmes was valued by participants, but factors that made this easier or more difficult to establish were unique to individual parents/caregivers and families, as well as to each setting. These ranged from parental/caregiver involvement, commitment, motivation, insight and therapy attendance in all settings, to factors such as poor social dynamics and resources, which were especially prevalent in NPOs and hospitals and affected the prescription and commitment to home programmes. Similarly, busy parents with decreased time to carry out home programmes in private practice resulted in therapy and home programmes been a lower priority. Decreased direct contact time with parents/caregivers in schools was expressed as a more child centred approach, more superficial relationships with parents/caregivers and less awareness of the context and social dynamics of families, i.e. their assets and competencies, needs and concerns. Goals were especially more therapist directed by this group.

Language barriers were prevalent in NPOs and hospitals, which not only increased the time taken to form a meaningful relationship with parents/caregivers and understand their routines and circumstances for home programme formulation, but also impacted on home programme dissemination. These were not factors in private practice, where few language or cultural differences were present, therapy sessions were consistent and frequent, and contact with parents and time to develop and modify home programmes was regular. In NPOs, schools and hospitals, additional barriers such as high client loads, staff shortages and decreased time shortened contact time with parents/caregivers and made home programmes less individualized. However, a relationship with parents/caregivers was regarded as essential by all participants, with a greater value placed on deeper and more meaningful relationships, and greater importance placed on finding out parental/caregiver needs in both NPOs and private practice.

A lack of standardized and collaborative assessment and formalized goal setting procedures was found across all settings. Although participants valued parents as primary decision makers, goals appeared more therapist directed with education necessary to enable parents/caregivers to understand their child's condition and to ensure goals were realistic. Role clarification and expectations of therapy were especially important for participants in private practice, whereas empowering parents/caregivers and providing reassurance was of greater importance within other settings.

Participants from all settings valued home programmes that were not separate exercise regimes, but formed part of the child and family routine, which was described as therapeutic caregiving. Despite this, separate exercises described as the 'therapeutic component' were mentioned by participants, especially those in private practice. Home programme content consisted mainly of handling, positioning and mobilization, with the emphasis on active movement, therapeutic play and including the child as part of the family. Adaptive equipment and assistive devices were valued more by participants in NPOs and hospitals, who believed this to be a motivating factor for parents/caregivers with regards to home programme involvement and implementation.

Several comments from participants in all settings showed that they believed home programmes would be more successful if they were realistic, appropriate and manageable, and if the child and family priorities were included. Participants modified home programmes according to these characteristics, which formed part of supporting the implementation. This was mainly though contact and communication, regular reviews, positive reinforcement and feedback, which was most frequent and possible by participants in private practice, and least possible by participants in schools. This correlated to more contact with parents/caregivers in private practice, as well as the increased use of technology such as Whatsapp and email. There was less direct contact with parents/caregivers within schools. Similarly, reviews of parental and child performance to ensure they understood the home programme were of greater importance for participants in hospitals, where therapy sessions were less frequent. These reviews, together with informal progress assessments, clinical observations and parental reports, formed part of home programme evaluation, which is the last phase of the model home programme (Novak & Cusick, 2006).

CHAPTER 5
DISCUSSION

Introduction

Occupational therapists and physiotherapists who completed the questionnaire and/or took part in the interviews provided valuable insights regarding the content, design and implementation of home programmes for children with CP in South Africa, which has not been described previously. Their approach to home programmes was generally comparable to the Novak and Cusick home programme model (Novak & Cusick, 2006), but many aspects unique to each service delivery setting, and to the South African context, were highlighted. These differences are not surprising given that the Novak and Cusick model was based on literature from well-resourced settings. Based on the results of the questionnaires and interviews, a description of these differences, with possible reasons for them, will be discussed, as well as recommendations for home programme implementation in the South African setting.

This chapter initially focuses on the demographics of the participants within the study. This was not one of the research objectives, but is an important aspect that influences the findings. The opinions and experiences of participants, based on the framework of the model home programme of Novak and Cusick (2006) are then considered. This is particularly in relation to Phase 1 of the model: establishing a collaborative relationship with parents/caregivers and the external and internal factors affecting this relationship, as well as to Phase 2: collaborative goal setting. Objectives in terms of the content and characteristics of home programmes are described under Phase 3: the construction of the home programme, but due to the heterogeneity of CP, these were not as specific as the original objective intended. Current practice of the design and implementation of home programmes in different service delivery settings, as compared to the model, are further considered under phases 4 and 5: supporting the home programme and evaluating the outcomes. Lastly, modifications to the home programme model that take these different factors into account are suggested, with adaptations for the South African context.

5.1 Demographics

The response rate of 9% from the questionnaire (Part 1) of the study was below what was expected, especially given that a response rate of 35 - 40% is considered acceptable for survey responses (Baruch & Holtom, 2008). This was in spite of the extensive effort of the researcher to increase the questionnaire responses. A possible reason for this might be that, although therapists who were SANDTA members had a special interest in neurodevelopmental therapy for the treatment and management of persons with neurological disorders, not all therapists who received the questionnaire were involved in home programmes for children with CP, as the questionnaire required. The percentage of this population within the sample group was unknown. The low response rate could also be due to factors such as busy therapists and time constraints or lack of interest.

Of the participants that responded to the questionnaire, a higher percentage were physiotherapists (compared to occupational therapists), which is partly a reflection of the greater number of physiotherapists that are SANDTA members, as well as there being a greater number of physiotherapists within South Africa (South African Neurodevelopmental Therapy Association, www.sandta.org.za; Health Systems Trust, indicators.hst.org.za) (Table 4.2). The geographical breakdown of the responses also reflected the greater number of SANDTA members located within Southern Gauteng and the Western Cape (South African Neurodevelopmental Therapy Association, www.sandta.org.za) (Table 4.1). There were no respondents from government clinics, which could be due to the low number of NDT trained therapists working within this setting (South African Neurodevelopmental Therapy Association, www.sandta.org.za), or due to a lack of therapy services in poorly resourced areas where clinics are often located. Both these factors pose problems for children with CP attending government clinics, who are either not receiving the most effective therapy services or are not receiving therapy services at all.

It is also interesting that half the participants within Part 1 of the study, and over half of those interviewed in Part 2, worked with children from low resourced settings, but the majority of NDT trained therapists in South Africa actually work in the private sector (South African Neurodevelopmental Therapy Association, www.sandta.org.za). The sampling therefore reflects different work settings where children with CP receive intervention services rather than where the majority of NDT trained therapists work. This is in keeping with the study's objective of understanding the views and perceptions of therapists that work in different service areas. However, it also demonstrates that the majority of children with CP, who are in resourced constrained settings and not in the private sector, do not receive intervention from therapists with additional training and experience in NDT. It is also significant that the population of children with CP served by the study participants were in resource constrained settings and differed to the well-resourced settings where the model home programme was both developed and tested (Novak & Cusick, 2006; Novak et al., 2007; Novak et al., 2009).

The selection criteria of Part 2 of the study sought participants with the most training and experience with regards to the treatment of children with CP. It was believed that these therapists would provide the most valuable insights regarding home programmes because of their knowledge and experience. Those in NPOs had the most experience (over 20 years for three of the four participants and nearly 40 years for two participants) and additional training (Table 4.9 & Appendix J). These therapists displayed the strongest family centred approach, followed by those in private practice (where three of the five participants had over 30 years of experience), which was possibly attributable to their extensive experience. The attitude and the values of therapists (Thompson, 1998), as well as their experience and education (Hinojosa et al., 2002), have a significant impact on family involvement. Looking back at their own approach to therapy, more experienced participants described how, over time, they now have a greater understanding of families and a less dictatorial and judgemental approach to therapy, which results in them having more realistic expectations for families with regards to home programme involvement. These findings support the work of Schell and Schell (2008) who show that with experience, therapists develop clinical expertise which allows them to practice in a more effective, client-centred way. This is because they have high levels of professional knowledge and clinical reasoning that allows them to value what the patient brings to the treatment situation in terms of their concerns, expectations and preferences.

In support of this notion, the least family centred practitioners in this study were the younger participants with less experience and fewer additional qualifications or training specific to the treatment of children with CP (Table 4.9). These findings support the view that there needs to be a greater emphasis on family centred services within university curriculums to equip therapists with the skills and attitudes necessary to work with families (Thompson, 1998). This is especially necessary given the lack of knowledge, skills and experience of community service therapists, which was regarded as problematic by the more experienced participants in the study, particularly in light of the complex nature of CP. It is not clear how successful this would be because professional development in these skills appears to be best developed through mentoring and learning *in situ* from experienced therapists. More experienced participants within the NPOs interviewed in the study often partnered with government hospitals to provide education and learning opportunities for younger therapists in an attempt to improve and develop their skills, ultimately providing a better service for children with CP and their families in these institutions.

5.2 Phase 1: Establishing a collaborative relationship with the child's parents/caregivers

The phase of home programme development that presented the greatest contrast to the Novak and Cusick (2006) model was the development of a collaborative relationship between the therapist and parents/caregivers of the child with CP. Although participants in this study confirmed the value of a family centred approach and the necessity of working with parents to form partnership relationships with regards to home programmes, this was not always implemented exactly as the Novak and Cusick model and literature intends.

Although participants indicated that they employed a family centred and individualized approach in home programmes in Part 1 of the study (Figure 4.2), the development of a relationship with the child and an assessment of the child, rather than a relationship with the parents/caregivers, was prioritised as the starting point for designing the home programme (Figure 4.3), which is more consistent with the traditional child centred approach to therapy (Rosenbaum et al., 1998; Hanna & Rodger, 2002). Home programmes in this study were described as therapist initiated, with a partnership with parents rated as 5th most important, after the therapist's role of supporter, educator and problem solver (Figure 4.4), which were seen by therapists as more important than collaborating with parents.

Themes emanating from Part 2 suggest that active participation of the parent was encouraged and a holistic view of the child within the family and community context was considered (Table 4.10), which is in keeping with literature and the home programme model recommendations (Rosenbaum et al., 1998; King et al., 2004; Novak & Cusick, 2006). However, irrespective of the experience of the therapist, collaboration with the family with regards to home programmes was affected by the setting in which the therapist worked. Within schools, contact and communication with parents/caregivers was not always direct because parents did not attend individual treatment sessions. An extra effort was required to arrange parental meetings which appeared to be few and sporadic, often due to transport difficulties and parental/caregiver availability. Similar to other studies (Pillay & Di Terlizzi, 2009), a greater degree of parental involvement within LSEN Schools is recommended, but there is a need to be aware of the challenges present within the South African context.

There were also no comments regarding the roles, responsibilities and health of the parent/caregiver, as well as an understanding of the physical environment of the home by school participants in Part 2 of the study, suggesting that home programmes were more child-focused and less family centred in this setting. The academic focus within a school setting makes it difficult for therapists to incorporate a holistic approach towards the child, even within therapy, but if therapists are to be effective, they need to take the family and all areas of the child's life into account (Rosenbaum & Stewart, 2004). Participants indicated that this was not always possible due to resource and time constraints, such as high client loads and few therapists practising in this setting.

5.2.1 The effect of language and culture

Contact with parents/caregivers was more direct and regular for therapists in NPOs and government hospitals, but challenges regarding parental involvement were similar for participants working in these settings and had a definite effect on family centeredness and partnership relationships when formulating home programmes for children with CP. Some of the greatest barriers participants faced in developing collaborative relationships with parents and making home programmes family centred were language and cultural differences. Irregular therapy attendance, the lack of parental involvement and therapy resource limitations also playing a role. These challenges were not considered within the Novak & Cusick model home programme (Novak & Cusick, 2006), but have a significant impact on home programmes for children with CP in resource constrained settings for several reasons.

Firstly, it is difficult to develop a partnership without effective communication because basic information, such as understanding the family routine, the social dynamics, roles of the parent/caregiver and available resources become difficult to obtain. This hampers the development of a family centred home programme because it is a further impediment to the development of a deeper and more meaningful relationship of trust and understanding between therapists and parents, which this study and others confirm are important (Blue-Banning et al., 2004; McWilliam et al., 1998). All the participants within NPOs and hospitals had a different first language to the majority of clients they treated. This is true of many health care workers within the South African context, especially given the language diversity within the country (Schlemmer & Mash, 2006). Translators and therapy assistants who shared a common language with the children and parents/caregivers were highly valued and considered essential in the prescription of home programmes. They were often described as a link between the participant and the family, especially by NPO participants. This highlights the positive impact and critical role therapy assistants and translators can have on relationship development, and the need for adequate training and incorporation of them in the therapy team. Indeed, the value and incorporation of translators within the NPOs of this study could have played an additional role in the family centeredness of this group of therapists.

School participants tended to rely on the children themselves to communicate and translate information about home programmes to their parents/caregivers. In reality, a translator is also needed in this setting when the therapists and parents do not speak one another's language. This will be beneficial for translating information about the family circumstances and their needs to the therapist before home programmes are formulated. Effective communication is especially necessary during the initial assessment and goal setting phases (Novak & Cusick, 2006). The child cannot be expected to play this role.

Secondly, cultural differences affected the collaboration with parents/caregivers in home programmes in NPOs, schools and hospitals. The barriers these may have created between therapists and parents/caregivers were not as marked as the importance of understanding the social dynamics, often related to culture, that affected the family context. In agreement with other studies (Humphry, 1995; Humphry & Case-Smith, 1996; Thompson, 1998), participants confirmed the need to consider family value systems, cultural beliefs and priorities, and to contextualise and understand the socioeconomic realities of each family. The model home programme approach emphasises the importance of family needs and home programme individualization (Novak & Cusick, 2006), but does not consider the additional challenges of parents/caregivers that live in poorly resourced settings, or the scope of resources available in service delivery settings with high client loads, limited staff and limited contact time with families.

5.2.2 Other external factors affecting collaborative relationships

Other external barriers that affected the ability of therapists to offer consistent family centred support and collaborate frequently with parents on home programmes were the parent's socioeconomic status, social support systems they had access to, and the resources available within the service delivery settings.

Therefore, the context of the family must be considered with reference to their access to resources. This includes both physical resources, e.g. financial constraints and transport difficulties to attend therapy and in turn obtain home programmes, as well as the availability of assistance and emotional support to carry out the home programme. Services in the NPO and hospital contexts were often long distances from homes, resulting in higher transport costs that further increase when additional equipment, such as a wheelchair, needs to be transported. Furthermore, additional caregivers are often required to look after other children left at home during the disabled child’s therapy sessions. These are only some examples of the costs and organisation pertaining to therapy attendance that often result in it being infrequent and the collaborative relationship with the parents or caregivers difficult to maintain. In addition, participants frequently reported multiple caregivers and a lack of caregiver consistency that resulted in different caregivers attending therapy sessions. This also affected the ability to develop meaningful relationships with parents/caregivers, as well as transference of information and skills to carry over into the home programme.

As with other studies (Humphry, 1995), home visits helped therapists to understand and consider these dynamics, and to fully grasp the needs and concerns of the family, as well as gain insight into what was practical and feasible to implement in home programmes. Such visits also provide the possibility of updating the home programme within the child’s home and reduce the travel burden for the family. A relationship with a consistent caregiver who is at home with the child is also developed as a result. Unfortunately, however, participants felt that home visits were not prioritised or made possible in hospitals and schools, both government run institutions, due to a lack of time (high client loads), man power (staff shortages), lack of hospital vehicles and funding.

A lack of time, due to high client loads and staff shortages within NPOs, hospitals and schools, further impacted home programmes due to the decreased contact time the parent and child had with the therapist. It is questionable whether there is enough time in these settings to develop a deep relationship of trust and understanding, to find out family needs and priorities, and to educate, explain and empower parents/caregivers to ensure home programmes are family centred and individualized. Cognisant of the effort it often takes to attend therapy, this may be a reason for poor parental participation. Families might not value home programmes that are not individualized and personalized because of these resource challenges. The high staff turnover in government settings amplifies this problem and hinders therapist consistency and the continuity of care, a component valued by parents/caregivers (Case-Smith & Nastro, 1993). This not only impedes the development of collaborative relationships, but also the progression of home programmes that should naturally occur as parents/caregivers increase their knowledge and skill, and as therapists get to know the child and their family situation.

These inequalities and inequities that are prevalent in poorly resourced settings in South Africa are not considered within the home programme model of Novak and Cusick (2006), highlighting the difficulties of having a truly family centred approach within the South African context. Furthermore, there is limited research examining such barriers to home programme implementation, particularly for the population of children with CP and their families. This results in a lack of guidelines on how to overcome them. Humphry (1995) discussed family centred services within resourced constrained contexts and identified similar challenges. Recognising and appreciating the value orientation of parents/caregiver was highlighted. She suggests that the temporal orientation of parents/caregivers is directed towards present, immediate needs and concerns due to a lack of resources, making goal formulation for the future a lesser priority. Home visits were also regarded as a way of learning more about the sociocultural reality of parents/caregivers and understanding the parental/caregiver values and the challenges family’s face, which are often vastly different to those of therapists. Physiological needs such as food, clothing, access to services and assistive devices that are often lacking (Lygnegård et al., 2013; Hartley et al., 2005) are of greater priority than home programmes.

In contrast to these external challenges, the setting most conducive to implementing a family centred approach and the sector most similar to the setting of Novak and Cusick (2006) was within private practice, which is not altogether surprising. Within this setting, there was regular contact with parents/caregivers through frequent therapy, easy access between the parent/caregiver and the therapist, minimal time and resource constraints and few communication barriers. Despite this, the relationship between participants and parents was not always characterized as partnership based and collaborative, but comments suggested a more business type relationship or transaction. The therapist was often viewed as the expert and there was a level of detachment by the parents/caregivers who felt that because they were paying for therapy, they expected the therapist to ‘fix’ their child. This is in contrast to the Novak and Cusick (2006) model that emphasises parents as experts regarding their child, and therapists as technical experts that enable and empower parents (Rosenbaum et al., 1998; Bazyk, 1989). The business type transaction seen in private practice settings may not have been common within the Australian context of the model because of a different health care system. Services were largely tax-funded and subsidized with a minority of parents privately paying for therapy (Healy et al., 2006).

5.2.3 Internal factors affecting collaborative relationships

Participants within all settings felt that parental participation in home programmes was related to the parent’s level of motivation and commitment, attitude, ‘buy-in’, interest and dedication (Table 4.10). Such characteristics and behaviours can appear to stem from a lack of parental involvement, but could also result from other underlying issues that relate more to understanding, insight and ‘readiness’ to engage in home programmes. Previous research suggests that parents/caregivers of children with CP go through stages of understanding and accepting of their child’s disability, and that participation in home programmes occurs when they are emotionally able, which often takes time (Piggot et al., 2002). Some participants recognised the need to be sensitive and understanding of this process and how it relates to home programme involvement, whereas others were less empathetic and appeared to have a more judgemental attitude. For example, some participants felt that parents/caregivers were *“compassionate, concerned and involved to a degree we can’t even begin to imagine”* (9, NPO), whereas others said that the *“caregiver (was) not always…as caring and as dedicated as one would hope for them to be…some are content to do nothing”* (29, GH).

A limitation of this study was that these views and perspectives were those of therapists and not parents/caregivers, and I can only speculate regarding the reasons for the level of parental/caregiver participation within these specific contexts. Nevertheless, the findings demonstrate that a form of preparation in the form of providing empathy, understanding and education needs to occur before parents/caregivers can fully participate and become primary decision as the Novak and Cusick (2006) model home programme suggests. Given the underlying questions and feelings parents/caregivers have about having a child with CP (Rentinck et al., 2010), there appears to be a gap in the services provided by therapists in these settings that would enable parents/caregivers to journey from possible feelings of hopelessness to empowerment.

However, it is questionable whether therapists are trained or equipped to address the underlying problems of parent's accepting and dealing with a child with CP and the additional global difficulties and lifestyle changes that often accompany this diagnosis. Moreover, if this was challenging for these therapists who, by selection, are a more experienced and trained group, how much more of a challenge it must be for less experienced therapists. Therefore, therapy that addresses the deeper struggles hindering parent/caregiver home programme involvement could be outside the scope of occupational therapists or physiotherapists and require referral to another professional (e.g. a psychologist or social worker).

That being said, providing support and education to assist parents/caregivers to understand the lifelong condition of CP, including the potential areas of improvement provided by a home programme, are certainly within the area of expertise of therapists (Rosenbaum, 2003; Novak & Cusick, 2006). This was also demonstrated in the theme (a family centred approach) from Part 1 of the study where participants reflected on the purpose and description of home programmes as a means of involving the family by teaching the parents what to do while supporting their specific needs and encouraging their active participation (Figures 4.5; 4.6; 4.7). Home programmes were defined as a way of empowering parents/caregivers, enabling and equipping them, and providing practical guidance, education and access to information. This was *"to make sure they are equipped for their role as a caregiver"* (34, SNS).

Participants, as well as previous research (Thompson, 1998; Rosenbaum et al., 1998), acknowledge that dealing with the parents/caregivers is as important as dealing with the child. Home programmes, while offering support in terms of the condition and techniques, must be tempered by the person the therapist is dealing with. The interpersonal skills of the therapist, and the characteristics of the relationship between therapists and parents/caregivers are important during this process and enhance family centeredness (Case-Smith & Nastro, 1993; Dunst et al., 2007). The literature describes characteristics of the relationship between therapists and parents/caregivers, such as openness, friendliness, sensitivity and flexibility, as improving parental involvement and home programme success (McWilliam et al., 1998; Blue-Banning et al., 2004; Novak, 2011).

A collaborative relationship with the parent therefore depends on listening as well as guiding and empowering. Participants, especially those in NPOs and private practice, believed that talking through personal issues and ensuring their emotional well-being was often more important than hands on therapy time and improved participation, showing interest and listening to parents was of greater value, in accordance with previous research (Law & King, 1993; Gajdosik, 1991; Thompson, 1998). For example: *"I once had a mother that told me 'today you're not going to treat my child, today you're going to listen to me, because nobody understands my situation and I just want to talk to you.' So sometimes I feel that they must have the openness to come and discuss their feelings and so forth, and then I don't treat the child that day. I listen to the mother."* (37, PP).

Participants recognised that these personal circumstances were often related to parental/caregiver roles and responsibilities, which were associated with parental/caregiver involvement and their ability to carry out the home programme. This included whether time was available for home programmes, due to other competing responsibilities, and was reported by most participants. Those in NPOs and hospitals found that decreased value was placed on home programmes and was instead placed on other, often more pressing, priorities such as a lack of basic resources. The health of the primary caregiver, who was often the grandmother in the NPO and hospital settings, was also paramount and related to what she was physically able to carry out in terms of home programme activities. These findings are not new for poorly resourced settings (Brehaut et al., 2004), and reiterate the need for therapists to be aware of, respect and understand these issues (O'Tool, 1989; Goldbart & Mukherjee, 1999b; Goldbart & Mukherjee, 1999a), and to make home programmes more family centred, individualized, appropriate and realistic (Hinojosa & Anderson, 1991)

In resource-constrained settings, competing responsibilities and other roles that caused time constraints were mostly attributable to social dynamics and poor support structures. In private practice, time constraints were also problematic, but were due to other reasons, such as single parents, parent’s work responsibilities or because of other activities and routines such as sporting activities of other children. Role clarification within therapy, and ensuring that parents/caregivers had realistic expectations of the therapist was of even greater importance in private practice. Participants felt that this was because parents/caregivers had an unrealistic expectation of the therapist to take responsibility for the child’s progress. However, other comments contradicted this view and suggested that parents/caregivers in private practice were more involved in home programmes compared to parents in resource-constrained settings because they had a greater understanding regarding the impact and value of home programmes. This positive perception could result from the often better social circumstances and availability of resources in private settings, and parents/caregivers that are able to prioritize and place greater value on home programmes, which was perceived as greater involvement. Perhaps this was also related to the extra time necessary in resource constrained settings for therapists to explain, and for parents/caregivers to understand, their child’s condition and the impact of home programmes due to language barriers.

Therefore, a major finding of this study is the importance of parental/caregiver insight and understanding of the value of home programmes, and how this affects participation in home programme implementation. According to the Novak and Cusick (2006) home programme model, increasing parental competency is part of collaborative goal setting (Novak & Cusick, 2006). However, the emotional state of parents/caregivers, including what they are able to cope with considering other roles and responsibilities they might have, should first be considered and understood during the initial phase of forming a collaborative relationship. Emphasis should be placed on preparing parents/caregivers so that they can be more involved in goal setting, which will simultaneously increase satisfaction, control and competence in home programmes (Novak, 2011).

5.3 Phase 2: Collaborative goal setting

The home programme model emphasises the importance of partnership relationships between parents/caregivers and therapists which includes the process of setting home programme goals (Novak & Cusick, 2006). Parents/caregivers should be regarded as primary and capable decision makers who know what is best for their child and who are aware of family needs and priorities (Broggi & Sabatelli, 2010; Viscardis, 1998; Jansen et al., 2003). Private practitioners and participants in NPOs appeared more cognisant of parental/caregiver goals and what they would like their child to be able to do, or what would make their lives easier in terms of home programmes. In contrast, participants in hospitals seemed to rush into the goal setting process. This may be another consequence of infrequent therapy sessions and decreased therapy time within government hospitals, resulting in participants feeling the need to maximize the time available to empower and equip parents/caregivers. However, these therapists are likely missing important aspects of collaboration in the process. Within schools, home programme goals were set from a more academic perspective, with greater input from the multidisciplinary team than from parents/caregivers, which limited parental/caregiver participation.

Within all settings, the reason provided by participants as to why goals were based on assessments that were often initially therapist led related to parents/caregivers *“not knowing what they want”* (28, NPO). Parents/caregivers also tended to set unrealistic goals for their child and often believed the child would develop typically after therapy intervention. Participants acknowledged that they should not *“dash the hopes”* (12, NPO) of parents/caregivers, while simultaneously providing education and making goals more realistic. In similar ways to Phase 1 of the model (developing a collaborative relationship with parents/caregiver), there was also a realization that active participation of parents/caregivers in goal setting could often take a few sessions, or even years, to develop. This was because it takes time to understand and realise the full implications of cerebral palsy, with parents/caregivers often being overwhelmed initially. Participants realised that it may therefore take parents/caregivers time to accept their child’s condition, be able to set realistic goals and to realise the importance of a home programme, which is in line with previous research that emphasises the readiness of parents regarding participation in home programmes (Piggot et al., 2002).

The need to enhance parental knowledge, skill and competency in goal setting, as the model home programme recommends (Novak & Cusick, 2006), was prevalent in the comments made by participants, but the findings highlight a greater need to listen to parents (Thompson, 1998; Law & King, 1993) and involve them when establishing goals (Jansen et al., 2003; Peplow & Carpenter, 2013). The lack of formalised goal setting procedures evident across all settings might also play an additional role in decreased parental participation. Home programmes could be of greater value if they include goals that are quantified and the benefits more clearly defined, as shown in previous research (Novak et al., 2007; Novak et al., 2009).

In contrast to the model home programme approach by Novak and Cusick (2006), the goals of home programmes in this study were determined more by therapists than by parents/caregivers, especially in schools and hospitals. It was evident that goals were aided by an assessment of the child, but this should also be in collaboration with parents/caregivers and focus on the strengths, needs and priorities of the family (Crais et al., 2006; Novak & Cusick, 2006), which was not always evident by participants.

5.4 Phase 3: Constructing the home programme (home programme content)

The study provided further information regarding the actual construction and content of home programmes for children with CP in South Africa. Home programmes were mainly focussed on handling techniques, positioning, stimulation and exercises, with specific goal areas focused on improving child factors, performance skills and participation (Figure 4.12; 4.13; 4.14). Participants emphasized that these activities were incorporated into daily tasks that formed part of the child and family routine (Figure 4.11) and because of this, no specific length or duration of the programmes could be determined (Figure 4.16).

The concept of therapeutic caregiving and therapeutic play was highlighted by participants from all settings, and especially so by those working in NPOs. These were described as a way of providing ideas and practical guidelines regarding handling, positioning and facilitating of the child to make everyday activities functional, therapeutic and fun. If the goals, such as maintaining range of movement and functional positioning, were incorporated into the parent's everyday management of the child, it was regarded by participants to be much more practical and beneficial for the child.

These findings are consistent with previous research, including the model home programme, that highlight the importance of embedding home programme activities within daily routines that are more manageable and realistic for families, especially in light of competing responsibilities and time constraints (Novak & Cusick, 2006; Novak et al., 2007; Novak, 2011; Wiart et al., 2010; Hinojosa & Anderson, 1991). Affirming this, several comments from all participants, across all settings, described how home programmes should not overwhelm parents or become an extra burden. Although participants indicated that they believed home programmes to be more successful when they incorporated activities into daily routines (Figure 4.15; Table 4.12), this was not always reflected in their practice when details of home programme content were examined more closely. One participant, for example, indicated that the programme covered some ADL to satisfy the parents but, exercises were still essential, and, in their opinion, needed to be incorporated (2, PP).

There seemed to be some guidelines, general handling and activity components that were incorporated into daily routines, but then a specific component that was referred to as the 'conventional home programme' by participants in hospitals, schools and especially private practice. This comprised of mobilisation and positioning, specific stimulation and separate stretches performed at an allocated time (Table 4.12). Such viewpoints suggest that the concept of embedding these separate exercises into daily routines, for example by doing the stretches as part of getting dressed, appears to be somewhat misunderstood by most participants. Some felt that parents/caregivers preferred something more concrete, such as a list of exercises. This, however, contradicts the view presented in research where it is asserted that parents/caregivers prefer home programmes that are part of routines, and that do not demand lifestyle changes (Hinojosa & Anderson, 1991; Thompson, 1998).

Another reason for providing a list of separate exercises, especially noted by private practitioners, could be because the majority of participants in this study (and all the participants in the private setting) were physiotherapists, who might be expected to adopt a more traditional approach to therapy, i.e. separate physical exercises with less of an activity based approach. Indeed, there was little comment on other specific stimulatory activities (e.g. visual perceptual activities) within the content of home programmes from this group, supporting this possibility. School participants provided much more detail regarding home programme content, which may correspond to a higher frequency of therapy sessions and a deeper knowledge of the child. However, there was less carry over into the home environment in this setting, with home programmes been more child focused and less family centred, making it questionable whether the activities in the home programmes were in fact embedded into routines, especially if routines are not known by the therapist, or the family context is not understood.

Another important finding and difference between private and public settings regarding home programme content was the value placed on equipment and assistive devices, which was especially expressed by participants in Part 2 of the study. In hospitals and NPOs, it was believed that these, even if they were handmade or inexpensive, increased both therapy attendance and home programme implementation because they provided encouragement and motivation. Perhaps even a small resource, such as a positioning device, provided more assistance and was greatly valued in light of the limited resources in the NPO and hospital contexts where therapy sessions are infrequent. In contrast, private practitioners tried to discourage equipment which, they believed, might take the place of home programmes or active movement of the child. For example: "*If they've got fancy equipment it does make it easier but it doesn't solve the issue…the kid has got to do it themselves…*" (2; PP).

The last part of home programme construction involved home programme dissemination (Novak & Cusick, 2006) (Figure 4.17). Participants in this study agreed with previous research that home programmes were more likely to be carried out if they were explained and written down (Molineaux, 1993). It was also important for participants, as in other studies (Bazyk, 1989), to consider what parents preferred in terms of how home programmes were demonstrated or explained. Options in terms of home programme dissemination, especially those that involved technology such as videos, were greater in private practice than in other settings because of the availability of these resources. There were also no difficulties with written home programmes, due to the absence of language barriers, in the private setting. The participants in NPOs and hospitals made use of a translator or a demonstration to explain home programmes when language barriers existed or if parents/caregivers were not literate, an important consideration when comparing the home programme model to the South African context.

5.5 Phase 4: Supporting the implementation of home programmes

A lack of home programme support, through regular contact and communication, was identified as a problem in all settings apart from private practice. Ongoing support of home programmes in private practice can be related to the higher frequency of therapy, a greater amount of parental/caregiver contact, no language barriers, and the availability and use of technology such as cell phone and email contact. These enabled easier and more regular communication between therapists and parents/caregivers, allowing for continual review of home programmes and the provision of regular support, as is recommended (Gajdosik, 1991). In schools, therapists and parents/caregivers made use of contact books, email or telephone for communication, but the lack of direct contact with parents/caregivers made it difficult to provide continual support and close monitoring of the home programme. The least contact and communication was found in hospitals and NPOs due to infrequent therapy. In these settings, there was a greater emphasis on parent and child performance reviews, feedback and positive reinforcement, which is also considered part of home programme support and is consistent with the model home programme and other studies (Novak & Cusick, 2006; Gajdosik, 1991; Taylor et al.,2004; Katz-Leurer et al., 2009) (Table 4.13).

Interestingly, although participants in hospitals and NPOs encouraged feedback and questions as part of home programme support, they felt that parents/caregivers were often not forthcoming in this exchange, and therefore placed a greater emphasis on parental performance reviews to ensure adequate understanding of the home programme. One participant mentioned that they spend time asking if the parent has any questions, what they are finding difficult to do with the child and if something that they were taught during the previous session was not working. She encouraged parents to ask questions in order to facilitate the correct implementation of the home programme, but found they very seldom did. She felt that the parents receiving therapy within the NPO lacked the reflective ability, or felt that it was not their place to question the therapist because *”they’re not used to complaining because no one ever bothers, so it’s just not in their makeup to complain or to ask questions”* (12, NPO). Thus, the ability to provide support again reflects the importance of the open communication exchange between therapists and parents/caregivers, which, in this study, was affected by cultural and language barriers in some service settings. This can result in parents/caregivers not feeling as if they are active partners within this process, even when participants provided encouragement, praise and reassurance.

In order to counteract these barriers and offer support for home programmes in these settings, there is a need for therapists to be creative in facilitating the process of open communication and sharing, and to find ways to enhance the relationship between themselves and parents/caregivers. Translators or assistants, who in a number of the NPOs were themselves mothers of children with CP that had undergone further training, can play a valuable role in this regard. Apart from translating, they are also able to draw on their personal experience to gain feedback regarding the feasibility of home programmes and provide the support that parents/caregivers need.

Similarly, participants in NPOs and hospitals made use of support groups to further motivate parents to implement home programmes through the sharing of positive experiences and child improvements stemming from home programmes. These methods could be formalised to provide further support for home programmes, which was generally reported as lacking in this study. Participants in NPOs, hospitals and schools who have high client loads, do not have the means and the capacity to maintain regular contact and communication with parents/caregivers and alternative ways of providing support is needed. Referring parents to a programme such as the Hambisela training programme (Hambisela Training Program for Parents and Carers of children with Cerebral Palsy, http://positiveparentingtips.net/wp/?p=5968) will enable them to not only gain greater insight and understanding of their child with CP, but will also provide ongoing emotional support for dealing with the situation and the lifestyle challenges it involves. This could be another key factor to improve parental involvement in home programmes in poorly resourced settings, particularly in light of the support recommended by the model home programme (Novak & Cusick, 2006) as well as the positive correlation between ongoing support and parental empowerment and motivation (Novak, 2011).

5.6 Phase 5: Evaluating home programme outcomes

Home programme evaluation was also lacking and was largely subjective in all settings (Table 4.14). The Novak and Cusick model home programme emphasises the achievement of family goals that include family perspectives as well as the use of robust instruments (Novak & Cusick, 2006). However, standardized measures and tests, with the exception of Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968) and the Functional Independence Measure (FIM) (Stineman et al., 1996) were specified by only a few participants. Other assessments of client factors included measuring range of movement with the use of a goniometer.

Home programme effectiveness was largely in the form of caregiver feedback (Figure 4.23), improved functional performance of the child, increased parental/caregiver participation, and a subjective evaluation of parental/caregiver satisfaction in that *"…we have got results in that we've got happy families and children who are up and participating actively…"* (9, NPO). Participants acknowledged the lack of availability and use of standardised measures and related this to either time constraints, unavailability of measures due to their expense, or to measures being inappropriate in that they were too broad and lengthy for application to the heterogeneity of CP. Goal achievement was therefore mostly assessed through clinical observations, parental reports and reassessments of client factors that were documented in therapy notes and patient files.

An improvement in parental/caregiver involvement and competency was also highlighted as a measure of effectiveness of home programmes and was assessed by whether parents/caregivers were carrying out the home programme or not. Hospital participants and private practitioners related this to the level of parental/caregiver commitment and cooperation. Only two participants, one in an NPO and one private practitioner, acknowledged parental/caregiver and family perspectives with regards to goal achievement. This could be a reflection of the lack of parent/caregiver initiated goals within this study and/or the need to cultivate a more family centred approach that is partnership based, during home programme evaluation.

Furthermore, there is no doubt that greater attention to standardised measures with regards to home programmes needs to be investigated, especially those that involve families and that take the discussed challenges specific to the South African context into account. Perhaps home programme outcomes should instead be based on parental satisfaction and whether the home programme has increased participation of the child within the family and community, and whether activities and caregiving tasks are easier for the parent/caregiver because the home programme is relevant and appropriate. This aspect of parental satisfaction was not only lacking in this study, but also within the Novak and Cusick (2006) home programme model.

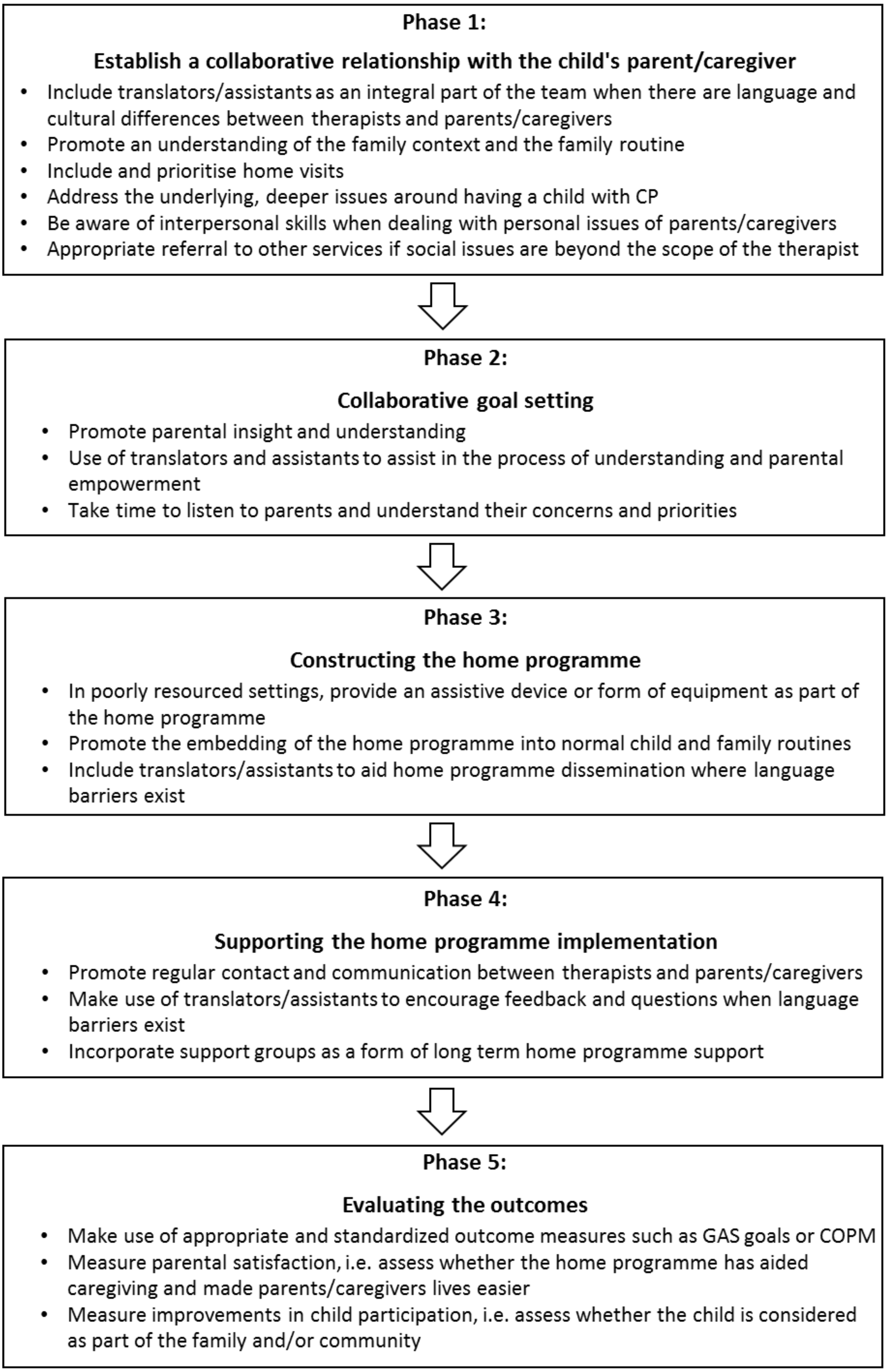
5.7 The South African home programme model

Since aspects of all the phases of the model home programme approach by Novak and Cusick (2006) were lacking in this study, modifications to the home programme model that take the discussed factors into account are suggested. These include specific adaptations for the South African context. Although the Novak and Cusick (2006) model home programme approach is broadly relevant to the South African context, differences revealed in this study highlight modifications that could be useful for improving home programme participation and success, particularly within poorly resourced settings.

Overall, differences between the model home programme approach by Novak and Cusick (2006) and the private practice setting of this study were small. This is likely because of the similarities between this sector and the literature from which the model was developed (Novak & Cusick, 2006), resulting in private practitioners been able to more easily adopt this model into their practice. The participants in NPOs, hospitals and schools, however, reported several challenges they need to overcome if the model is to be applied in their service settings.

Recommendations to address these challenges are therefore presented in a modified model that takes the South African context into account (Figure 5.1). The phases remain the same, but additional suggestions and a change in emphasis on already identified components are made. The biggest modification is the use of a translator or assistant to aid the process of collaboration and improve home programme support. When possible, it is proposed that therapists in public institutions identify a caregiver who has a child with CP and can develop the necessary skills to become part of the team and assist with all phases of the home programme. This is especially valuable to improve communication between the therapist and parent/caregiver when language barriers exist.

Furthermore, it is suggested that home visits are added to the first phase of the model, with the idea that they will provide a greater understanding of the social dynamics and home environment of the family, as well as aid collaborative goal setting within phase 2. When social issues or deeper emotional concerns exist, it is recommended that therapists refer parents to additional services and that they prioritise listening to and understanding parent's concerns. Assistive devices, even those that are small and of low cost, are effective in achieving parental participation in resource-constrained settings and will be a beneficial inclusion within home programmes. Therapists also need to place a greater emphasis on embedding home programme activities into daily routines rather than prescribing separate exercise regimes. Additional support should be offered through support groups and translators, and some appropriate formal evaluation of the home programme should be included, preferably one that incorporates a measure of parent satisfaction.



Phase 1:

Establish a collaborative relationship with the child's parent/caregiver

- Include translators/assistants as an integral part of the team when there are language and cultural differences between therapists and parents/caregivers
- Promote an understanding of the family context and the family routine
- Include and prioritise home visits
- Address the underlying, deeper issues around having a child with CP
- Be aware of interpersonal skills when dealing with personal issues of parents/caregivers
- Appropriate referral to other services if social issues are beyond the scope of the therapist

Phase 2:

Collaborative goal setting

- Promote parental insight and understanding
- Use of translators and assistants to assist in the process of understanding and parental empowerment
- Take time to listen to parents and understand their concerns and priorities

Phase 3:

Constructing the home programme

- In poorly resourced settings, provide an assistive device or form of equipment as part of the home programme
- Promote the embedding of the home programme into normal child and family routines
- Include translators/assistants to aid home programme dissemination where language barriers exist

Phase 4:

Supporting the home programme implementation

- Promote regular contact and communication between therapists and parents/caregivers
- Make use of translators/assistants to encourage feedback and questions when language barriers exist
- Incorporate support groups as a form of long term home programme support

Phase 5:

Evaluating the outcomes

- Make use of appropriate and standardized outcome measures such as GAS goals or COPM
- Measure parental satisfaction, i.e. assess whether the home programme has aided caregiving and made parents/caregivers lives easier
- Measure improvements in child participation, i.e. assess whether the child is considered as part of the family and/or community

Figure 5.1 South African home programme model

5.8 Study limitations

The greatest limitation of this study was the low response rate for Part 1, which further restricted the number of participants that met all the inclusion criteria for participation in Part 2. This limited sample size means that the perspectives considered are from a relatively small number of therapists, and it cannot be assumed that their views are typical or representative of all therapists treating children with CP in South Africa, which somewhat limits the transferability of the results. Similarly, the selection of a more experienced, mature and knowledgeable group of participants, which was part of the inclusion criteria of Part 2, results in the findings been biased toward this specific group. It is unknown how home programmes prescribed by younger, less experienced therapists might differ from this group, and indeed the model home programme approach.

Furthermore, therapists are only one of the role players involved in home programme design and implementation. To describe a full spectrum of practice, the views and perceptions of parents/caregivers in these contexts would need to be investigated. Parents/caregivers of children with CP, and their experience of home programmes, has been highlighted in previous research (see e.g. Novak, 2011; Hinojosa & Anderson, 1991), but perspectives specific to the settings investigated in this study, and to South Africa more broadly, would be more comparable.

Potential differences in perspectives between the two different disciplines examined in this study, namely, occupational and physiotherapists also need to be acknowledged, although these were likely less noticeable given the additional standardised NDT training that formed part of the inclusion criteria. The NDT course is an intensive fulltime course presented at postgraduate level and is based on the curriculum suggested by the European Bobath Tutors Association (EBTA) (South African Neurodevelopmental Therapy Association, www.sandta.org.za). Overarching principles of promoting function, active movement, family involvement and a holistic approach to therapy (Mayston, 2008) are prevalent within this approach, and therefore implemented by the participants. Few differences between the two groups were observed, although physiotherapists were by far the majority of respondents willing to take part in the study.

CHAPTER 6
CONCLUSION

This study provides information about how occupational and physiotherapists design and implement home programmes for children with CP and their families in South Africa, and how their approach compares to current literature. A clear description of what constitutes a home programme was investigated, with findings suggesting that such programmes comprise a range of activities that were difficult to specify. As such, definitions concerning home programmes can be extended from current definitions to include tasks, activities or goals that were identified. Home programmes were further described as ways in which therapists empower and support parents/caregivers in relation to their care for their child with CP, and promote active participation of all role players. Although these findings regarding the content of home programmes are not all new, this study offers a more comprehensive definition of home programmes that builds on current definitions can be proposed, with home programmes being described as:

Tasks and activities that can include positioning, specific handling, active mobilization and stimulation with or without the use of equipment or assistive devices and that have been collaboratively identified by parents/caregivers and therapists, form part of normal child and family routines and that include activities of daily living and play. The primary purpose of home programmes is to equip and support parents/caregivers to care for their child with CP, to find ways to make their lives easier and to improve child and family participation and interaction.

This definition highlights the importance of collaboration between parents/caregivers and therapists, and of embedding home programme activities within daily routines while providing parental support and empowerment. These characteristics are found in the literature and form part of the model home programme approach by Novak & Cusick, (2006), which was used as a basis for the analysis in this study (Novak & Cusick, 2006). Participants recognised that these factors improve home programme success, but challenges regarding home programme design and implementation in poorly resourced settings that differed from the settings used by Novak and Cusick, were identified.

Difficulties within the South African context include forming collaboration and partnership based relationships and a true family centred approach that is not as simply defined in less resourced areas where a large number of children with CP are treated. Language and cultural differences present a challenge for many therapists working in NPOs, hospitals and schools. Additional challenges, such as time constraints and parental involvement, are also true for better resourced areas and families in private practice, which also hinders home programme success in those settings. Therapists try to overcome these barriers by providing simple, functional and relevant home programmes that do not overwhelm parents/caregivers or create additional burdens in light of existing responsibilities and home circumstances. There was also an emphasis on providing education to improve parental/caregiver insight regarding their child with CP and empowerment in providing better care. Even so, the needs and priorities of families were not always understood or fully considered by participants in this study and home programmes were not always embedded into daily routines. This resulted in parental/caregiver participation in home programmes not always being optimal.

To be truly family centred with regards to home programmes, these challenges need to be addressed and ways to overcome them investigated. The findings of this study highlight strategies in which therapists are trying to overcome such shortfalls and additional ways are proposed in the form of a ‘South African home programme model’ (Figure 5.1), with further study recommendations below.

Study recommendations

The following recommendations can be made:

- There is a need for greater and more formalised incorporation of translators/assistants in settings where language and cultural barriers exist to enable more partnership based relationships and collaborative goal setting, as well as to enhance home programme support.

- A greater incorporation and priority should be placed on home visits and this will assist with the individualization and family relevance of home programmes, as well as provide necessary additional support.
- There needs to be a greater consideration of family routines and an effort to incorporate home programme activities into everyday tasks.
- More creative ways to enhance home programme support in the absence of regular contact and communication will be beneficial.
- Given the correlation between family centeredness and experience, a greater emphasis should be placed on equipping younger therapists with the skills needed to apply a practical family centred approach in therapy and home programmes. The South African Neurodevelopmental Therapy Association as well as an NPO, Malamulele Onward, is attempting to meet this need by providing a week long introductory course to CP. This could possibly become part of university curriculums to assist the process.
- In order to appreciate a full spectrum of views about home programmes for children with CP in South Africa, future research to understand the perspectives of parents/caregivers and their preferences will be valuable. Addressing the existing challenges in home programme involvement and implementation would be clearer if parental/caregiver values were more clearly identified and defined within all settings.
- A larger sample size of therapists would improve the generalizability of the results as well as the inclusion of a range of therapists (i.e. with less training and/or experience).
- Standardized measures that are relevant to CP and the South African context need to be incorporated in order to evaluate the effectiveness of home programmes, particularly in terms of parental satisfaction, and whether home programmes are useful and helpful for both children with CP and their families. These measures need to be easy to use in clinical practice.
- Finally, implementation of the South African home programme model to determine its relevance and effectiveness would be beneficial.

The group of therapists who took part in the questionnaire and who were interviewed included many aspects of the model home programme approach designed by Novak and Cusick (2006) when providing home programmes for children with CP and their families, in spite of the challenges and the differences that exist. Valuable insights have enabled modifications to the model that could improve the implementation of home programmes in South Africa and therefore provide more personalised, relevant and useful occupational and physiotherapy services for children with CP and their families.

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Appendices

A. Questionnaire for Part 1

B. Ethical clearance certificate

C. Permission letter to SANDTA

D. Information sheet for Part 1

E. Open ended questions for in-depth interviews for Part 2

F. Information sheet for Part 2

G. Informed consent for Part 2

H. Informed consent for audio recording for Part 2

I. Qualitative data analysis example: Part 2

J. Home programme purpose and description (themes, categories, subcategories and codes: Part 1)

K. Qualifications and work experience of participants in Part 2 (additional details)

L. Design, content and implementation of home programmes (themes, categories, subcategories and codes: Part 2)

APPENDIX A

QUESTIONNAIRE FOR PART 1

1. **Within which province are you located?**

☐KwaZulu-Natal

☐Southern Gauteng

☐Northern Gauteng

☐The Free State

☐The Western Cape

☐The Eastern Cape

☐Other

If other please specify:

2. **Within which service delivery setting do you work?**

☐Government hospital

☐Private practice

☐NPO

☐Special needs school

☐Government clinic

Other (please specify):

3. **What is your Qualification?**

☐Occupational therapist

☐Physiotherapist

Please specify the year of qualification:

4. **Do you have an NDT qualification?**

☐Yes

☐No

Please specify the qualification and the year this was obtained:

5. **Are you currently working with children with cerebral palsy (CP)?**

☐Yes

☐No

6. **Do you have any other qualifications that assist you in treating children with CP?**

Please specify the qualification and the year this was obtained:

7. **Years of experience working with children with CP after NDT qualification**

☐No NDT qualification

☐Less than 1 year

☐1-2 years

☐2-3 years

☐3-6 years

☐Over 6 years

Any comments?

8. **Total years of experience working with children with CP**

☐Less than 1 year

☐1-3 years

☐3-6 years

☐6-10 years

☐Over 10 years

Any comments?

9. **Average case load of children with CP treated in 1 month (average number of children treated not the number of treatment sessions)**

☐5-10

☐10-20

☐Over 20

Any comments?

10. Average case load of children with CP treated in 1 week (average number of children treated not the number of treatment sessions)

☐5-10

☐10-15

☐15-20

☐Over 20

Any comments?

11. What are the predominant ages of the children with CP that you treat?

☐Below 2 years old

☐2-10 years old

☐10-15 years old

12. What are the predominant GMFCS levels of the children with cerebral palsy that you treat? (you may indicate more than one answer)

☐GMFCS I

☐GMFCS II

☐GMFCS III

☐GMFCS IV

☐GMFCS V

☐All GMFCF levels

13. How frequently do you prescribe a home programme?

☐Always

☐Never

☐Sometimes

14. **What is your understanding of a home programme for the young child with CP?**

15. **Please describe a typical home programme**

16. **What is the purpose of a home programme? Why do you prescribe home programmes?**

17. **What is your starting point when designing a home programme?**

☐Assessment of the child to identify problem areas

☐Setting goals

☐Establishing a relationship with the parents/primary caregiver

☐Selecting therapeutic activities appropriate to the child

☐Establishing a relationship with the child

☐Other (please specify) or add any comments?

18. **Who initiates the design and implementation of the home programme? (you may indicate more than one answer)**

☐Therapist

☐Family

☐Parent/Primary caregiver

☐Child

☐Other (please specify)

19. **How do you determine goals of the programme? (you may indicate more than one answer)**

☐Determined by the assessment of the child

☐Determined by the parent/primary caregiver and family

☐Determined by the preferences of the child

☐Determined by previous experience of the therapist

☐Other (please specify)

20. Would you describe your approach to home programmes as

☐Child centred

☐Family centred

☐Both

☐Other (please specify)

21. Do you assess the needs, difficulties and resources of the family?

☐Always

☐Never

☐Sometimes

Any comments?

22. Do you consider the daily routine of the child within the family and community context?

☐Always

☐Never

☐Sometimes

Any comments?

23. Do you incorporate functional activities of daily living?

☐Always

☐Never

☐Sometimes

Any comments?

24. How would you describe your role with regards to home programmes? (you may indicate more than one answer)

☐Professional

☐Technical expert

☐Problem solver

☐Consultant

☐Partner

☐Educator

☐Support to child and family

☐Goal setter

☐Advocate

☐Changing role (depending on the needs of the child and family)

☐Other (please specify)

25. What is the content of a typical home programme? (you may indicate more than one)

☐Stretching programme

☐A list of physical exercises parents/primary caregiver assist the child to perform

☐Activities incorporated into daily tasks e.g. dressing, bathing etc.

☐A list of gross motor, fine motor and perceptual tasks

☐Adaptive equipment and assistive devices

☐Recreational activities and play

☐Other (please specify) or add any comments

26. Does the content of the home programme differ for differing GMFCS levels of CP?

☐Always

☐Never

☐Sometimes

Please explain:

27. Would you describe your home programmes as

☐Specific / individualized (tailored for each child)

☐General (those with a similar presentation receive the same home programme)

☐Both

Any comments?

28. How do you explain and implement the home programme? (you may indicate more than one)

With the use of

☐Pictures and written explanation

☐Personalized photographs and written explanation

☐Verbal explanation

☐Verbal explanation with demonstration

☐Other (please specify)

29. Is the home programme in the home language of the parents/primary caregiver?

☐Yes

☐Yes with the use of an interpreter

☐No

☐Sometimes

Any comments?

30. Do you consider the home environment of the child and task performance within this environment?

☐Always

☐Never

☐Sometimes

Any comments?

31. Do you include a home visit / are you able to include a home visit?

☐Always

☐Never

☐Sometimes

Any comments?

32. How long is a typical home programme?

☐Less than 30min/day

☐30min/day

☐60minutes/day

☐No time frame

☐Part of daily routine/ daily activities

☐Other (please specify)

33. How many times a week do you expect the home programme to be carried out?

☐1-2 times

☐2-3 times

☐3-5 times

☐Everyday

☐Other (please specify)

34. How do you evaluate the effectiveness of the home programme? (you may indicate more than one)

☐Visible improvements of the child in activities prescribed in the home programme as observed by the therapist and parents/primary caregivers

☐Visible improvements of the child in functional activities as observed by the therapist and parents/primary caregivers

☐The achievement of GAS goals (Goal attainment scales)

☐Comparisons of the initial assessment with a reassessment

☐Parental/caregiver feedback

☐Feedback from the child

☐Other (please specify)

35. **What factors do you think facilitate home programme implementation in your specific setting?**

36. **What factors do you think hinder home programme implementation in your specific setting?**

37. **Any other comments regarding the home programmes for young children with CP that you prescribe?**

38. **Would you be willing to participate further in this study by engaging in an informal interview about your perceptions of home programmes for children with CP as well as your personal experiences in relation to the design and implementation of these programmes?**

☐Yes

☐No

If your answer is yes, please provide your contact details below
(This will only be available to the researcher)

39. **Please indicate if you have provided/ will provide an example of a home programme (by following the procedure provided in the information sheet)**

☐Yes

☐No

Appendix B

ETHICAL CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Mrs Lauren Anne Davies

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140621

NAME: (Principal Investigator)	Mrs Lauren Anne Davies
DEPARTMENT:	Occupational Therapy SANDTA, KZN, Southern & Nothern Gauteng, Free State, Western & Eastern Cape
PROJECT TITLE:	Current Occupational Therapy and Physiotherapy Practice in Implemeting Home Programmes for Young Children with Celebral Palsy in South Africa
DATE CONSIDERED:	27/06/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Denize Franzsen
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	01/10/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

LA Davies
Principal Investigator Signature

Date 22/10/2014

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C

Occupational Therapy

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2192, South Africa
Tel: +27 11 717-3701 • Fax: +27 11 717-3709 • E-mail: denise.franzsen@wits.ac.za

PERMISSION LETTER TO SANDTA

Dr. Dorothy Russell
Chairman of the National Executive Committee
SANDTA

Dear Dr. Russell

I, Lauren Davies, am an Occupational Therapist, currently in my first year of an MSc (Occupational Therapy) by dissertation, through the University of the Witwatersrand. The title of my research is:

Current occupational therapy and physiotherapy practice in implementing home programmes for young children with cerebral palsy in South Africa

The purpose of this research is to understand the current clinical practice of therapists in terms of home programmes for young children with cerebral palsy. I hope to obtain data from the specific population of occupational therapists and physiotherapists with NDT training and who are currently treating young children with cerebral palsy.

The first part of the study is in the form of a questionnaire that has been placed in an online form (Survey Monkey®). The second part will be in the form of semi-structured, in-depth interviews with therapists willing to participate further and who meet certain criteria. Their contact details will be requested at the end of the questionnaire.

The intention is to interview participants who are practicing within one of the five service delivery settings in South Africa namely: private practices, special needs schools, non-profit organizations, public/government hospitals and government clinics to obtain a spectrum of views and to allow comparisons.

Due to confidentiality, I am unable to directly access the email addresses available through SANDTA for the first part of this research. Can you please assist me in this regard by sending the questionnaire to all the occupational therapists and physiotherapists on your data base? It will be beneficial to this study if the questionnaire is sent to all of these persons.

Please will you inform me of what process to follow in order for this questionnaire to be distributed.

For any ethical concerns or questions you may have, please contact the Chairperson of the Ethics committee: Prof P Cleaton Jones at anisa.keshav@wits.ac.za or 011 717 1234.

Thank you for your assistance.

Kind regards,

LA Davies

Lauren Davies
084 574 8212
0418620M@students.wits.ac.za

D Franzsen

Denise Franzsen
Supervisor

Gillian Saloojee
Supervisor

APPENDIX D

INFORMATION SHEET FOR PART 1

Occupational Therapists and Physiotherapists

Dear Colleague,

I, Lauren Davies, am an Occupational Therapist, currently in my first year of an MSc (Occupational Therapy) by dissertation, through the University of the Witwatersrand. The title of my research is:

Current occupational therapy and physiotherapy practice in implementing home programmes for young children with cerebral palsy in South Africa

If you have training and experience in neurodevelopmental therapy, treat young children with cerebral palsy and regularly provide home programmes for these children, I am inviting you to participate in this study.

The purpose of this research is to understand the current clinical practice therapists are using in terms of home programmes for young children with cerebral palsy (between the age of two and ten years old).

The literature has shown how valuable and effective home programmes are, but does not specify the content of the home programmes or provide clinical guidelines for clinicians to follow. This research has the potential to form a baseline from which we can understand home programmes that are implemented in South Africa in order for us to determine effectiveness and later 'best practice' for the children with cerebral palsy that we treat.

The first part of the study is in the form of a questionnaire (in a Survey Monkey® format with the link at the end of this page) Information from both physiotherapists and occupational therapists is requested in the questionnaire. This includes general information about your experience and the service area in which you practice, as well as some information regarding home programmes for children with cerebral palsy that you implement.

The questionnaire will take approximately 25 minutes of your time. If you complete and return the questionnaire this will be assumed as informed consent.

If you are willing, please provide me with an example of a home programme if available; specifying the service delivery setting, age and GMFCS level of the child. In order for your details to remain anonymous please use the following link: www.dropitto.me/laurendavies with HP4CP as the upload password. Click on ‘choose file’ and you will be directed to your documents to upload the home programme. Alternatively, if you do not mind disclosing your details, you may email the programme to me using the details below.

The second part of the study will be in the form of semi-structured, in-depth interviews in which you will be asked about your perceptions of home programmes for children with cerebral palsy as well as your personal experiences in relation to the design and implementation of these programmes.

If you are willing to participate in this second part of the study please provide your contact details in the space provided at the end of the questionnaire.

Your input to this study will be valued and appreciated. If at any time you wish to withdraw from the study, you may do so without any consequences. Your personal information will be kept confidential at all times and will be coded for research purposes. The data will be stored in the Occupational Therapy department of the University of the Witwatersrand for six years according to regulations set by the Health Professions Council of South Africa (HPCSA).

If you have further queries regarding the study, please contact me.

For any ethical concerns or questions you may have, please contact the Chairperson of the Ethics committee: Prof P Cleaton Jones at anisa.keshav@wits.ac.za or 011 717 1234.

Thank you for your input and assistance,

Kind regards,

LA Davies

Lauren Davies
084 574 8212

0418620M@students.wits.ac.za

D Franzsen

Denise Franzsen
Supervisor

G Saloojee

Gillian Saloojee
Supervisor

In order to take part in the questionnaire please follow the link:

https://www.surveymonkey.com/s/HP4CP

Appendix E

INTERVEIW QUESTIONS FOR PART TWO

<table>
<tr><th>Non-profit organization</th><th>Special needs School</th><th>Government hospital</th><th>Private practice</th></tr>
<tr><td colspan="4">What is your understanding of family centred practice/ service?
Do you use this frame of reference when designing and implementing a home programme – is it applicable / are you able to in your setting?
- Therapist’s interpersonal skills important?
- Parent or therapist as expert?
- Consider family involvement preferences?
- Child centred vs family centred?
What makes this difficult/easy in your setting?</td></tr>
<tr><td colspan="4">What do you consider to be the role of the therapist and the role of the parent within the home programme?</td></tr>
<tr><td colspan="4">How would you describe the parent – therapist relationship with regards to home programmes?
Is it easy or difficult to establish a good relationship with parents/ family members in your setting?
Why/ Please explain?</td></tr>
<tr><td>- Caregiver consistency and therapist’s consistency? (staff turnover if a care centre)
- Language and communication?
- Limited therapy time (1/month) – transport problems of parents?
- Parental attitude?
- Roles and expectations?
- Age, gender and ethnicity differences between therapist and caregivers?
- Time spent on education?</td><td>- Language and communication difficulties?
- Contact time?
- Parents understanding of their role?</td><td>- Caregiver consistency?
- Same therapist each time?
- Time constraints of therapist? (length of session)
- Caregiver responsibility?
- Treatment area?
- (Noisy overcrowded area)
- Age, gender and ethnicity differences between therapist and caregivers</td><td>- Caregiver commitment & involvement?
- Drop children at therapy and don’t stay?</td></tr>
<tr><td colspan="4">How do you set the goals of the home programme?
- Child assessment - Strengths or deficits into account?
- Needs, priorities and concerns of family (family dynamics and functioning/ routine etc.) – how many children; other responsibilities; work, health of caregiver, young mom, granny?
- Any standardized measures?</td></tr>
</table>

- Home visit?			
- Physical environment at home? What usually and how influence HP? - Cultural circumstances? What mean by this? - Social circumstances? - Parent's insight and understanding of child? - Child participation?	- Insight of parents? - Socioeconomic status? - Financial situation? - Assistance? - Childs participation – relationship with the child? How?	- Hindering social factors? Like what exactly? - Resources? - Education of parents? - Realistic? - Valuable? To family? Child? Therapist?	- Easy access to resources - Equipment that can be easily afforded - Parental education, knowledge and understanding? No language barrier? - More time to set goals? - Child participation? Other activities? Tired child? Busy parents?
How do you design the home programme? Range of supports, tasks and activities? What exactly?			
- User friendly? - Functional?	- Clarity, concise?	- Individualized? - Explanation and demonstration? - Functional tasks?	- Access to resources like a camera and computer make easier?
How do you implement the home programme? - In daily activities? How? - Easy? ADL and play? - Separate programme? - Family inclusion?			
Do you support implementation of the home programme? How? - Contact and communication? Easy/ difficult and why? - Support groups? - Parental involvement and communication? - Additional support? - Contact with parents – how often and how? Available to parents? - Feedback?			
Do you evaluate outcomes of the home programme? How? In your personal opinion do you feel that HP are really effective? Is there evidence that your ideas and suggestions are been carried out? What evidence? - Goals? Improvement? Function? Benefit? Results? - Any standardized measures? - Family involvement? Collaborative decisions? - Realistic? - Effective – why or why not?			
If you think of a typical home programme you give to parents, how satisfied/happy are you with the quality of the home programme - Good , comprehensive/complete - Too complex?			

What in your experience makes a successful home programme? - Based on your past experience what have you included that you know has worked - Based on your past experience what have you excluded that you know has not worked
Problems/ difficulties in your particular setting with regards to home programmes? - Service delivery limitations? - Lack of contact with MDT or if MDT overwhelming for parents? - Resources? What exactly and how does it impact the home programme? Equipment at home? - Measure for equipment but only get years later in government? Money for transport to get to therapy? – Buggy in taxi costs more. Child on back and heavy? - Family related problems? (Social setting, culture, belief system, home environment? What and how?) - Any child related factors? - Skills of the therapist? what the therapist needs to make home programmes more successful
What makes home programmes easier in your particular setting? - Access to photos – WhatsApp parents - MDT - Resources and assistive devices at home?
Any other comments you would like to add?

Appendix F

INFORMATION SHEET FOR PART 2

Occupational Therapists and Physiotherapists

Dear Colleague,

Thank you for participating in my research project regarding home programmes for children with cerebral palsy by completing the questionnaire.

Thank you in advance for your willingness to participate in part two of this study.

The second part will be in the form of semi-structured, in-depth interviews in which you will be asked about your perceptions of home programmes for children with cerebral palsy as well as your personal experiences in relation to the design and implementation of these programmes.

The intention is to interview participants who are practicing within one of the five service delivery settings in South Africa namely: private practices, special needs schools, non-profit organizations, public/government hospitals and government clinics to obtain a spectrum of views and to allow comparisons.

To minimize expenses, these interviews will take place with the use of Skype with video and voice recording. The schedule of this meeting will be at your convenience and will take approximately one hour of your time.

Once again, your input to this study will be valued and appreciated. If at any time you wish to withdraw from the study, you may do so without any consequences. Your personal information will be kept confidential at all times and will be coded for research purposes. The data will be stored in a safe place for six years according to regulations set by the Health Professions Council of South Africa (HPCSA).

If you have further queries regarding the study, please contact me.

For any ethical concerns or questions you may have, please contact the Chairperson of the Ethics committee: Prof P Cleaton Jones at anisa.keshav@wits.ac.za or 011 717 1234.

Thank you for your input and assistance, Kind regards,

LA Davies

Lauren Davies

084 574 8212

0418620M@students.wits.ac.za

D Franzsen

Denise Franzsen

Supervisor

G Saloojee

Gillian Saloojee

Supervisor

INFORMED CONSENT FOR PART 2

I.. (Name of participant) agree to take part in Lauren Davies' study. I understand that I can withdraw from this research at any time.

Signature: ....

Date: ....

APPENDIX H

INFORMED CONSENT FOR AUDIO RECORDING FOR PART 2

I... (Name of participant) consent to a Skype interview which includes audio recording. I understand that I can withdraw from this research at any time.

Signature: ....

Date: ....

QUALITATIVE DATA ANALYSIS EXAMPLE: PART 2 (VERBATIM INTERVIEW COMMENTS INTO CODES)

Theme: Phase 1: Establishing a collaborative relationship with the child's parent / caregiver

NPO Participants:	⬛ Participant 9	🟪 Participant 12	🟥 Participant 28	⬛ Participant 44	
Special Needs School Participants:	🟩 Participant 5	🟧 Participant 34	🟩 Participant 14		
Government Hospital Participants:	🟫 Participant 40	🟥 Participant 1	🟨 Participant 29		
Private Practitioners:	🟩 Participant 46	🟦 Participant 2	🟥 Participant 37	🟦 Participant 21	🟪 Participant 32

Category: Therapists attitude towards a family centred approach		
Subcategories	**Codes:**	**Actual comments from participants that fit into this code**
Involving the family/ caregivers	Not just the child	**NPO Participants** ▪ The family has got much more influence in a child's life than any therapist or professional and whatever practice you have or whatever modalities you decide to use the family needs to be an integral part of that. (9) ▪ What I understand is that it is not just the child who has the disability that is to be considered but the whole family or whatever kind of family that may be. (12) ▪ …over the years I mean I used to give home programmes on paper but over the years I have shifted from that because of my philosophy of it is not just the child…(12) ▪ I think on the one hand it is more difficult (implementing a family centred service) because you've got more than just that child to consider but and if one looks at the effectiveness…I think if you do not consider the whole family you're not going to be effective. (12) ▪ …we actually really need to focus in on the needs of the patient… what's relevant to that child… ideally you take both into account (child and family).(28) ▪ Well I would say that is where you don't just take the child's needs into account you look at the family as a whole not actually just family, the community as a whole so the child has to be integrated into the family and into the community…so you can't just look at the child in isolation… (44)

		Special Needs School Participants
		▪ I think a family centred service should be obviously focusing holistically on the whole family and incorporating everyone so whether it's care of the parents or children or helping the parents to care for children and involving everything from medical care to counselling. (5) ▪ …the family is a big part of the team when working with the child. So it means your focus will be a lot on the family where the child comes from, who the family members are, where they live how does the family dynamic work because that's the environment the child spends most of his time at. (34) ▪ …get the parents involved and looking at what they need at home and what the needs are as a family and then kind of build around that. (14)
		Government Hospital Participants
		▪ …the children are not on their own. The children are part of a family and we need also to see them as part of the family and handle them as part of the family. (40) ▪ …t's not always the mother, it's sometimes the granny, it was fathers also – they come with the child.(40) ▪ …involving as many people involved with the child…from mother to the carer, sisters, brothers, family members, neighbours, other therapists, just to try and get a whole understanding of this child and the treatments involved…(1) ▪ I used to think the kids are the priority. Why are you not doing the activities? What is wrong with you?...(1) ▪ *Not focusing only on the child…but looking at the child within his family and within his setup and involving anyone of the family that you can, the mom, the dad the sister or whatever a granny anyone that you can involve them and then also to serve them or help them as well, you know, give them support as well and assist the whole family that has to look after the child, not only looking at the child. (29)*
		Private Practitioners
		▪ I always say an ordinary child can still make a success of their lives without parents but a child with special needs can't and with a CP child it's more…those who have made a success were definitely those with good family support…(46) ▪ …the family is the key and we're part of the team but the family's the main people and we work within the family setup…(2) ▪ …involve the family throughout……they are part of the team...It's not only the child that's involved, but the whole family is involved, because it also has consequences for the whole family... they have to make decisions according to that… (37)

		▪ …the actual therapy needs to be child and family driven so when you're setting goals and you're doing the initial assessment with the family you really need to understand what the child's social background is, what the house looks like, what the parents actually want from this child and what kind of level the child is functioning at, sort of within their home but also within the community so it (a family centred approach) is really just involving the family and the decision making around goal setting and treatments and all of that. (21) ▪ I would say that the family where there was the direct mother or grandmother who whoever is looking after the child, sometimes it might not actually be a direct family member…they're involved in the therapy…(32)
	Caregivers/ parents as active partners	**NPO Participants**
		▪ We actually have quite a number of fathers who are very involved…..I've got fathers who came for a whole year because mom had the younger baby and she couldn't leave the baby at home so the father came with the baby every month…and I thought that was phenomenal and some of the fathers contact me and they ask how the child's doing they check up on appointments so we've got a good relationship not with a lot of fathers but probably we have some contact with up 30% of them so that's great. (9) ▪ There are some of the children that stay there year round so in those cases especially the caregivers at the centre's would be the primary caregivers and even at the day care centre's we treat the caregivers as the primary caregivers in how we train them. Yes so they can look after the children in the most beneficial way during the time that they're there. (44)
		Special Needs School Participants
		▪ I think parents that are maybe used to being given stuff and told what to do by the Medical Profession and then you know or they don't, ja they want you to do it they don't want to do it themselves…I didn't always find that that was associated with poverty. (5) ▪ And so making them a big part in the therapy and as the multidisciplinary team, they're all important. (34) ▪ …sometimes those you can't include you must provide them with the home programme. You talk to them and say you know what, I can't get to your child every week, so I need you to assist me and to help with this. And then you also feel like the responsibility is shared. So the parent can't come and say you never gave attention to my child, what is wrong? Because then you have given the parent responsibility. (34) ▪ …if I think of my case load, I would be able to see most of my parents once a week if I made the effort. (14) ▪ …with some of my parents we have a very good relationship. I do find that it's definitely a

		partnership …(14)
		Government Hospital Participants
		▪ …the mother is with me in the session and I work sometimes on the mother, sometimes I ask the mother to help. I include the mother in the therapy session…(40) ▪ Fortunately most of the parents are really doing...you can see the difference, but not all of them. (40) ▪ I cannot say I get this child better. It is the mother and I that get this child better. (40) ▪ …we also there to help them and that we value them and that they very special to us and that we very passionate about who we care for…(37) ▪ …then other cases we've got those really caring parents then I mean you just see the benefits and the improvement and the relationship is really personal and both ways we care, you know really care about each other. (29)
		Private Practitioners
		▪ Your success with the child and the follow up has everything to do with the support of the parents. (46) ▪ …the kids who have been coming for few years and they come quite often the parents kind of know and then I just try and update, 'this is what we've done today, did you see that this worked better let's try this at home, can you try this' and then they come and assist, so ja I don't mind this too much (if they are not involved in every session) because sometimes it gives me space. Using a space to actually try things and not always have them having to do, I can do my activities not always having to adapt my activities to fit with their needs because I can't always do it at the same level. (2) ▪ Because it's a long term (disorder)… because when the kids are younger it's easier to get the parents involved. Once they're older 6/7/8 years old, 9 year olds, they're still involved but the kids need to start taking over more then so the parents are more involved in the beginning because they are the primary caregiver. (2) ▪ …it's easier to get the parents involved when the kids are younger…(2) ▪ …the kids can't carry over themselves (if they have greater difficulties) as much so the kids are reliant on you to do things because the kid can't take it over so ja, the more involved (a child with greater difficulties) the more you need the parents on board ja. (2) ▪ But if the child screams, the mother is there because she also has to discipline and see how they have to be controlled or what…(37) ▪ They come to you for help, so they're actually expecting help. So they're open. It is the exception that I don't find a parent that's not willing to cooperate…some of them are excellent;

		some of them are not so excellent…(37) ▪ It is easier if the parents usually come to you for help. They are open and they want help and they are really willing to accept what you're telling them. That makes it really easier…(37) ▪ …some of them actually amaze me on how much they do. (37) ▪ …they not necessarily seen therapists as the be all and the end all and I find in private practice parents challenge us and they will go 'well you say this and well I read this on the internet you know why are you saying what you are saying', so they question you more which makes them more part of the process…not that top down approach it's more of an equal, you more on an equal footing I would say (21) ▪ …if you involve them in therapy as well because there's a difference, you (the parent) can just appear and come along and sit and watch (the therapist) do things with their child or if you're actually there. With kids it's quite hard just to do a one therapist activity because quite a few of the kids basically can be fairly severe so if I'm helping them sit or the mother's helping them sit and then the other person will help them play…(32) ▪ I think that (a partnership with parents) is the biggest thing that gets left behind that I think it actually makes the biggest impact…(32) ▪ You come in, you assess your child for an hour but you're going to go home and you're going to at least do something, the first one's generally something really simple. It might be sitting and playing in long sitting or it might be something to do with dressing, if your child has behavioural problems it might be like they need to be involved in cleaning or doing something… if you establish it right from the beginning then parents know that that is expected of them ja. (32)

APPENDIX J

HOME PROGRAMME PURPOSE AND DESCRIPTION

(THEMES, CATEGORIES, SUBCATEGORIES AND CODES: PART 1)

Themes	Categories	Subcategories	Codes
A family centred approach	Involving the family	Teaching the parents what to do - empowerment	- Enable & equip caregivers to care for and look after child - Provide education/access to information - Provide advice & practical guidance - Engage child in a fun way
		Supporting parents needs	- Not added burden/strain - Family specific - Address caregiver needs & concerns
		Encourage active participation	- Collaborative goal setting/understand therapeutic goals - Increase involvement - Ensure primary ownership & responsibility of rehabilitation - Interaction & well-being of child, caregiver & family
Select therapeutic activities	Meeting the individual needs of the child	Specialized stimulation, handling techniques & exercises	- Child specific stretches /maintain ROM - Therapeutic positioning - Handling, facilitation and preparatory techniques - Exercises to improve postural control & muscle strength - Visual perceptual & sensory stimulation
		Individualized programme to improve client factors & performance skills	- Facilitation of milestones and development - Improve coordination & hand function/fine motor skills - Improvement of gross motor skills & mobility
		Individualized programme to improve	- Maintain and improve function & independence - Enhance active participation in

		participation	purposeful & functional activities - Home games & fun activities for therapeutic play - Equipment management & assistive devices
Support implementation	Ensuring carry over at home	Extension of therapy into the home environment	- Continuation/follow through of therapy - Substitute & reinforce therapy (limited treatment time &contact with parents) - Increase/maintain effect & result of therapy - Therapeutic/functional goals into daily activities
		Daily care of the child with CP	- Handling, positioning and play during ADL - Exercises/activities as part of daily routine/ADL - Specific to child's needs - 24 hr management/daily therapeutic care - ADL Modifications within the home environment
		Prevention of further disability	- Correct movement patterns & handling - Prevent secondary impairments - Prevent/minimize complications

APPENDIX K

QUALIFICATIONS AND WORK EXPERIENCE OF PARTICIPANTS IN PART 2 (ADDITIONAL DETAILS)

Therapist	Qualification (yrs.) NDT (yrs.)	Additional training	Experience (children with CP (yrs.)	Experience (NGO) (yrs.)
		NPOs		
9	- Physiotherapist (1985) - Basic NDT (1988)	- NDT Baby Course (1989) - Advanced Level ll -The Very Young Child with CP (2002)	23	4,5
12	- Physiotherapist (1975) - Basic NDT (1977)		39	12
28	- Physiotherapist (1976) - Basic NDT (1995)	- Subtle Problems with Movement and Posture (1996) - Advanced Baby Course in NDT (1997) - Advanced Neurodevelopmental Level II Therapy Course; Functional Walking (2004) - Basic and Intermediate Seating Course (2004) - Advanced NDT Level II Course; The Early Assessment & Treatment of Infants with Cerebral Motor Disturbances (2008) - Advanced NDT Level II Course; Evaluation and Treatment of Children with CP Focusing on the Upper Limb (2006)	36	26
44	- Occupational Therapist (2005) - Basic NDT (2011)	- NDT Advanced Baby Course (2013) - Masters in Early Childhood Intervention (2007) - Basic Seating Course (2012) - Intermediate Seating Course (2013)	6	10 months
		Special Needs Schools		
5	- Physiotherapist (2007) - Basic NDT	- Advanced Dyskinetic Course (2012) - Basic & intermediate Seating	5,5	5

	(2010)	Course (2014)		
34	- Occupational Therapist (2010) - No basic NDT	- Introduction to the Assessment and Treatment of Cerebral Palsy (1 week; SANDTA; 2014) - Basic seating course (2014)	4	2
14	- Physiotherapist (2010) - No NDT	- Introduction to the Assessment and Treatment of Cerebral Palsy (1 week; SANDTA; 2011)	3	2
Government Hospitals				
40	- Occupational Therapist (1986) - Basic NDT (2003)	- Sensory Integration (2000)	28	28
1	- Physiotherapist (2010) - Basic NDT (2014)	- Two day course on the Child with Hemiplegia	4,5	4
29	- Physiotherapist (2009) - Basic NDT (2013)	- Intermediate Seating Course (2012) - JP Maes Dyskinetic course (2014)	5,5	5,5
Private Practice				
46	- Physiotherapist (1978) - Basic NDT (1981)	- Baby NDT (1988, 2002, 2000) - Advanced refresher NDT - Integrative Myofascial Release; DCD; Baby Skills for Action; Sensory Awareness Courses; NTT (2011) - 3D Gait Analysis Course; aquatic PT course (2012) - Developmental Delay Course, Seating Workshop (2013)	37	(unknown)
2	- Physiotherapist (1981) - Basic NDT (1983)	- Masters in Physiotherapy (2006) - Diploma in Remedial Education (1986) - Dyskinetic Cerebral Palsy (2014) - NDT Advanced Baby Course (2013) - “Bringing Orthopaedics, Somatosensory Concerns and Motor learning to Paediatric Neuromotor Rehabilitation using Orthotics Modifications and TheraTogs” (2011) - NDT Advanced Refresher level II (2009) - NDT Advanced for Instructors	33	10

		(2007) - NDT Advanced Refresher II (2007) - NDT Advanced Refresher II (2004) - NDT Refresher (2000) - Advanced Refresher course (1996) - NDT CP into Adolescent and Adult life (1998) - NDT Advanced Speech Practicum (1999) - NDT Advanced Refresher course (1995) - NDT –Advanced OT practicum (1994) - NDT Baby Course (1990) - Nancie Finnie “Parents, Professionals and the Handicapped (1983)		
37	- Physiotherapist (1982) - Basic NDT (1984)	- Basic NDT (1990) - Adult Hemiplegia (1985) - Baby NDT (2012)	31	Over 20 yrs
21	- Physiotherapist (2003) - Basic NDT (2010)	- Advanced Baby Course (2013) - Aqua Therapy – Paediatrics (2012) - Theratogs (2011)	6,5	6,5
32	- Physiotherapist (2009) - Basic NDT (2012)	- Advanced Dyskinetic Course (2014) - Advanced Baby Course (2014)	Approx. 5	Approx. 4

APPENDIX L

DESIGN, CONTENT AND IMPLEMENTATION OF HOME PROGRAMMES

(THEMES, CATEGORIES, SUBCATEGORIES AND CODES: PART 2)

Themes:	**Category:**	**Subcategory:**	**Code:**
Establishing a collaborative relationship with the child's parent/caregiver	Therapists attitude towards a family centred approach	Involving the family/caregivers	- Not just about the child - Family/caregivers as active partners
		Parental buy-in	- Perceived level of motivation & commitment - Therapy attendance & involvement
		Understanding the effect of the family context & resources	- Social dynamics & support - Resource constraints - The value of home visits - Physical environment - Cultural differences
	Personal factors affecting relationships in therapy	Effective relationships between all role players	- Effective communication (language) - Taking time to establish a relationship of trust & understanding - The emotional state of primary caregiver - Freedom to share hopes, problems & to ask questions - Formal / informal support groups
	Define roles and expectations	Parental expectations about therapy & home programmes	- Parental insight & understanding - Perceived value of therapy & home programmes
		Encourage caregiver competency	- Parents as experts - Parents as part of the team
		Therapist as technical expert	- Facilitate change - Knowledge, experience & maturity of the therapist
	External factors affecting relationships in therapy	Therapy based resource constraints	- Limited time with child & caregiver (high client load) - Staff shortage (therapists) & changes (employed caregivers & therapists) - Physical environment of therapy location
Collaborative goal setting	Identify goal areas (ask the 'miracle' question)	Family & caregiver needs & priorities	- What is the most important (first things first) - Find out their needs
		Parents as primary	- Enhance the capacity of

		decision makers	- parents (increase knowledge & skill) - Family vs therapist initiated goals
	Comprehensive assessment	Therapist & parent perspectives of child and family needs	- Individual assessment of the child - Assets & competencies - Goal areas identified (by the therapist)
		Technical information to parents	- Understanding their child's condition - Realistic goals & solutions
		Working together (with other team members)	- Support / lack of support from hospitals, clinics, schools & other - The need for a multidisciplinary team
	Lack of formalized goal setting procedures	Observable outcomes only	- Lack of standardized measures
Constructing the home programme	Embedded within everyday activities	Incorporated into ADL & part of daily routine	- Not a separate exercise regime (not something extra) - Part of normal life (part of the child & family routine) - Therapeutic caregiving
		Supports (adaptive equipment & assistive devices)	- An adjunct to home programmes - Low cost equipment (within the resources of the family) - Availability & funds
	'Home exercise programme'	Tasks, activities & exercises	- Mobilization & positioning - Stimulation and activities - Separate exercises e.g. stretching, ROM etc.
	Child & family preferences (pleasing for the parent; not stressful for the child)	Active engagement and participation of the child	- The child is part of the family - Using play & making it fun - Child specific - Active movement & involvement
		Realistic expectations upon parents/ caregivers	- Understand competing responsibilities - Appropriate & manageable (do not overwhelm)
		Home programme dissemination to parent/caregiver or child	- Ensure clear understanding - Verbal explanation & demonstration - Written information & pictures/ photographs
Supporting the programme implementation	Parental support & assistance	Enable parents to seek support	- Contact & communication - Positive reinforcement & ongoing interest - Support groups

		Arrange reviews	- Review parent and child performance - Feedback & questions
Evaluating the outcomes	Home programme outcomes	Change noticed	- Therapists observations of goal achievement - Increased caregiver involvement & competency
		Measuring outcomes	- Non-use of standardized measures & documentation - Informal progress assessments