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# THE EFFECT OF AN INTENSIVE FIVE DAY COURSE OF NEURODEVELOPMENTAL THERAPY ON THE OCCUPATIONAL PERFORMANCE OF CHILDREN WITH CEREBRAL PALSY LIVING IN A POOR RURAL AREA

Shelley Ann Broughton

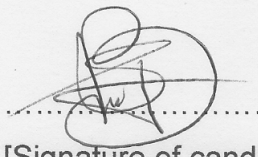
A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

Durban

2012

**DECLARATION**

I, Shelley Ann Broughton, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



.....

[Signature of candidate]

25 day of APRIL, 2012.

## ABSTRACT

This study investigated the effects of a five-day “block” of intensive NDT on the gross motor function and occupational performance of 34 children with CP from an under resourced rural area of South Africa, functioning at GMFCS Levels I-V. The repeated measures research design used two pre-intervention (baseline of change) and two post-intervention (immediate and sustained change) assessments. The GMFM–66 and PEDI–Modified Functional Skills Scale (MFSS) were used to assess change in motor skills and occupational performance in self-care, mobility and social function over a 21 week period. The intervention included individual NDT therapy, caregiver training and provision of adapted equipment.

Participants showed significant positive improvement in scores post-intervention compared with the pre-intervention period, in: GMFM-66 total score ($p=0.050$); PEDI-MFSS: self-care skills ($p=0.001$), mobility ($p=0.002$) and social ($p=0.000$). The greatest gains were made in the self-care domain. In this sample, positive change was effected by a five-day intensive NDT programme.

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This study was granted ethical clearance from the Human Research Ethics Committee, University of the Witwatersrand: No. M070467 (certificate included in Appendix B)

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## DEFINITION OF TERMS

Cerebral Palsy

"describes a group of permanent disorders of development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, behaviour, and/or by a seizure disorder". Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, Jacobsson B, Damiano D., 2005, pg. 572).[1]

Gross motor function

"the ability to use large muscle groups that coordinate body movements involved in activities such as walking, running, jumping, throwing, and maintaining balance" (Mosby's Medical Dictionary, 8th edition, 2009, p. 569).[2]

Activities of daily living

Activities that are oriented toward taking care of one's own body (adapted from Rogers & Holm, 1994, pp. 181–202).[3] ADL also is referred to as basic activities of daily living (BADLs) and personal activities of daily living (PADLs). These activities are" fundamental to living in a social world; they enable basic survival and well-being" (Christiansen & Hammecker, 2001, p. 156).[4]

Self-care

Basic activities of personal management, such as dressing, hair brushing, tooth brushing and eating. Self-care is the term used when no assistance is required (adapted from Reed & Nelson Sanderson, 1999, pp. 147).[5]

Mobility

**Functional mobility—**Moving from one position or place to another (during performance of everyday activities), such as in-bed mobility, wheelchair mobility, and transfers (e.g., wheelchair, bed, car, tub, toilet, tub/shower, chair, floor). Includes

functional ambulation and transporting objects (American Occupational Therapy Association, 2008).[6]

Social function

Organized patterns of behavior that are characteristic and expected of an individual or a given position within a social system" (Mosey, 1996, p. 340).[7]

Intensive Neurodevelopmental Therapy.

For the purposes of this study, "Intensive Neurodevelopmental Therapy" refers to the a holistic programme addressing abnormal/atypical patterns of coordination and movement directed towards working on activities of daily life.[138] The treatment was administered via hands-on treatment of children with cerebral palsy, the training of caregivers and the provision of adaptive equipment over a relatively short and intensive period of time. The intensive therapy was provided daily for a five-day period by a transdisciplinary team of neurodevelopmentally trained therapists.

Mid-level Rehabilitation Workers

In this study the term "mid-level rehabilitation worker" refers general worker who can bridge the gap between members of the community and the rehabilitation service personnel and who perform multiple functions within the rehabilitation services context. Mid-level refers to a level between the community and the specialised rehabilitation services.

## ABBREVIATIONS

| | |
|---|---|
| AAC | Augmentative and Alternative Communication |
| ACT | Anticonvulsant Therapy |
| ADL | Activities of Daily Living |
| AFO | Ankle Foot Orthosis |
| APT | Appropriate Paper Technology |
| BDIST | Battelle Developmental Infantry Screening Test |
| CP | Cerebral palsy |
| GMAE | Gross Motor Ability Estimator |
| GMFCS | Gross Motor Functional Classification |
| GMFM-66 | Gross Motor Function Measure - 66 |
| GMFM-88 | Gross Motor Function Measure - 88 |
| ICC | Intraclass Correlation Coefficients |
| ICF | International Classification of Functioning, Disability and Health |
| LL | Lower limb |
| MACS | Manual Ability Classification System |
| MFSS | Modified Functional Skills Scale |
| NALEDI | National Labour and Economic Development Institute |
| NDT | Neurodevelopment Therapy |
| OTPF II | Occupational Therapy Practice Framework: Domain and Process II |
| PDMS | Peabody Developmental Motor Scales |
| PEDI | The Paediatric Evaluation of Disability Inventory |
| PEO | Person Environment Occupation |
| RCT | Randomized Controlled Trials |
| SAHRC | South African Human Rights Commission |
| SCPE | Surveillance of Cerebral Palsy in Europe |
| SI | Sensory Integration |
| UL | Upper Limb |
| WHO | World Health Organization |

# CHAPTER 1
# INTRODUCTION

## 1.1 BACKGROUND

Cerebral palsy (CP) refers to a group of non-progressive, but often changing disorders specific to the development of motor control, which occurs due to damage of the central nervous system before, during or soon after birth.[1,8] Cerebral palsy is characterised by motor impairment and can present with global physical and mental dysfunction. Furthermore, many children with CP have additional disabilities of varying types and degrees, such as cognitive deficits, visual, hearing, speech and language disorders and epilepsy.[1]

The various debates throughout the world with regard to the definition of cerebral palsy (CP)[9] ;aetiologies; risk factors;[10] classification; assessments;[8,11] and outcomes,[12] highlight the complex nature of CP. Furthermore, the many approaches to the assessment and management of people with CP is a highly controversial topic within and between the various professionals involved in care of people with CP.[13] There is, however agreement that the goal in the management of people with CP is not to cure[14] or to achieve normalcy but to increase functionality, improve capabilities and sustain health, in terms of motor skills, cognitive development, social interaction and independence in daily living activities.[14,15] It would appear from the literature that the best clinical outcomes result from early, intensive management[16] within a multi-speciality team approach. According to Taylor (2001),[16] the team should ideally include a paediatrician, a physiotherapist, an occupational therapist, a speech and language therapist, a social worker, a psychologist, an educator and the child's parents/caregivers.

From an occupational therapy perspective, according to the Occupational Therapy Practice Framework: Domain and Process II (OTPF II)(2008)[6] the therapeutic outcomes that are emphasised relate to areas of occupational performance, including independence in "*activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure and social participation*."[6] Occupational therapists promote health and prevent disease through facilitating

engagement in occupations that are personally meaningful and fulfilling, that provide opportunity to develop and allow for the expression of personal identity.[17] They therefore aim to treat the occupational performance needs of the child with CP by facilitating their active participation in all aspects of daily living.[18] Intervention involves effecting change in the child's occupational performance so that he or she can engage in occupations that support participation in everyday activities and all spheres of life.[19]

Engagement in occupations is reliant on performance skills, which are the child's demonstrated "abilities".[20] These are supported and enabled by numerous body functions and structures.[20] Although various performance skills may be affected by CP and its associated disabilities, one of the primary areas of concern is related to motor and praxis skills.

There is also little research addressing the efficacy of therapy with regard to participation in daily living activities. A study by Knox et al (2002)[21] is one of the few that demonstrates that Neurodevelopment Therapy (NDT) significantly improves gross motor and occupational performance skills, as measured by standardised valid and reliable assessments, in children with CP.[21]

The lack of evidence for practice to achieve the best outcome for children with CP is also reflected in research on the effectiveness of various treatment approaches used by therapists when treating children with CP. This includes the commonly used NDT approach, which indicates conflicting, and in some cases inconsistent results.[22] The influence of NDT is particularly difficult to evaluate because NDT does not consist of *specific treatments* that can be delivered in a standard manner and the procedures used depend upon the therapists' skill level. Evaluating the effectiveness of NDT is further confounded by:

- the constructs of NDT itself having changed over time,
- the common practice of combining NDT strategies with other therapy techniques and medical treatments,

- the complexities surrounding CP creating a high number of variables and the complex nature of diagnosis, which is usually determined by motor type; distribution and severity.[23]

In South Africa the complexity of the diagnosis of CP is added to by considerable social welfare considerations like poverty. The South African Human Development Report (UNDP, 2003) reported that at least 48.5 per cent of the South African households (21.9 million people), live in severe poverty.[24] According to Miles (2004) [25] this leads to deprivation of basic human needs, which can result in developmental delays and physical, psychological and intellectual barriers for all concerned, not only those with CP.

This means that in South Africa, with limited resources,[26] managing and coping with the functional limitations and severe long-term dependence of children with CP adds to the burden of the family and in many cases the primary caregiver.[25] Further pressure is created in poor rural areas, where communities are disadvantaged and poorly-resourced, and where most families live under extremely difficult conditions because of limited access to support services such as rehabilitation and specialised education.[26]

With access to therapy being so difficult, infrequent and irregular, the effectiveness and efficiency of current treatment practices requires careful consideration. This study therefore pertains to the question of whether a different model of practice based on an intensive block of NDT therapy would be effective in improving the performance skills related to gross motor function and occupational performance in the areas of activities of daily living including self-care, mobility as well as social participation[6] of children with CP living in poor rural areas of South Africa.

## 1.2 PROBLEM STATEMENT

The efficacy of interventions for children with CP living in rural areas of South Africa has not been studied.

The majority of children with CP in South Africa are dependent on the public service for rehabilitation therapy, where therapy is usually only available on an infrequent (monthly) basis[27] and may or may not include neurodevelopmental therapy. It would appear from studies conducted in developed countries that intermittent intensive blocks of therapy accelerate motor performance and the acquisition of motor skills.[28,29] It has not been established whether similar intervention strategies might be appropriate in underdeveloped, poor and remote areas of South Africa or whether providing intermittent intensive blocks of therapy would have an effect on the development motor skills with resultant changes to the level of occupational performance of children with CP.

## 1.3 PURPOSE OF THE STUDY

The purpose of this study was to investigate the effectiveness of a five-day "block" of intensive NDT therapy on the performance skills related to gross motor function, and the occupational performance areas of self-care, mobility and social participation of children with CP living in the rural areas of the Eastern Cape in South Africa.

## 1.4 AIMS AND OBJECTIVES OF THE STUDY

This study is a follow-up to a pilot study conducted in Limpopo in 2005. The objectives were: -

- To investigate the effects of a five-day "block" of intensive NDT on the gross motor function of children with CP, living in a poor rural area.
- To investigate the effects of a five-day "block" of intensive NDT on the occupational performance areas of self-care, mobility and social participation of children with CP, living in a poor rural area.

## 1.5 HYPOTHESIS

*Null Hypothesis*

A five-day "block" of intensive NDT will have no effect on the performance skills related to gross motor function or the occupational performance in self-care,

mobility and social participation of children with CP, living in a rural area of South Africa.

*Alternate Hypothesis*

A five-day "block" of intensive NDT will be effective in improving performance skills related to gross motor function and the occupational performance in self-care, mobility and social participation of children with CP, living in a rural area of South Africa.

## 1.6 ASSUMPTION

An assumption made for this study is that an intensive NDT treatment programme is a holistic programme addressing abnormal/atypical patterns of coordination and movement directed towards working on activities of daily life.[138] Clients are encouraged to practice activities at home and with their caregivers. Home programmes, assistive devices, adaptive equipment and caregiver training form an integral part of the treatment.[138,139]

In this study the therapy provided by the therapists as well as the home programmes and adaptive equipment used by caregivers after their training, were all considered part of intensive NDT treatment. It was outside the scope of this study to differentiate the role all the different aspects included in the treatment programme in terms of the effectiveness of the programme of intensive NDT and therefore the different aspects are not considered in detail.

## 1.7 SIGNIFICANCE OF THE RESEARCH

There is a need to provide evidence-based practice for the appropriateness, the outcomes and the effectiveness of therapy interventions for children with CP in a rural South African setting. The study outcomes will add to the pool of knowledge for professionals involved in interventions for children with CP. This includes physiotherapists, occupational therapists, and speech and language pathology therapists among others.

Information gained from this study will assist in developing an evidence base for therapeutic intervention and models of service delivery for children with CP.

Establishing whether a five-day block of intensive therapy would be effective in improving performance skills and facilitating participation in personal activities of daily living will assist in determining “best practice” for the management of children with CP in poor areas where there is limited access to therapists with specialised skills.

The data obtained from this study will form part of a larger study that is aimed at developing appropriate and effective therapy intervention programmes and services for children with CP in South Africa. This study needs to be viewed in the context of a longitudinal research study and as part of the larger study, in which information gained from each study component will be used to plan further studies and to explore the subject of best practice for therapists working with children with CP in poorly-resourced South African communities.

# CHAPTER 2
# LITERATURE REVIEW

## 2.1 INTRODUCTION

This chapter is a review of the available literature that was relevant to the study. The literature review for this study is presented in non exhaustive subtopics covering that emphasise the main objectives of the study. The review covers information pertaining to cerebral palsy, the effects of cerebral palsy (CP) on the child and family related to the International Classification of Functioning, Disability and Health (ICF) and participation in occupational performance. The intervention process including assessment, treatment, Neurodevelopmental Therapy (NDT), and the effectiveness of treatment will be discussed. In addition, background information is provided regarding access to rehabilitation for children with CP living in disadvantaged areas in South Africa, along with the environmental and community factors that have an influence on their participation in everyday life.

The literature search was conducted in the following databases: Medline Plus, Pubmed, BMJ Clinical Evidence, Science Direct, ExLibris, Wiley Interscience, Cochrane Libraries and OvidSP. The search included all English articles between 1990 and 2011 and texts on related topics were also included. The keywords used to channel the search were ‘cerebral palsy’, ‘child disability’, ‘participation’, ‘occupational performance’, ‘neurodevelopmental therapy’, ‘assessment’, ‘service delivery’ and ‘rehabilitation’.

## 2.2 CEREBRAL PALSY

The term cerebral palsy (CP), first described by Little in 1843[30] has now become well recognized and is used to describe a group of people with neurodevelopmental disabilities. Cerebral palsy refers to a heterogeneous condition, which has proved difficult to define because of the diversity in terms of aetiology, types of CP and severity of impairments.

In an attempt to enhance the understanding of the term “Cerebral Palsy” in literature, research and in clinical settings, The Executive Committee for the

Definition of Cerebral Palsy was established in order to propose an updated definition and classification of CP in 2004.[1,31] The activity limitations relevant to occupational therapy were recognised for the first time in this definition and according to a review of the Executive Committee's findings by Bax et. al., (2005)[1] cerebral palsy

> "Describes a group of permanent disorders of development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, behaviour, and/or by a seizure disorder" (pg 572).[1]

In a commentary on the "new definition and classification" of CP Armstrong (2007)[32] suggested that the second sentence of the definition should be removed entirely and possibly replaced with:

> "A full description of the individual with CP requires classification of the motor abnormalities, associated impairments, anatomic findings, and definition of function according to the World Health Organization (WHO) International Classification of Functioning, Disability and Health(ICF)" (pg 166).[32]

Armstrong proposed that a sentence of this nature should not actually be part of the definition, but would link the definition to a more extensive classification system, which required further clarification from the Executive Committee.[32] Reddy (2005) [33] in her commentary highlighted that the "new definition" addressed the most likely sequelae of CP by including the concepts of functional limitation and participation within the community context, [33] an aspect also of importance to occupational therapists.

### 2.2.1 Prevalence of Cerebral Palsy

However while there is still controversy about the definition and classification of CP, the management of the condition must be considered a priority because CP is an important public health problem internationally affecting the physical and psychological health of children[34] and has been reported as the most common

physical disability in childhood.[35,36] Although it is a non-progressive disorder it is a lifelong condition that children carry into adulthood. The available literature estimates that the prevalence of CP in developed countries averages at 2 to 3.3 per 1000 live births.[35,37-41]

The prevalence of cerebral palsy is largely unknown in most underdeveloped countries because it is not usually captured in the population census or any other surveys. Brehaunt et. al., (2004)[42] suggested that the prevalence of CP in developing countries might be higher than in developed countries. According to the White Paper on Integrated National Disability Strategy (1997:1),[26]

> "There is a serious lack of reliable information on the nature and prevalence of disability in South Africa. This is because, in the past, disability issues were viewed chiefly within a health and welfare framework. This led naturally to a failure to integrate disability into mainstream government statistical processes (p 1)."[26]

It would seem that despite a paucity of information that the prevalence of CP in South Africa may be higher than that in developed countries. In 2005 the World Health Organisation produced a report[43] that indicated that of the 18 million children in South Africa 10% presented with a significant disability of neurogenic origin. A South African study published in 2002 suggests that the prevalence of CP in children under the age of 10 years, in a rural part of Kwazulu-Natal may be as high as 10 per 1000,[44] whilst the KwaZulu-Natal Department of Health estimated the prevalence of cerebral palsy to be 1.5 to 4 per 1000 births.[45] It would seem that despite a paucity of information and lack rigorous methodologies for the collection of statistics, the trends in the studies and the government reports[46] indicate that the prevalence of CP in South Africa may be higher than that in developed countries.

### 2.2.2 Classification of Cerebral Palsy

Determining the prevalence rate also depends on the correct identification of CP and this should be according to international criteria which state that CP usually presents within the first 12 to 18 months and is diagnosed by slow motor

development and a presentation of abnormal quality of movement such as unusual postures, asymmetric gross motor function or unusual muscle stiffness or floppiness.[13,15,47] Traditionally children with CP have been grouped according to the predominant type of movement disorder present.

Based on previous research on classifying CP from the time of Bax (1964)[48] and then Hagberg et. al., (1975)[49] to more recent literature including Mutch (1992)[8] and Carnahan et. al., (2007)[50] the Reference and Training Manual of the Surveillance of Cerebral Palsy in Europe (SCPE)[51] completed a suggested classification system for CP in 2007. The SCPE suggest a classification system based on the following four steps: -

- Determine whether it is a case of CP;
- Determine the type of CP based on neurological signs and topography;
- Assess the severity of the motor function loss with tools such as: the Gross Motor Functional Classification (GMFCS) and the Manual Ability Classification System (MACS) for upper limbs.
- Assess the presence and severity of associated impairments.[52]

Step one involves an effective diagnosis of CP through regular evaluation of the child's development and symptoms by an interdisciplinary team of health professionals that have expertise in different areas.[7,9] The assessments should include comparisons of the child's motor skills, evaluation of the child's medical history and any problems experienced by the mother whilst pregnant, assessment of muscle tone, evaluation and comparisons of development in a variety of areas, assessment of posture, and testing of reflexes.[9] It is the careful assessment and evaluation of all of these factors in combination that enable the doctor to make an effective diagnosis of cerebral palsy.

Step two refers to the classification of the type of CP, which relies on a description of the quality and distribution of tone. The modified Swedish classification, which used the physical components of the condition including tone, and the number and distribution of the affected limb(s) was previously widely used to determine the type of CP.[8] Bax et. al., (2005)[1] when reviewing this classification with regard to

the first characteristic of tone, suggested a compromise and recommended that children with CP should be classified according to the dominant type of tone or movement abnormality. This method was adopted and published by SCPE[51] in 2007 and describes three groups based on the predominant neuromotor abnormality, namely:

- spastic,
- dyskinetic which is further differentiated into dystonia and choreoathetosis, and
- ataxic.[51]

Any additional tone or movement abnormalities present should be listed as secondary types.[1,53] Mixed lesions combine characteristics of all these groups and although in clinical practice the predominant type is identified, mixed types are now increasingly diagnosed.[54] The severity of tone may be classified as mild, moderate or severe.[8] There are however other classifications by distribution of tone as well as the quality of tone like dyskinetic; ataxic-hypotonic and mixed CP (e.g. spastic and dyskinetic) still in use.[55]

The second characteristic that requires grouping pertains to the distribution of the affected limb(s) (topography). The most frequently used topographical classifications that describe the distribution of motor involvement are hemiplegia, diplegia and quadriplegia.[56,57] Monoplegia and triplegia may be included in the classifications, but these are relatively uncommon.[57]

Of greater interest to occupational therapists is step three and four of the SCPE classification. The third step involves assessing the severity of the motor function loss and step four assesses the presence and severity of associated impairments.[51] Carnahan et. al., (2007)[50] used the Gross Motor Function Classification System (GMFCS) by Palisano et. al., (1997)[58] in conjunction with the Manual Ability Classification System (MACS) by Morris et. al., (2006)[59] to develop a system of grouping children with CP more effectively according to the severity of the motor function loss. They[50] also emphasised the need for proper classification of CP for the clinical assessment and management as well as for research purposes.

### 2.2.3 Gross Motor Function Classification System (GMFCS)

The Gross Motor Function Classification System (GMFCS)[58] has been widely used to classify individuals with CP into one of five levels, based on their functional mobility or activity limitation.[47,53] The five ordinal levels of functional ability described by the GMFCS have been detailed in Appendix A, and are represented across four age groups: less than two years, two to four years, four to six years and six to 12 years.[60] According to Morris et. al., (2006) the GMFCS was developed in order to standardise a system for describing and classifying the severity of movement disability in children with CP.[59] Papavasiliou et. al., (2007)[61] and Carnahan et. al., (2007)[62] suggest that the GMFCS provides a functional disability assessment that is very important in both the identification of CP and the prognosis for therapy. The administration and application of this measure is not time-consuming and children can also be evaluated retrospectively.[63]

Palmisano et. al., (1997)[58] established an inter-rater reliability of 0.55 on the GMFCS for children under two years of age and 0.75 for children two to 12 years of age. More recently Wood and Rosenbaum (2000)[64] found a higher inter-rater reliability (0.93) and a high, test retest reliability (0.79) on this measure. Furthermore, the positive predictive value of the GMFCS used at one to two years to predict walking by age 12 years was 0.74, whilst the negative predictive value was 0.90.

According to Palisano et. al., (2000) the GMFCS[64] is a valid tool for predicting gross motor function in children with CP based on functional abilities and limitations. Their study demonstrated a high correlation between the GMFCS levels and Gross Motor Function Measure (GMFM) scores. These findings are supported internationally by the results of a study by Papavasiliou et. al. (2006) which suggested that the GMFCS (Greek version) can be used reliably to classify children with CP and recommended the use of the GMFCS in clinical settings and research. From a rehabilitation perspective however occupational therapists must also assess the presence and severity of associated impairments and consider the child with CP in the broader context of their “health condition” as described by the ICF in relation to activities and participation.[65]

## 2.3 CEREBRAL PALSY IN RELATION TO HEALTH AND PARTICIPATION IN LIFE THROUGH ENGAGEMENT IN OCCUPATION

The ICF has been recognised as important when considering any health condition and CP should be no exception as this condition can have a devastating effect on many aspects of a person's development, and functional ability to engage occupation and participate throughout their life. The ICF (Figure 2.1) provides

> "a coherent view of different perspectives of health from a biological, individual and social perspective" (p 28)[65]

and has been recognised as a useful framework for social policy, research, education and clinical practice.[66] This classification indicates not only how the "health condition" of the child with CP may be influenced by deficits in body structure and function but also how it relates to limitations in activities and restriction in participation in everyday life.

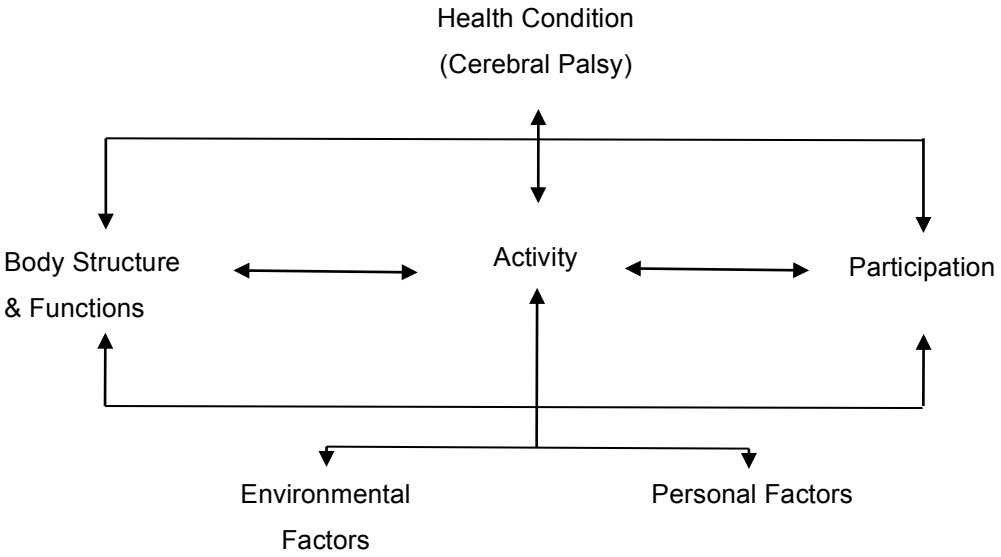



**Figure 2.1. The ICF Model[65]**

The overall context of the child is also included by considering how their condition may be influenced by or conversely influences "environmental factors" as well as "personal factors". The "environmental factors" can be physical, social, cultural or institutional in nature, whilst the "personal factors" can be gender, age, education and lifestyle.

### 2.3.1 Personal and Environmental Factors that Affect Children with Cerebral Palsy

According to Sawyer et. al., (2011)[67] the care of children with disabilities occurs mostly at home and the primary caregivers of these children are usually their mothers. The role of caregiver places significant demands in terms of time and energy on both the family and the primary caregivers. Caring for any child takes an inordinate amount of time and the demand increases even more when the child is disabled,[68] and more still when the child requires assistance with mobility.[67]

Given that CP is a lifelong disability; families of children with CP face unique stressors and demands over time, because as the child grows their needs change.[69] Families who are raising a child with disabilities seem to face more challenges than families raising a child without special needs.[70] Shevell et. al., (2003)[55] concluded that the many challenges faced whilst caring for a child with CP lead to considerable personal, familial and societal burden.[55] Furthermore, the family face recurrent grief, which is renewed at subsequent developmental stages and transitions of the child's life.[71] The caregivers and families may also have to face additional emotional problems, including: depression, distress, low self-esteem and chronic sorrow, whilst dealing with the possibility of the negative implications on the general health of caregivers.[42] According to Gallimore et. al., (1993),[72] successfully coping with disability requires adjustment to various areas of daily life, including: family subsistence, services, home/neighbourhood safety and convenience, domestic workload, child care tasks, child peer groups, marital roles, instrumental or emotional support, father/ spouse/ partner role, and parent information.[72] An example of one of the caregiver stressors is that ordinary handling of a child with CP during activities of daily living (ADL) may result in increased tone and discomfort. Specific therapeutic handling techniques may assist caregivers with completing everyday activities such as dressing, undressing, bathing and toileting.[23; 42]

This burden of care is exacerbated in the face of poverty when there are inadequate financial resources to meet daily living needs. Various studies suggest that poverty is generally associated with poor housing, overcrowding,

nutritional problems, neighbourhoods that fail to offer a safe environment for play and poor social support structures.[73,74] This results in added difficulties for the caregiver of a disabled child especially when the family lives far from hospital services and the children they care for are dependent on them for activities of daily living.[75]

These contextual factors were emphasised by, Rosenbaum and Stewart (2004)[66] when using the ICF as influencing and modifying many of the components of dysfunction in CP. Limited interaction with the environment can also compromise participation and for example, a child's inability to explore actively and to learn about space, independence and social interaction causes limitations in terms of learning ability and socio-emotional growth.[47,53] A child's ability to develop and participate in activities can be affected by the context/environment in which an occupation is performed; the specific demands of the activity; and the child's body functions and structures or client factors.[6]

### 2.3.2 Body Structure and Function in Children with Cerebral Palsy

The body's capacity is reflected in the body structures and functions, such as mental (affective, cognitive, perceptual), sensory, neuromuscular, and movement-related body functions.[65] The description of the impairments in CP have largely been based on deficits of body structures related to movement, the neuromusculoskeletal and movement-related body functions which are most often the primary deficits in CP.[65]

Simkiss (2002)[76] reviewed the associated difficulties in children with CP and confirmed that at least 82% of children with CP have one or more disability other than neuromusculoskeletal dysfunction. Simkiss (2002)[76] listed the associated difficulties in CP as gastrointestinal problems (including gastro-oesophageal reflux and constipation); dental decay[76] and other specific impairments including:

- *Mental functions - Cognitive Impairment*

  The National Institute of Neurological Disorders and Stroke (2001)[16] records revealed that about 33% of children with cerebral palsy are mildly intellectually impaired and 33% are moderately impaired or severely impaired. Other

studies suggest that cognitive impairment is commonly present in 60% - 75% of cases with CP.[57,77,78] According to Sankar and Mundkur (2005)[77] children with spastic quadriplegia are likely to have a greater degree of cognitive impairment than children with hemiplegia.

- *Seeing and Hearing Functions*

  Pellegrino (1997)[79] stated that "visual impairments are also common in children with cerebral palsy". Sankar and Mundkur (2005)[77] concluded that CP could be associated with visual impairment (28% of children) as there is increased presence of nystagmus, amblyopia, strabismus, optic atrophy and refractory errors.[77] Katoch et. al., (2007)[80] found that 68% of their sample had significant visual impairment, whilst an Egyptian study found that 76% showed ocular abnormalities.[81]

  According to Majumdar et. al., (2006),[78] hearing impairments and disorders occur in 12% - 14% of children with CP.[78] In a national register survey of children with CP in England, Surman et. al., (2006) determined that 7 - 8% of the children registered had hearing impairment and 2.2 - 2.4% had severe hearing loss.[82]

- *Ingestion Functions and Oral-motor Disorders*

  Gangil et. al., (2001),[83] found that coughing and choking, extensor dystonia during feeding and regurgitation, during feeding resulting in recurrent chest infections were common. Furthermore, oral motor dysfunction, vomiting, drooling, hypertonic tongue and inadequate tongue lateralization were high, up to 100% in the study. Ravel (2002)[84] found that more than 90% of children with CP have oral motor dysfunction and defined feeding and nutritional deficits as "difficulty with eating and swallowing". Other studies confirmed that associated oral-motor dysfunction also affects physical growth.[85,86]

- *Voice and Speech Functions*

  Speech impairments were seen in 31.5% of the studied children,[78] whilst Andersen et. al., (2008)[87] found that 28% of the children studied had impaired or no speech. Geytenbeek (2011)[88] highlighted the need to distinguish between dysfunction in speech, (expressive) language and verbal cognition.[88]

- *Joint and Bone Functions*

  According to Bischof et. al., (2002), some children with CP develop pathological long-bone fractures as a result of factors such as Vitamin D deficiency, poor nutrition status, non-ambulation, anticonvulsant therapy (ACT), lower limb rigidity, joint contracture, hip dislocation and disuse osteopenia.[89]

Given the prevalence of associated disorders in children with CP, it is evident that they need to be identified and considered together with the dimensions of "activity" and "participation".[66] According to the ICF model, "body structure and functions" are directly related to activity limitations and participation restrictions[65] and "deficits of the body structures and functions result in dysfunction in activities and participation related to mobility, learning and communication, amongst others".[53]

### 2.3.3 Activity and Participation in Children with Cerebral Palsy

The interrelationship between the child with CP, their impairments, activity limitations and participation restrictions and the contextual factors must be understood when planning a suitable management strategy to assist them and their families.

In the context of occupational therapy, Law et. al., (2005) referred to participation as taking part in the occupations of everyday life and highlighted that participation is the ultimate goal of OT intervention.[90] Participation has to be considered in relation to performance skills, performance patterns and activity demands as well as the environment in which that person lives. The ICF demonstrates an understanding of the complexity of this view of participation as it recognises the interrelationships between body structure and function, activity, participation and personal and environmental factors.[65] This is supported by other models in OT, including the Person Environment Occupation (PEO) model that recognises the complexity of participation in occupations by considering the interaction between person, occupations and environment.[90] As illustrated in Figure 2.2 (PEO superimposed on ICF), the WHO's model of disability and health has strong

similarities to the PEO model used in occupational therapy with regard to the emphasis on participation.

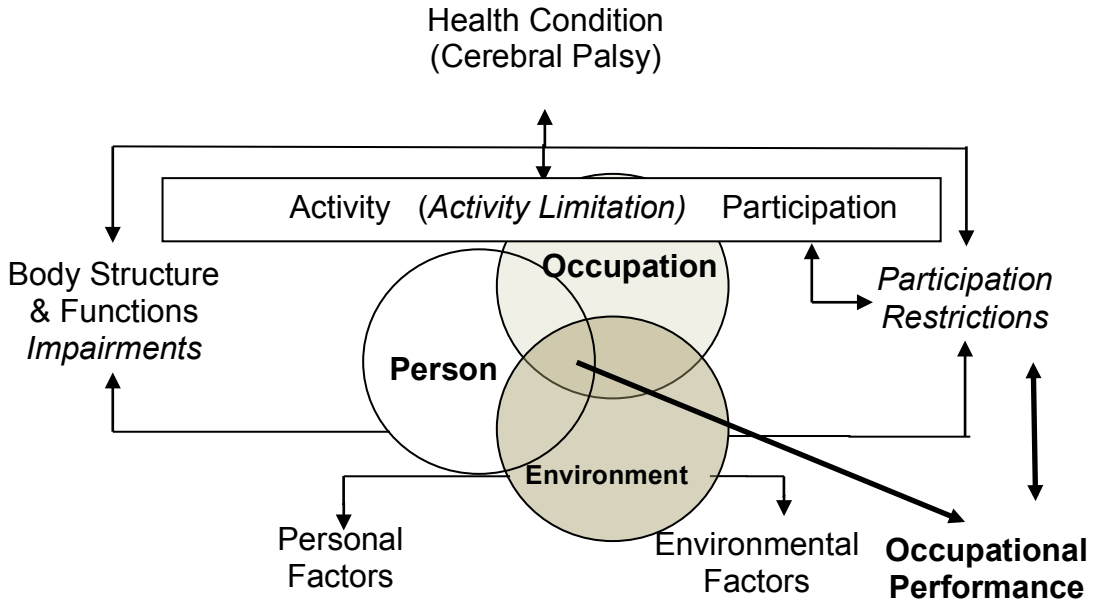



**Figure 2.2: The Person Environment Occupation model of occupational performance superimposed on the ICF model for disability and health.**

All the categories in the ICF activities and participation including self-care, interpersonal interaction, major life areas and community life are aligned with the occupational performance areas described in the Occupational Therapy Practice Framework II (OTPF II).[6] The OTPF II defines OT outcomes or function in these occupational performance areas in relation to performance patterns, the context or environment, activity demands and performance skills which are supported and enabled by numerous body functions and structures[20] or client factors. The OTPFII emphasises the importance of capacities provided by body structure and function in achieving performance skills necessary for occupational performance in the major life areas included in the ICF. Performance skills represent a person's demonstrated abilities in motor, cognitive, sensory perceptual emotional in the actions they perform supported and enabled by numerous body functions and structures.[20] The areas of occupational performance in the OTPF II are listed as sleep, personal management or self-care, play or leisure, education or work skills and social participation.[6] Therefore while both gross motor abilities and self-care are included in the activities and participation categories of the ICF, the OTPF II differentiates gross motor abilities into motor performance skills and self-care;

mobility into the occupational performance area of activities of daily living; and social function falls into the occupational performance area of social participation.

Since the primary occupations of childhood are play, social participation and self-care activities, the desired outcome in this occupation-based framework of practice is to achieve optimal function in these areas of occupational performance within the child's environmental and cultural context.[91]

A number of studies have provided evidence that children with CP have activity limitations associated with mobility, along with difficulties performing activities related to the performance skill of mobility such as sitting and walking. These limitations in activity and participation extend into the occupational performance including self-care activities, feeding problems and socio-emotional deficits. Bower et. al., (1996)[23] and Buttler et. al., (2001)[92] both concluded that activities related to self-care are likely to be affected by the performance skills like gross motor abilities in CP. If the "health condition" of a child with CP is to be addressed all of the aspects discussed above must be considered and addressed by various health professionals.

## 2.4 MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY

Ideally the management of children with CP should involve: early diagnosis, comprehensive team evaluation and holistic management, using a multidisciplinary approach.[93] Sankar and Mundkur (2005)[77] and Hayes (2010)[94] suggest that the multidisciplinary team should include a developmental paediatrician or neurologist, an orthopaedic surgeon, a speech and language therapist, a physiotherapist and an occupational therapist. Papavasiliou (2009)[93] suggested a "multimodal treatment approach", where various effective and safe treatment options are implemented in an integrated, systematic, individualised rehabilitation plan.

Since no clinically meaningful interventions have as yet been developed to repair the lesion to the brain and CP cannot be cured, the management of CP is based on a number of different theories and concepts, which aim to facilitate all aspects

of development. Thus the goal of intervention or service provision for children with CP is to facilitate and improve functional independence in all areas of life[15] participation in activities and quality of life.[13] Various approaches to treatment within occupational therapy management such as NDT,[95] Perceptual Motor Training (PMT), Sensory Integration Therapy (SI)[96,97] and Family Centred Therapy are used, with the view of achieving these goals. Papavasiliou (2009)[93] however suggested that the best treatment outcomes are achieved through "well-trained, flexible, open-minded and devoted therapists who adjust to what fits most to the individual patient" (p 394), regardless of treatment technique.[93]

In 1988 the emphasis on intervention for children with CP according to Tardieu et. al., (1988)[98] was aimed at minimizing the development of secondary problems affecting body structures, i.e. contractures and deformities. While this was supported by both Rosenbaum (2003)[56] and later Papavasiliou (2009),[93] they emphasised that intervention should also include aspects aimed at dealing with body functions like strengthening weak muscles; dealing with activities and participation restrictions; and promoting functional independence at home, at school and in the community. Thus objective evaluation of the functional occupational performance outcomes should be an essential element of the treatment approach.[93]

Therefore treatment that aims to promote participation in occupations through active training protocols,[93,99,100] lifestyle modifications[93,101] and mobility-enhancing devices[93,102] should also be utilised. This is supported by recent research in motor learning, which suggests that "motor learning" is maximised by participation in task related activities and that therapy should include meaningful functional outcomes.[99,103,104] The entire treatment process including the assessment, measures to be used and the intervention available in relation to the CP child should consider these outcomes.

### 2.4.1 Assessment of Children with Cerebral Palsy

Thus in accordance with recent clinical thinking the occupational therapy assessment of the child with CP should focus on occupational performance and

function rather than on impairment and their ability to achieve motor milestones.[105] According to Schneider et. al., (2001)[105] an objective functional scale is required to evaluate the functional consequences of the abnormal muscle tone or involuntary movement in children with CP. In the early nineties various clinicians began to focus on the ability of the child to complete activities of daily living at home and in the community[106,107] and numerous studies at that time focused on measuring function related to both movement and occupational performance areas.[108]

According to the OTPF II assessment of occupational performance involves synthesizing information from the occupational profile to focus on specific areas of occupation and contexts that need to be addressed; noting effectiveness of the performance skills and performance patterns; and selecting assessments, as needed, "to identify and measure more specifically contexts or environments, activity demands, and client factors, performance skills and performance patterns"(p 648).[6]

Ketelaar et. al., (1998) concluded that of 17 measures available to assess function in terms of performance skills related to motor abilities and occupational performance in children with CP, the methodology used in the Gross Motor Function Measure (GMFM) and the Paediatric Evaluation of Disability Inventory (PEDI) was significantly better than that used in previously developed tools.[109] These were the only two assessments that met the criteria for reliability and validity with respect to responsiveness to change[109] and they provided different sources of information as they focused on different aspects of function.[109] When comparing the two measures, both Nordmark et. al.[110] and Han et. al.,[111] concluded that the GMFM-66 and the PEDI Functional Skills Mobility domain are complementary assessments that could be used interchangeably. Nordmark et. al.,[110] also found that in a group of children with more severe impairment, the PEDI, was more sensitive to change than the GMFM.

#### 2.4.1.1 The Gross Motor Function Measure (GMFM)

The Gross Motor Function Measure (GMFM)[112] is currently considered the best available tool to measure change in gross motor function over time or in response

to intervention, in children with CP.[112] As the GMFM was developed specifically for children with CP, the test items included are relevant to the motor disorder common to CP.[60] The test is a standardised observational instrument administered by an experienced paediatric therapist, who has undertaken training (self-training manual), to assess how the child with CP can perform different gross motor functions.[109,113] The GMFM is a "criterion referenced" measure meaning and that a child is assessed on individual change of specific skill (i.e., walking) or domain (i.e., gross motor function) as opposed to comparing with norms for typically developing children.[113] It examines five dimensions of function including: lying/rolling, sitting, crawling/kneeling, standing, and walking/running/jumping. Given that be GMFM is administered in a controlled environment, the results reflect capability (what a child can do) as opposed to performance (what a child does do) in everyday settings[114] thus measuring function in motor ability. Although the GMFM is not bound by age limits, typically developing children can usually accomplish all the items by the age of five years. The usefulness of the GMFM for older children with CP therefore depends on their relative abilities and disabilities.[60]

There are two versions of the GMFM, the original 88-item measure (GMFM-88)[112,115,116] and a more recent version consisting of a subset of 66 items, taken from the original 88 items after Rasch analysis (GMFM-66).[60] In order to proceed with test items, a therapist places the child in a prescribed starting position and elicits an item response. The procedures are scored on a four-point scale (0-3) and the test takes 45 to 60 minutes to administer. Although both tests are scored in a similar way the GMFM-88 uses an ordinal scale to analyse the results, whilst the GMFM-66 is interpreted using an interval scale, thereby improving its ability to quantify changes in motor function.[112] The Gross Motor Ability Estimator (GMAE) is a computer programme provided to allow clinicians and researchers to compute the GMFM-66 scores along with visual item maps of the child's function.[112]

The GMFM has been shown to be a reliable, valid, and sensitive measure of change in motor function. According to Guyatt et. al., (1987)[117], the ability to measure meaningful change over time (responsiveness) is a type of validity that

evaluative measures should demonstrate. Russell et. al., (2002)[112] demonstrated intra-class correlation coefficients (ICCs) of 0.99 for the intra-rater and inter-rater reliability and the test-retest reliability of the GMFM-88.The initial construct validity[115,116,118] of the GMFM was supported by Drouin et. al., (1996)[114] when significant linear relationships were reported between gait speed and dimensions D (standing)(0.91) and E (walking, running and jumping) (0.93) of the GMFM-88.[119] Damiano and Abel (1998)[120] confirmed these findings by demonstrating a strong correlation between computerised gait analysis parameters and GMFM-88 scores.[120]

Studies by Russell et. al., (2000)[121] and Shi et. al., (2006)[122] have shown the GMFM-66 to be highly reliable (ICCs 0.97-0.99) and sensitive to change.[121,122] Subsequently, Wang H. and Yang Y. (2006)[123] reported that a receiver operating characteristic curve analysis revealed greater sensitivity to change in the GMFM-66 than the GMFM-88.[123] Although the GMFM is aimed at assessing a broad range of abilities in children with CP, the "floor" and "ceiling" effects can affect the sensitivity of the test. Russell et al. 2000[116] and Stanley et al. 2000[4] found that if a child is already performing at baseline or near 100%, there are limited degrees of freedom for change.

#### 2.4.1.2 The Paediatric Evaluation of Disability Inventory (PEDI)

The Paediatric Evaluation of Disability Inventory (PEDI) was developed by Haley et. al., (1992)[124] in order to measure the functional limitations and monitor progress of children with disabilities.[124] The PEDI is presented in the form of a checklist aimed at identifying different function in activities in the occupational performance areas of self-care and social functioning as well as the performance skill of in and outdoor mobility.[109,124] The PEDI consists of items that are intrinsically relevant to daily functioning and focuses on contextual influences.[124] The PEDI has a number of intended uses including:

- The detection of delay or deficit in individual children; and
- Monitoring changing function over time in individual children and groups of children.

The inventory can be administered via completion of a parental report, structured interview or professional observations of the child's functional behaviour. The inventory takes 20 minutes to one hour to administer.[124] The original PEDI, when completed on parent interview has been shown to be sensitive to changes following therapy.[21] Children can be assessed according to three scales (typical functional skills, caregiver assistance and modifications or adaptive equipment used).[109,113]

The PEDI can either be used as a discriminative (when norm-referenced) or as an evaluative measure (when criterion-referenced scaled scores are used). The measure is designed for use with disabled children between the ages of six months and seven and a half years.[109,113,124] Dumas et. al., (2001) found that the self-care classification levels could be used to assess change.[125] Furthermore, the PEDI has been found to be responsive to change over six months when used with children with CP.[109,126]

The PEDI has strong psychometric properties as a number of studies have supported the PEDI as a reliable and valid assessment of functional performance in children with disabilities.[127-129] Concurrent validity of the Development Edition of the PEDI was established when significant differences between the disabled and nondisabled group scores[127] were found by Feldman et. al.,(1990). The reliability of all six scales was calculated using Cronbach's alpha coefficient and revealed excellent internal consistency. Inter-interviewer reliabilities were established for parents/caregivers and rehabilitation team respondents, using ICCs derived from an analysis of variance model. The results suggested that reliable interview data could be obtained and recorded from either a rehabilitation worker or family respondent.[124]

Further concurrent validity of the PEDI was supported by moderately high Pearson product moment correlations (0.70–0.80) when compared to the Battelle Developmental Infantry Screening Test (BDIST).[127] The Pearson correlation coefficients between subscales of the Peabody Developmental Motor Scales(PDMS) and the summary scores for each domain of the PEDI were also

moderate to high (0.64–0.95), suggesting high concurrent validity and that these two tests measure similar aspects of a child's performance.[129]

Haley et. al., (1991) confirmed the content of the Development Edition of the PEDI using a validity questionnaire.[124,128] Nichols and Case-Smith (1996) used a series of three studies to establish the reliability and validity of the PEDI. The ICCs were high for the summary scores of each domain and moderate to good for the content areas. The inter-respondent reliability of content areas within each domain had ICCs that ranged from 0.18 to 0.94 however, suggesting varying degrees of reliability on the items. The results suggest that reliability was increased when the PEDI was administered to both the parent and the primary therapist.

Despite strong psychometric properties, it should be noted that there may be a "floor effect", in terms of validity, when used on young children (six months to two years), as this age group would not be expected to achieve many items with regard to dressing, use of utensils and toileting.[113,129] Haley et al. 1992[119], the original authors of the PEDI acknowledged that the "floor" and "ceiling" effects could affect the sensitivity of the test in that there are limited degrees of freedom for change in children already performing at 100% or very young children performing at the baseline.

### 2.4.2 Intervention for children with Cerebral Palsy, including Neurodevelopmental Therapy

Within the range of possible rehabilitative treatments suggested for children with CP, conservative treatments include physiotherapy,[11,130-132] occupational therapy,[11,133] speech and language therapy (ST),[11] conductive education[134] and splinting.[135] More invasive treatments may be combined with conservative techniques and include: intramuscular chemodenervation (botulinum neurotoxin or neurolytic agents); and surgical techniques (orthopaedic surgery, pump-infused intrathecal baclofen and dorsal rhizotomy).[11,93,102,136,137]

The physiotherapist and occupational therapist play pivotal roles in enhancing motor control in the child with CP.[130,133,136] Although there is little research regarding the efficacy of therapy with regard to participation in daily living

activities, numerous studies have been conducted on the efficacy of NDT in improving gross motor function in children with CP and NDT remains one of the most recognised and enduring treatment techniques used by therapists when treating children with CP.[95]

Current NDT practice is based on the systems approach to motor control, with neuroplasticity as the primary mechanism for neurological recovery[93] which is carried over into therapy using the following principles:

- Abnormal/atypical patterns of coordination and movement need to be suppressed and unwanted movements controlled, but *never* at the expense of any individual's participation in everyday life.[138,139]
- More normal motor activity for use in daily activities should be obtained, using techniques of facilitation as required. Only the child's more normal selective activity can result in reducing the effect of abnormal/atypical tone.[138,139] Bobath (1990) stated "the emphasis in treatment is now on the active participation of the patient with the therapist to learn to control his spastic hypertonia himself" (p133).[136,138]
- A multidisciplinary/trans-disciplinary approach is required as the whole person should be involved: sensory, perceptual, adaptive and motor behaviours.[138,139]
- Treatment is management and all treatment needs to be directed towards working on activities of daily life.[138] Clients are encouraged to practice activities at home and with their carers. Home programmes, assistive devices, adaptive equipment and caregiver training form an integral part of the treatment.[138,139]
- An individual problem-solving approach is required to apply these ideas and to thoroughly analyse the child's skill (i.e. analysis of the task, activity and participation).[138,140]

These principles support the practice of occupational therapy and the implementation of the OTPFII, which emphasises the development of performance skills necessary for independence in all areas of occupational performance.[133] Thus when using NDT an emphasis is now placed on observing and analysing the child's specific functional abilities[140] and identifying clear treatment goals aligned to the child's context.

The aims of treatment are to achieve active participation in specific, relevant performance skills and occupational performance areas,[136,138] by influencing muscle tone and improving postural alignment through the use of specific handling techniques and equipment. There are however no standardized, quantifiable interventions that can be prescribed in discrete units and individualised occupational therapy programmes vary considerably according to the needs of the child with documentation of efficacy remaining limited.[133] There have been some studies however which indicate that various approaches in occupational therapy programmes have had a significant effect on certain outcomes in relation to client factors, activity participation and self-perception[141] whilst occupational therapy home programmes have been found to be effective with children who have spastic hemiplegia.[142]

Other specific factors in treatment have been identified as having a positive effect on the outcome of intervention. These include:-

- The use of specific measurable goals in treatment rather than general aims to increase the acquisition of skills;[143]
- Providing intermittent intensive periods of therapy to accelerate motor performance;[29]
- Stretching tight muscles, regular change of position, provision of appropriate equipment, and encouraging mobility to prevent or slow down the development of secondary deformities;[98,101,144,145] and
- Strategies that included involvement of both parents and children to effectively achieve developmental outcomes.[146,147]

#### 2.4.2.1 Effectiveness of Intervention Programmes for Children with Cerebral Palsy

The complexities surrounding CP create a high number of variables that make assessing the effectiveness of treatment a challenging task. Not only are the effects on the neurological and functional development of the child highly variable, but also the impact on the degree of impairment, activity limitation and participation is also different for each child. Research in this area is further

complicated by the complex nature of diagnosis, the heterogeneity of the population resulting in numerous variables that have to be controlled.[148]

Reviews and research completed in the 1990s focusing on the efficacy of intervention strategies, rehabilitation programmes, training methods or treatment regimes for enhancing motor and general development in children with CP has shown there is limited evidence for the effectiveness of current practice. Following a review of 37 studies of physiotherapy interventions for children with CP, Hur (1995)[149] indicated that most of the studies consisted of small samples, had poor controls and lacked the required rigor in both experimental design and analysis. Of the 37 studies reviewed by Hur, only seven used a comparative design and only two of those seven showed a significant treatment effect.[149]

Evidence for both occupational therapy and physiotherapy was still lacking in later systematic reviews of the 2000's. When Steultjens et. al., (2004)[128] reviewed 17 studies they found that there was insufficient evidence overall to suggest that occupational therapy was effective in any intervention category for children with CP, as the majority of the studies produced statistically insignificant results and methodological issues.[133,128] When Anttila et. al., (2008)[148] reviewed 22 randomised control trials (RCTs) they found moderate evidence for the effectiveness of physiotherapy in only two of the eight intervention categories identified. These categories included developmental status using NDT once or twice a week and the amount and quality of hand use after constraint-induced therapy. There was conflicting evidence for the use of training on gross motor function and the evidence was limited for the other intervention categories, due to poor methodology, the variations in populations, interventions and outcomes, and the statistically insignificant results.[148] Many studies also raised questions about the specificity of the effects observed, either because of a lack of information about the therapy provided[92,143] or because of concerns related to outcomes measures[130] and compliance with treatments.[151] Many studies have been inconclusive about the effectiveness of NDT,[22] so its effectiveness will therefore be reviewed in some detail.

#### 2.4.2.2 Effectiveness of Neurodevelopmental Therapy

The controversy about the effectiveness of NDT must be considered in the light of the interaction of other variables such as age, type and severity of CP, intellectual level, parental participation, goal setting, child's co-operation, and intensity of therapy, all of which research on the effects of NDT in children with CP found have an influence on the outcome of the intervention.[92,143]

While no clear scientific evidence exists to establish NDT as superior to other treatment techniques[152] Brown and Burns (2001)[22] in their systematic review concluded that the current research literature, at that time, did not clearly demonstrate the efficacy or inefficacy of NDT as a treatment approach. Studies evaluating the effectiveness of NDT in the treatment of children with CP have however shown improvement in aspects of motor performance, including gross motor ability, postural control and stability.[100,153] Previously Bower et. al., (1992 & 1996)[92] had also provided some support for NDT by showing that selecting specific functional goals for treatment rather than general aims and providing intensive rather than non-intensive therapy enhanced motor skills acquisition over a treatment period of two weeks.[92]

Thus research on effectiveness of NDT based the intensity and frequency of treatment as well as the inclusion of functional tasks and activities in therapy is considered. Law et. al., (1997)[154] compared an occupational therapy programme (aimed at improving specific performance skills) with an intense (24 times during a 16 week period) NDT programme (aimed at improving impairment and quality of movement) incorporating upper limb casting. Fifty children with CP were studied in a crossover trial and although both groups were found to improve, no significant difference was found between the two groups in hand function or quality of upper extremity function at the end of the trial.[154] These results support the Bobath's (1984)[95] assertion that as long as functional goals are prioritised, treatment techniques used to achieve them may not make a difference to the outcomes gained.[95] Jonsdottir et. al., (1997) however reported that studies investigating the effects of NDT on "reaching tasks" in children with CP,[132] found NDT to be significantly more effective than practice alone in improving postural alignment

during reaching, indicating the importance of incorporating functional goals in NDT to improve motor components.

Controversy over the intensity and frequency of treatment using NDT is an on-going concern in a number of studies[21,28,29,35,92,130,143,151,155] and in 1991 Mayo[130] found that a regime of weekly NDT (intensive) was substantially better than a 12 monthly (basic) regime, for motor development. In 1975 Carlsen[155] used a randomized controlled trial to demonstrate that two hours of NDT (weekly) over a six-week period, improved motor function by statistically significant levels,[155] but the use of discriminatory rather than evaluative outcomes measures may have affected at the validity of the results. Knox et. al., (2002)[21] demonstrated, using a repeated measures design, that a six-week course of NDT (75 minutes, three times per week) significantly improved gross motor and occupational performance skills, in children with CP.[21] The small sample size and lack of control group may however have limited the power of the results of this study.[21] Bower et. al., (2001)[29] found, however that intensive daily treatment (an hour a day for three months) resulted in limited and temporary improvements in motor function[168] while Trahan et. al., (2002)[29] demonstrated that an intermittent intensive (4 times/week for 4 weeks) NDT programme was less tiring for the child with CP, resulting in more permanent improvement in motor function.[29]

More recent studies in which therapy was provided in variable intensities to groups of children have not however, provided conclusive evidence of the effectiveness in relation to this variable. Reddihough(2003),[35] for example was unable to measure any improvement in upper limb function in a group of 10 children who received four times the amount of NDT normally provided.[35] Tsorlakis et. al., (2004)[28] supported the need for intensive application of treatment, particularly in children with spastic CP from the results of a study examining the effect of intensive NDT (five times a week for 16 weeks) on the gross motor function. Although all infants in a study by Ustad et. al., (2009)[131], showed gross motor progress when compared with their baseline, the evidence was inconclusive when the effects of daily physiotherapy were compared to physiotherapy less frequently as usual. Thus the intensity of NDT in therapy programmes as well as the application of

specific functional outcomes in relation to NDT need to be further researched. No studies that addressed the efficacy and effectiveness of NDT on motor performance skills and occupational performance outcomes in South Africa were found.

### 2.4.3 Management of Children with Cerebral Palsy within the South African Context

The South African Integrated National Disability Strategy (INDS) (1997)[26] reported that more than 80% of black children with disabilities in SA live in extreme poverty and in hospitable environments. The report also indicated that rehabilitation services have traditionally been neglected in South Africa. As a result children with CP

> "have very poor access to appropriate health care facilities and early childhood development opportunities" (p 9).[26]

Rehabilitation services have predominantly been based within the Department of Health and the Departments of Labour and Education have accommodated relatively few "rehabilitation related programmes". In general these services tended to be fragmented and uncoordinated mainly due to the lack of a comprehensive national inter-sectorial rehabilitation policy.[26] Since 1997 there appears to have been initiatives from the South African health sector to improve access to rehabilitation for children with disabilities and their caregivers. In 2002 the South African Human Rights Commission (SAHRC) emphasised that there was

> "an enormous task in transforming the institutions, attitudes, practices, buildings, facilities and environments that continue to deny people with disabilities their right to dignity, equality and freedom" (p 5).[156]

Currently in South Africa pregnant mothers, children under the age of 6 years and adults with a permanent disability are provided with free medical care within the public health sector.[157] Unfortunately,

> "free health care for children under six years old has not always automatically been extended to include rehabilitation and the provision of assistive devices" (p 22).[26]

Children with CP from poorly resourced areas are dependent on the public sector for their health needs and only about 30% of children with disabilities in South Africa are being reached by the current public sector services.[44] According to a Department of Health discussion group report back (Paediatric Neurology and Developmental Paediatricians, 2002[158]), many rural families experience major problems accessing services because they have to travel extremely far distances in order to reach appropriate centres. The most disadvantaged are the poor who do not have the finances or the time to travel long distances.[158] Frye and Magasela (2005)[159] of the National Labour and Economic Development Institute (NALEDI), emphasized that 'poverty is one of the most urgent social and economic factors that has to be addressed in South Africa'. Miles (2004)[25] highlighted that a child with barriers gives rise to: "additional impoverishment because of expensive 'cures' and extra time that is needed to look after the child."

Philpott (2006)[160] highlighted the need to improve access and ensure that services were appropriate for children with disabilities and their families.[160] The immense gap between the needs of children with disabilities and available rehabilitation services in South Africa was highlighted when Saloojee et. al., (2006)[161] found that only a quarter of the children in need of rehabilitation were actually in receipt of services.[161] In another study, based in a rural area of KwaZulu Natal, Couper (2002)[44] observed that only one third of the children requiring rehabilitation were known to the health services.[44] These studies suggest that there are vast unmet needs in rehabilitation services in South Africa and highlight the urgent requirements for effective intervention strategies.

Given the socio-economic and political climate in this country, many of these families (or in many cases single caregivers[25]) have to deal with the multifaceted challenges of caring for a child with CP without the support of a multi-speciality team,[162] as well as dealing with difficult everyday living conditions and the needs of an entire family. The pressure is particularly great in poor rural areas, where the community is disadvantaged and poorly-resourced, and where most families live under extremely difficult conditions with very few resources and limited or no access to support services such as rehabilitation and specialised education.[26]

Even when rehabilitation services are available in rural areas of South Africa, there is little evidence on which to base practice to achieve the best outcomes for children with CP. Information pertaining to the effectiveness of current intervention practices in rural areas is not available as no South African studies have been conducted. This information is more readily available pertaining to several well-resourced areas of the world, where children with CP have access to a wide range of specialised services and support systems.[163] Studies conducted in developed countries suggest that intermittent intensive blocks of therapy accelerate motor performance and the acquisition of motor skills.[28, 29] This study was initiated in response to the need to explore effective management and intervention for children with CP living in rural areas of South Africa.

# CHAPTER 3
# METHODOLOGY

## 3.1 INTRODUCTION

This chapter provides an outline of the study and the methods used to collect the data. After describing the study design, the study population, the sample selection and the sample, the process of recruiting and training the study team (assessors, interviewers, interpreters and treating therapists); the procedures followed in collecting the data and steps taken to ensure the accuracy of the data is provided.

The study took place in 2007 over a period of 21 weeks and followed the steps outlined below:

**Step 1**
- Recruitment of subjects - Rehabilitation therapists at Butterworth and Tafalofefe Hospitals identified eligible children for the study and their caregivers were recruited. These children were screened for participation in the study.

**Step 2.**
- Recruitment of therapists -The assessment team and treating team of rehabilitation therapists were recruited for the study.

**Step 3.**
- Training of assessment team - The assessment team was trained in the use of the measurement tools and interviewing techniques

**Step 4.**
- First Assessment Set - The assessment team assessed the participants using the GMFM, PEDI and Parent Questionnaire eight weeks before treatment commenced.

**Step 5**
- Second Assessment Set – The assessment team re-assessed participants using the GMFM, PEDI and Parent Questionnaire one week before treatment commenced.

**Step 6**
- Intervention - The treatment team of rehabilitation therapists, trained in Bobath/NDT, administered five days of intensive neurodevelopmental therapy to participants.

**Step 7**
- Third Assessment Set – The assessment team re-assessed participants using the GMFM, PEDI and Parent Questionnaire one week after treatment commenced.

**Step 8**
- Fourth Assessment Set –The assessment team re-assessed participants using the GMFM, PEDI and Parent Questionnaire eight weeks later.

## 3.2 STUDY DESIGN

A quantitative quasi-experimental study, based on a repeated measures study design was utilised to address the study question. "What is the effect of an intensive five day course of NDT on the motor performance skills and occupational performance of children with cerebral palsy living in a poor rural area?"

A repeated measures research design measures the effects of treatment on a single sample of subjects using the same tests to assess the children before and after the intervention. In this study the repeated measures occurred at different points in time on the same children who were assessed twice before the intensive NDT based intervention and twice post NDT intervention. Thus by using this type of repeated measures design, the children who received the NDT based intervention programme acted as their own controls.[164]

All child participants were assessed on the GMFM and each parent/caregiver was interviewed on the PEDI and the Parent Questionnaire on four occasions. An interval of eight weeks between the first and second assessments and between the third and fourth assessments was chosen to establish a baseline "rate of change". This was also to allow enough time so that the parent/caregiver would be unlikely to remember their previous responses and therefore reduce the possibility of "carryover". "Carryover" effects refer to one of the internal validity issues inherent in studies that use a repeated measures design.[164]

The intervention consisted of a five-day course of intensive NDT based therapy where the parent/caregiver was required to be present for each of the treatment sessions in order to facilitate carryover into the home environment.

## 3.3 STUDY SITES

The Mnquma Local Service Area, within the Amathole Health District in the Eastern Cape was chosen for this study because it is a poor rural area where access to regular therapy intervention is difficult for most caregivers of children with CP. The Mnquma Local Service Area is classified as a Category C2 municipality, i.e. a municipal area of South Africa that is largely rural with a low

rate of urbanisation, along with limited municipal staff and budget capacity. More than half (68.49%) of the population in this area live in households with an income below the poverty line.[165] Furthermore, there was an existing hospital-based service for children with CP, which comprised of monthly clinic visits for the children who were examined and treated by either a community service therapist or a physiotherapy assistant.

The sites used for the assessments were: Butterworth Hospital, Tafalofefe Hospital and Nqamakwe Health Centre. These are the only three places in Mnquma Health District where therapy is available to children with CP.

The treatment sites where the children and caregivers were accommodated and where they received their five-day intervention block of NDT were Butterworth Hospital and Tafalofefe Hospital. These two sites were chosen because of the availability of appropriate treatment space, as well as accommodation for the children and caregivers who lived too far from the hospital to come in daily for therapy.

## 3.4 STUDY POPULATION, SAMPLE SELECTION AND SAMPLE SIZE

### 3.4.1 Study Population and Sample Selection

The study population comprised all children under the age of 16 years with a diagnosis of Cerebral Palsy (CP), living in the Mnquma Local Service Area.

### 3.4.2 Inclusion criteria

To be eligible for inclusion in the study participants had to meet the following criteria:-

- They were aged between six months and 16 years;
- They had a diagnosis of cerebral palsy (confirmed by a medical practitioner);
- They were attending therapy at Butterworth Hospital, Tafalofefe Hospital or Nqamakwe Health Centre; and

- They attended the available therapy services with their primary caregiver.

### 3.4.3 Exclusion criteria

Children were excluded from the study if: -

- Their caregivers were unable to attend the five-day course of NDT therapy as the caregiver training formed an integral part of the NDT therapy;
- They were in poor health or had acute infections e.g. children with upper respiratory tract or urinary tract infections;
- They for any reason were unable to tolerate the five days of NDT therapy; and
- They presented with uncontrolled seizures.

### 3.4.4 Sample Size

Sample selection for the study was done by identifying all suitable children who met the inclusion criteria from the study population. In the months prior to the study, the community rehabilitation therapists and physiotherapy assistant at Butterworth and Tafalofefe Hospitals identified eligible children for the study.

It was calculated that a sample size of 32 participants would have an 80% power to detect a difference of 3.6 points on the GMFM-66 score between the initial and final assessment, over a period of 4 months or less and allowing for a 10% dropout rate. The change of 3.6 was based on a Canadian study where a group of children with CP received intensive intermittent blocks of therapy over a period of 4 months (Trahan and Malouin, 1999).[29] Using two assessments post-treatment decreases the sample size required by 6% to 7% as it improves the power compared to a single measure, therefore a sample size of 30 was required.[166]

All available participants (51) were recruited for the study and assessed initially to accommodate a possible loss to follow up over the five month period of the study.

## 3.5 ETHICAL CONSIDERATION

Ethical approval was obtained from the Human Research Ethics Committee of the University of the Witwatersrand (Clearance Certificate (M070467)) (Appendix B). Institutional permission to conduct the study was requested from Mr. BL. Ntondini, the Director of Clinical Health Support Management Directorate, from the Eastern Cape Department of Health (Appendix C). Verbal permission was granted. Verbal permission to conduct the study was also sought from the hospital CEO of the Butterworth/Tafalofefe Hospital Complex.

The primary caregivers of the children with CP were invited to participate in the research study and to include their children in the intervention programme. The longitudinal nature of the study and the need to be available for the intensive NDT programme was explained in detail. The caregivers received an information sheet (Appendix D) explaining the study and were asked to sign informed consent (Appendix E) for their child to be included in the study. If the primary caregiver was illiterate, a thumbprint or verbal consent was obtained. The caregiver information leaflet and the consent forms were translated into Xhosa (Appendix F and Appendix G).

Confidentiality was ensured by the use of a cover sheet (Appendix H) on which personal identifying details were recorded. Each participant was given a study number, which was recorded on the front face sheet and each of the assessment and questionnaire forms. The numbered front face sheets were kept in a separate file by the researcher in a secure location. The participant's name or any other identifying information was not recorded on any assessment forms or other questionnaires as these were then marked with the study number. Information obtained from caregivers was therefore kept confidential and individual children and families were not identifiable on the data sheets.

Participants had the right to withdraw from the research at any time and were allowed to request feedback at any stage during the research.

## 3.6 MEASUREMENT TOOLS

The Gross Motor Functional Classification System (GMFCS) was used to group the study sample according to a functional classification of CP. A parent/caregiver questionnaire and two standardized validated measures of function were used for repeated assessments in the study. The Gross Motor Function Measures (GMFM-88 and GMFM-66, which are the same assessment, but with different scoring methods) and the Paediatric Evaluation of Disability Inventory (PEDI) were selected for this study as they are currently considered the best available outcome measures for children with CP and complementary to each other as they measure different aspects of function.[109]

### 3.6.1 Parent Questionnaire

The Parent Questionnaire was designed by Knox et. al., (2002)[21] to capture caregivers' perceptions of the changes they observed in their child's motor, self-care and social skills (Appendix I). Written permission was obtained from V. Knox to use the questionnaire in this study (Appendix K).

### 3.6.2 The Gross Motor Function Measure (GMFM-88 and GMFM-66)

This test is an evaluative, standardised, criterion-referenced observational instrument that was developed to measure "change in gross motor function over time (p 42)",[60] in children with CP. This measure has been studied for its reliability and validity.[60,118] It has also been shown to be sensitive to change during periods of therapy.[21,29,28] Since a literature search suggests that the GMFM is currently being used extensively in clinical practice as well as research studies to assess a variety of interventions[120,167,168] and based on the clinical relevance and sensitivity of the GMFM to change in motor function; the element of time required to complete the test; reliability of the GMFM to provide consistent scores when used repeatedly with the same subjects; and the validity of the measure,[60,112] the GMFM was chosen as a tool for measuring motor function in this study.

The GMFM was administered and scored using the original 88-item criteria (GMFM-88), as well as on the more recent 66-item criteria (GMFM-66) (Appendix

L). The GMFM items are presented in five dimensions:- lie and roll, sit, crawl and kneel, stand and walk, run and jump.[60,118] All items are scored on a four-point scale as per the specific descriptions for scoring each item detailed in the administration guidelines. On the GMFM-88 calculating individual dimension and total percentage scores can show the extent to which items are achieved. The scale is ordinal and differences between scores are not intended to represent equal differences of ability.[112] With extensive use in a variety of settings, a number of limitations of the GMFM–88, have been identified: -

- The large number of test items (88) makes the test long and difficult to complete for many of the children.
- When dealing with children with behaviour difficulties and low intellectual capacity the requirement that every item must be observed to receive a score can be problematic.
- The responsiveness of the GMFM-88 may be limited for children functioning at either of the extremes of the scale, due to the ordinal nature of the scale and the large number of items present in the middle of the scale.

The GMFM–66 is made up of a subset of the original 88-items that were shown to be one-dimensional.[112] In this study the GMFM-66 was used for statistical analysis as it was designed specifically for research purposes. The GMFM-66 is a method of scoring using only 66 of the original GMFM-88 test items that have been arranged in order of item difficulty.[121] In order to score the GMFM-66, a user-friendly computer programme called the Gross Motor Ability Estimator (GMAE) is used to calculate the overall level of motor ability of the child by means of an *interval level total score*. Many of the items were removed from the lying and sitting dimensions, making the GMFM-66 potentially less sensitive to change for the more severely involved child, and whose GMFCS levels were V or IV and furthermore responsiveness studies showed that the GMFM-66 appeared less sensitive to change in children over five years of age.[60]

Previously trained paediatric therapists who are familiar with assessing motor skills in children should administer the GMFM. The assessment requires the child to demonstrate various motor skills as directed in the GMFM administration

manual and scoring guidelines. The GMFM is not norm referenced, but the initial validation sample included children of five months to 16 years of age. The GMFM is appropriate for children whose motor skills are at or below those of a five-year-old child without any motor disability.[112]

### 3.6.3 Modified–Functional Skills Scale of the Paediatric Evaluation of Disability Inventory (PEDI-MFSS)

The Paediatric Evaluation of Disability Inventory (PEDI) is a comprehensive evaluation of functional skill development in children from the ages of six months to seven and a half years. Although the PEDI was designed for the functional evaluation of young children, it can be used for assessing older children with disability if their functional abilities fall below that expected of a seven and a half - year-old child with no disabilities.[124] The PEDI can be completed on parent interview and has been shown to be sensitive to the differences between children with different classifications and distributions of CP as well as changes following therapy.[21]

The PEDI consists of three scales (The Functional Skills Scale, The Caregiver Assistance Scale and The Modifications Scale), which may be administered separately or together as a unit.[124] As the Functional Skills Scales measured capability by identifying functional skills for which the child has demonstrated mastery and competence, this was chosen as the most appropriate scale to use for this study. The 197 test items cover three major domains: self-care, mobility and social function.[124]

For the purpose of this study, aspects of the PEDI were modified by the Principal Investigator (Dr Gillian Saloojee) to suit local conditions (Appendix Mii). Within each domain, some items were considered inappropriate, as they were not within the frame of reference of rural children living in South Africa, and these items were removed. In total, 140 of the original 197 questions were left in the assessment (59 of the original 73 in self-care, 36 of the original 59 in mobility and 45 of the original 65 in social function). Furthermore, grammatical and vocabulary changes were made to a number of items in order to facilitate local understanding,

interpretation and translation into Xhosa. Details of the omissions and question changes are reflected in Appendix Mi. In this study the PEDI – Modified Functional Skills Scale was completed by parent interview. The validity and reliability of the PEDI - Modified Functional Skills Scale (PEDI-MFSS) was not established. The Caregiver Assistance Scale and The Modifications Scale were not used in this study.

The PEDI-MFSS was scored by calculating subtotals of each domain, self-care, mobility and social function (participation). The modifications made prevented use of the available tables for determining normative standard scores.

## 3.7 MEASURES TAKEN TO ENSURE RELIABILITY OF TESTING DURING THIS STUDY

The reliability of any measure may be influenced by several sources of variation, including the assessors, the environment and the measure itself. Within a study, the potential sources of variance should be identified and controlled as much as possible.[113] Validity can be influenced by the number and variation of the participants as well as the applicability of the instruments used.

Apart from the GMFM, all the questionnaires were translated into Xhosa. The validity of this translation was ensured by translating the tests into Xhosa and then back translating into English. The translations from English into Xhosa were done by, a professional translator and the back translations were done by lay translators, whose first language was Xhosa (Appendix J and Appendix N).

During both the assessment and intervention phases of this study a number of steps were taken to maximise true response and minimise variability in the study results.

### 3.7.1 The Gross Motor Function Measure

- To reduce inter-rater variability all assessors were trained to a criterion level in the use of the GMFM, as recommended in the GMFM manual (page 2).[60] The inter-rater was not statistically piloted for this study.
- To reduce intra-rater variation when administering and scoring the GMFM, each individual GMFM assessment was administered by two physiotherapists or occupational therapists who were not involved in treating the children. For each set of assessments a minimum of four GMFM trained assessors (including the researcher), were recruited. The assessors were randomly paired at the beginning of each assessment day and thereafter pairs of assessors were randomly swapped during the set of assessments therefore the pairing did not take into account the qualifications of the assessors.
- To put a child at ease as much as possible, interpreters and parents were used to assist with play interactions.

### 3.7.2 Paediatric Evaluation of Disability Inventory Modified–Functional Skills Scale (PEDI-MFSS)

- To reduce inter-interviewer variability one interviewer was trained to administer all of the PEDI-MFSS assessments.
- To assist with communication and language difficulties, the PEDI-MFSS was translated into Xhosa.

### 3.7.3 Measures Implemented To Ensure Reliability and Quality of Data during Data Collection

To assist with full participation, co-operation, and to establish a climate of trust and openness so that the caregivers and children would give appropriate responses, the following steps were taken:

- Where possible, consideration was given to the environment in which the interviews or assessments took place. Designated areas were created so that the interviews could be conducted separately from the assessments and chairs were used to “screen” different assessment areas.

- The interviewer and interpreters made certain that caregivers and children clearly understood the requirements of each assessment or interview question. In addition, the caregivers were given a clear understanding of the time required to complete the assessments otherwise they became impatient, which affected the quality of their responses.
- A supply of refreshments to the participants (caregivers and children) was helpful because the process required long hours and both parties became hungry and thirsty.
- If, during an interview or assessment, the child became fractious or irritable, one of the interpreters volunteered to pacify and look after the child. This allowed the caregiver to concentrate on the interview without being concerned about her child or gave the child a well-earned break.

To ensure that the general quality of data collection remained of an adequate standard, the following steps were taken:-

- At the end of each interview and assessment, the researcher or assessor checked the response form or questionnaire to ensure that all questions had been answered and that the responses were consistent (i.e., that they made sense).
- A mini “debriefing” session with the assessors and the researcher took place at the end of each day where the proceedings were discussed and any problems or questions clarified.
- The GMFM assessor pairs rotated partners at random throughout the assessments.

## 3.8 SELECTION AND RECRUITMENT OF ASSESSMENT AND TREATMENT TEAMS

### 3.8.1 The Assessment Team

The assessment team consisted of the following:-

- Two teams of two physiotherapists or occupational therapists (including the researcher) who were not involved in treating the children administered the

GMFM assessments. The therapists were selected based on their training and experience in assessing children with motor co-ordination deficits. The GMFM assessment team received specific training and opportunity to practice the administration of this assessment. Details of the training received have been documented below (3.8.2). Two mid-level rehabilitation workers, who acted as an interpreters, assisted each team.

- The PEDI-MFSS was administered by another mid-level rehabilitation worker who was of Xhosa origin due to the need for specific knowledge of the Xhosa language and culture. The selected interviewer was required to be fluent in both English and Xhosa.
- Two trained research assistants were used to interview for demographic information and administer the Parent Questionnaires. Both research assistants had previous research experience and had been trained in interview skills and data collection skills by the principal investigator, Dr Gillian Saloojee in Johannesburg. The research assistants were selected on the basis that they are parents of children with CP and based on their previous experience with administration of demographic questionnaires and the Parent Questionnaire. Neither of the research assistants were of Xhosa origin, but were fluent in both English and Xhosa.

### 3.8.2 Training of Assessment Team

Over the initial period of two days of the first set of assessment, the assessment team received extensive training from the researcher in administering questionnaires, interviewing techniques and the process of obtaining informed consent.

The team of assessors for the GMFM received specific training and practice in using the GMFM through a morning workshop prior to commencing with the initial assessments. The researcher trained the GMFM assessment team. The training took place at Tafalofefe Hospital and took the form of discussions, training videos, demonstrations and the “self instructional CD-ROM” provided with the GMFM manual. The demonstrations, training videos and discussions allowed the assessors to work through several examples of each GMFM item. Furthermore,

assessors were given opportunity to familiarise themselves with the GMFM guidelines and score sheet prior to assessing any of the children. Russell et al (2002)[112] demonstrated ICCs of 0.99 for the intra-rater reliability, the inter-rater reliability and the test-retest reliability of the GMFM-88, in a study done on therapists performing the test who had undergone 1-day workshop training.

The rehabilitation worker who was identified for the administration of the PEDI-MFSS had no previous experience with this assessment. He therefore received additional specific training in the administration of that questionnaire by the principal investigator. As per the recommended training procedures,[124] the training involved the following strategies:-

- A thorough review of the PEDI-MFSS. The interviewer was given opportunity to discuss any difficulties with interpretation prior to commencing with the initial interviews.
- Practice in interviewing parents on the questionnaire by role-playing the process with fellow rehabilitation workers.
- The principal investigator reviewed cases one to five immediately following the completion of the questionnaire.

According to Berg et. al., (2004)[126] the inter-rater and intra-rater in their study demonstrated a very high level of reliability for the original PEDI, which was indicated both by small differences and high ICC of 0.95–0.99. The content validity and inter-rater and intra-rater reliability for the PEDI-MFSS has not been established.

### 3.8.3 The Treatment Team

The two, five-day blocks of intensive NDT were provided by volunteer occupational therapists, speech therapists and physiotherapists trained in NDT. The treatment weeks were lead by the principal investigator who acted as “team leader” and who was responsible for overseeing the quality of service delivery.

The volunteer therapists were recruited from throughout South Africa by word-of-mouth and through networking via the South African Neurodevelopmental Therapy

Association. The therapists eligible for inclusion in the treatment team were required to meet the following inclusion criteria:–

- All volunteer therapists on the treatment team were required to have successfully completed an eight weeks Basic Paediatric Course in NDT.
- All volunteer therapists on the treatment team were required to have a minimum of two years experience working with children with CP following the successful completion of their basic training in NDT.

Volunteer therapists who had no formal training or who had completed the Introductory Course to the Management of Children with CP were excluded from the "primary treatment team", but were invited to assist with the treatment weeks by being involved in the manufacture of assistive devices and the facilitation of "practice sessions" for any children not directly involved in therapy.

The study sample was divided into two groups, based on the participants' location. Each group received a five-day block of NDT based therapy. These "five-day blocks of therapy" were held at separate venues over two concurrent weeks. The "five-day blocks of therapy" intervention and the volunteer therapists for each of the weeks were arranged as follows:–

- The first five-day block of therapy took place at Butterworth Hospital and involved half of the participants. The treatment team recruited for this week included; the team leader (physiotherapist and principal investigator), five physiotherapists, two occupational therapists and two speech therapists.
- The second "block of NDT" was held at Tafalofefe Hospital and involved the remaining participants. The treatment team recruited for this week included; the team leader (physiotherapist and principal investigator), five physiotherapists, one occupational therapist and two speech therapists.
- The volunteer therapists were not the same people for each of the treatment weeks.
- The researcher was not involved in either of the treatment weeks.
- Two community service therapists were available to assist with positioning, issuing of equipment and any adjustments required for equipment. These therapists worked under the instruction of the NDT trained treatment team.

To ensure that the participants received the best possible course of treatment over five consecutive days, the following procedures were followed:-

- The treatment team was provided with a written outline of the proposed procedure for the treatment week from the assessment carried out previously on each participant, during the weeks preceding the intervention.
- Each child was assigned a "treating therapy team", consisting of two therapists (of different disciplines) who were chosen in accordance with the children's main aims. The treating teams were expected to practice transdisciplinary skills in order to achieve the treatment aims.
- Given that a transdisciplinary approach is based on the premise that one person may perform various professional roles by providing services under the supervision of other therapists from the other disciplines involved, specific disciplines were assigned, where possible as follows:
  - Children with specific feeding and communication deficits were assigned a speech therapist;
  - Children with specific upper limb and fine motor deficits were assigned an occupational therapist;
  - Children with specific sensory issues or visual deficits were assigned an occupational therapist; and
  - All the children were assigned a physiotherapist.
- Each treating team was provided with a summary of each child's treatment aims for the week, the day before the treatment week began.
- A full team "de-briefing" was conducted at the beginning of the week in order to: -
  - Introduce all team members – therapists, other volunteers and interpreters;
  - Outline the proceedings for the week;
  - Establish a high standard of work ethic amongst team members; and
  - Familiarise everyone with the available equipment, materials and resources.
- Daily "de-briefing" sessions were held at the end of the day in order to discuss cases, problem solve difficulties and assist where required.
- The team leader and identified senior therapists were available during specific periods during each day to mentor and assist younger therapists as required.

## 3.9 RESEARCH PROCEDURE

Written and telephonic contact was made with the most senior rehabilitation professionals and the deputy-director of rehabilitation, in the Eastern Cape Provincial Health Department. A letter explaining the nature of the study and outlining the information and participation required from the provincial therapists was sent to them (Appendix O).

The provincial therapists were requested to assist with identifying any children eligible for the study, invite those eligible to participate in the study and to arrange and book required venues. The provincial therapists were then required to liaise with the children and their caregivers to arrange assessment dates and facilitate attendance by all of the eligible candidates. The provincial therapists were also asked to identify and recruit a mid-level rehabilitation worker to assist with the study assessments and administer the PEDI-MFSS, and three local fieldworkers to act as interpreters.

All participants were assessed four times.

### 3.9.1 Pre Intervention Assessment Sets

The assessments and interviews were conducted at one of three venues, depending on the location of the participants and the distances they were required to travel:–

- The Butterworth Hospital venue consisted of a large rectangular room with tables and chairs available. The adjacent entrance area was used as a "waiting room" for the children and caregivers. Various areas were designated for the interviews and GMFM assessments by use of tables and chairs along with therapy mats and benches.
- The Tafalofefe Hospital venue consisted of a large dining hall with six large tables and two benches. The benches were used to demarcate a "waiting area" and for the children and caregivers to sit on. Areas in the hall were designated for the interviews and GMFM assessments using the therapy mats and a few available chairs.

- The Nqamakwe Clinic venue consisted of two offices/consulting rooms and a communal waiting area. The first office, used for the GMFM assessments contained a table and a bench, whilst the second office contained a table and chairs.

#### 3.9.1.1 First Assessment Set (eight weeks pre intervention):

Each caregiver was interviewed to obtain demographic information, socio-economic information and family background, whilst the child participants were classified according to the GMFCS levels. The Parent Questionnaire and the PEDI-MFSS assessments were administered to each of the participants' caregivers, while the GMFM-88 and GMFM-66 were carried out on each child participant (Test 1).

The principal investigator screened each child to assist with treatment planning, development of individual treatment aims and allocation of therapists for treatment.

The first set of assessments was conducted over four days, which included a morning workshop for training and combined training, assessments and interviews in the afternoon to clarify and solve any problems.

#### 3.9.1.2 Second Set of Assessments (prior to intervention):

The same assessments were repeated the week before the five-day block of NDT. This set of assessments was also conducted at Butterworth Hospital, Tafalofefe Hospital and The Nqamakwe Clinic over three and half days (Test 2).

### 3.9.2 Intervention Phase

All participants were requested to attend Butterworth Hospital, Tafalofefe Hospital a week after the second assessment for daily NDT sessions. Each of the children were allocated two NDT trained therapists, either physiotherapist, occupational therapist or speech therapist, depending on their individual primary goals. At the beginning of the course of therapy, the treating therapists were asked to set a minimum of three short-term goals in agreement with the caregiver and taking into

account the primary problems identified by the team leader. The short-term treatment goals are listed in Appendix P.

Each “hands-on” treatment session lasted 90 minutes, and each child received therapy for five consecutive days. Typically each NDT treatment session consisted of an analysis of each child’s occupational performance and movement abilities pertaining to the identified areas of impairment, the agreed short-term goals and their participation in daily living activities. Thereafter, the child received positioning, hands on treatment and facilitation in order to participate more effectively in the individually chosen functional activities. During their treatments, each participant was fitted for and issued with appropriate adaptive equipment that was individually chosen or designed to facilitate more normal movement and participation in their occupational performance activities. The treating therapists, who were assisted by local community service therapists and mid-level rehabilitation workers who helped with translation, were responsible for the design, fitting and use of the adaptive equipment. Much of the adaptation and fitting of equipment was done by the local community service therapists during the day, when the children were not receiving treatment. The adaptive equipment requirements for each child are listed in Appendix Q.

Caregivers were present throughout the therapy sessions during which they were trained to handle their children more effectively, and in the use and maintenance of the adaptive equipment, by the treating therapists (with the assistance of mid-level rehabilitation workers and volunteer community service therapists where necessary). During the week, caregivers were encouraged to practice their skills with their children, whilst they were not in therapy sessions. These practice sessions were undertaken under the supervision of volunteer community service therapists. As a result, by the end of the five-day course of therapy, each caregiver had been trained to continue a programme of suggested activities at home and had been instructed in the use and care of their equipment. Each caregiver was issued with a simple set of pictures as a reminder of home based activities that could be repeated following the intervention. Appendix R reflects an example how a typical day was broken up for the participants and caregivers.

### 3.9.3 Post Intervention Assessments

All children were assessed twice after the NDT intervention.

#### 3.9.3.1 Third Set of Assessment (after Intervention):

The Parent Questionnaires, GMFM-88, GMFM-66 and the PEDI-MFSS assessments were repeated the week after the intervention phase. The same group of assessors repeated the GMFM assessments, but the same pair of assessors did not necessarily assess the same children as they did initially. The assessment environments and schedules were consistent with the pre-intervention assessments.

#### 3.9.3.2 Fourth Assessment (8-weeks after Intervention):

All the assessments were repeated eight weeks later, at the same venues as the pre-intervention assessments.

### 3.9.4 General

During the five-month study period, the children continued to attend the monthly CP Clinic for therapy.

Caregivers were not paid for participating in the study, but transport money was provided as applicable. If, at the conclusion of an assessment the caregiver indicated that they needed to discuss any issues raised during the assessment, the researcher offered advice and support and indicated that these concerns would be dealt with during the intervention week, by the treating therapist.

Various problems were encountered during the five months of this study; generally they pertain to the availability of assessors and the withdrawal of a number of participants. Details of these problems will be presented in the results and discussion chapters.

## 3.10 DATA ANALYSIS

An Access database was used for entry of the demographic data and the PEDI-MFSS data and The Gross Motor Function Estimator was used for entry of the GMFM data. The data was analysed using Excel for Windows 2007 and SPSS ® (Version 15) for Windows statistical package (SPSS Inc, Chicago, USA). Data analysis was done in the following stages:

- Descriptive statistics and frequency tables were the initial methods of data analysis. Descriptive statistics were used to determine frequencies, means and standard deviations.
- The second stage used inferential statistics from the SPSS ® (Version 15) Statistical Software. Wilcoxon's Signed Rank Tests were used to compare pre-and post intervention test results. These two-tailed tests with a significance level of $\leq 0.05$ were used to determine statistical differences between any pair of test scores achieved at the different time intervals over the four assessments for the GMFM-88 and GMFM-66 and the PEDI-MFSS.
- The non-parametric statistical tests (Wilcoxon's Signed Rank Test) were used because neither the GMFM or the PEDI-MFSS followed a normal distribution pattern.
- An effect size analysis (Cohen's d) was completed for the three components of the PEDI-MFSS data, self-care, mobility and social to establish the size of the change that occurred in each occupational performance area over the course of the study.
- The Parent Questionnaire results were tabulated and each caregiver's pre (Test 1 and Test 2) and post (Test 3 and Test 4) responses were summarised.
- The list of adaptive equipment issued to each child was tabulated.
- A summary table was then created containing a summary of each child's test results, the summary of the Parent Questionnaire responses and the adaptive equipment issued to each child. The summary table was analysed by grouping the children into their GMFCS levels and comparing the number of children who demonstrated positive changes on the GMFM and PEDI-MFSS with the Parent Questionnaire responses. In addition, the most frequently issued adaptive equipment was calculated for each GMFCS level.

- Spearman's correlation coefficients were calculated for the change in scores between Test 1 and Test 4 and the percentage perceived improvement recorded on the Parent Questionnaire after the intervention period.

# CHAPTER 4
# RESULTS

## 4.1 INTRODUCTION

This chapter presents the results of the study, which are quantitative. The descriptive data includes the initial sample selection and interviews, demographic information about the children and their caregivers and finally information pertaining to their environment and living conditions. The individual results of the GMFM, the PEDI-MFSS are then presented separately and finally, the results are summarised.

Of the 51 children and primary caregivers who arrived for the study only 45 were eligible to be enrolled into the study, given all of the inclusion and exclusion criteria. None of the caregivers who were invited to join the study refused to be interviewed. While all eligible children and caregivers were invited to take part in the study and were enrolled into the study, a large dropout was expected given the longitudinal nature of the study as well as the social and environmental factors pertaining to a the rural site in which the study took place.

Therefore, the loss to follow up of 11 caregivers and children due to relocation, illness and transport/communication issues was not unexpected, with five participants not attending the 2$^{nd}$ assessment and six participants not attending the final assessment. Therefore, the final sample used for analysis purposes in this study was *n*= 34.

## 4.2 DEMOGRAPHIC AND CONTEXTUAL DATA

### 4.2.1 Demographic Characteristics of Children

#### 4.2.1.1 Age and Gender Characteristics

The youngest of the sample group of children was nine months and the eldest was 14 years. The mean age of the children was 4.75 years, the median was 3.75 years and the standard deviation (SD) was 3.4. More than two thirds of the

children were male (73.5%) and more than half of the children were under the age of five years (Table 4.1).

**Table 4.1: Age Groups for Children in the study sample (n = 34) with Cerebral Palsy**

| Age | (n) | Percentage |
|---|---|---|
| **0 - 4 yr** | 21 | 61.8 |
| **5 - 9 yr** | 10 | 29.4 |
| **10 - 14 yr** | 3 | 8.8 |
| | **34** | **100** |

#### 4.2.1.2 Clinical sub-types and Gross Motor Function Classification System (GMFCS)

Just less than half of the children (*n* = 16 (47%)) had spastic cerebral palsy and more than a third (*n* = 13 (38%)) had dyskinetic cerebral palsy (Table 4.2).

**Table 4.2: Clinical sub-types and Gross Motor Function Classification System Levels (n=34)**

| | | | GMFCS Levels | | | | |
|---|---|---|---|---|---|---|---|
| | ***n*** | **Percentage** | **Level V** | **Level IV** | **Level III** | **Level II** | **Level I** |
| **Spastic** | 16 | 47% | 7 | 4 | 4 | - | 1 |
| **Dyskinetic** | 13 | 38% | 7 | 3 | 3 | - | - |
| **Hypotonic** | 2 | 6% | 1 | 1 | - | - | - |
| **Ataxic** | 1 | 3% | - | - | - | 1 | - |
| **Mixed** | 2 | 6% | - | 2 | - | - | - |
| **Total** | **34** | **100%** | **15** | **10** | **7** | **1** | **1** |

Most of the children in the study sample (73.4%) were Level V (15 (44%)) or Level IV (10 (29.4%)) on the GMFCS (Table 4.2), which suggests that they had very limited independent motor function.

Fifteen of the children (44%) were on anti-convulsant therapy and an additional three children (8,8%) had previously taken medication for seizure activity.

### 4.2.2 Demographic Characteristics of Caregivers

Thirty four (n=34) caregivers were interviewed for demographic information at two hospitals and a health centre (clinic) in the Mnquma Local Service Area. Of the 34 primary caregivers interviewed, twenty-one (61.7%) were mothers; eleven (32.4%) were grandmothers and two (5.9%) were a relative.

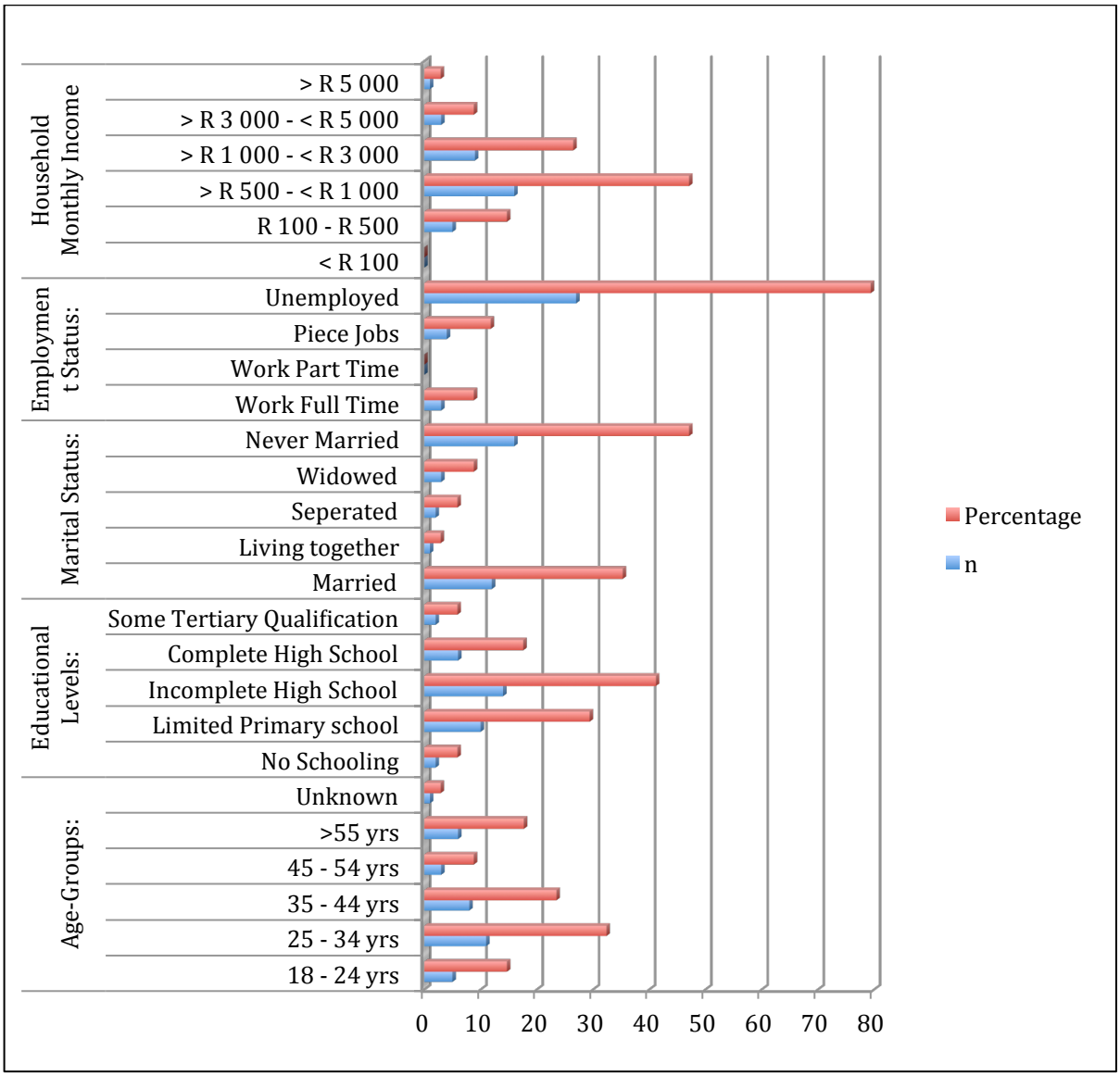



**Figure 4.1: Caregiver Demographics (n = 34)**

The mean age of the caregivers was 38 years. The youngest of the caregivers was 20 years and the oldest was 67 years. The majority of caregivers (24 (70.6%)) were under the age of 45 years. Almost all of the caregivers (32 (94.1%)) had received some level of education, but only eight (23.5%) had completed high

school or higher. The majority of caregivers had either an incomplete high-school education (14 (41.2%)) or a limited primary school education (10 (29.4%)).

More than half of the caregivers were never married (16 (47.1%)), separated (2 (5.9%)) or widowed (3 (8.8%)), whilst the remainder were either living with their partner or married (13 (38.2%)). More than three quarters of the caregivers were unemployed (27 (79.4%)). Only three (8.8%) were employed full time and the remaining four (11.8%) reported that they obtain "piece" jobs, which refers to intermittent, part-time, temporary employment (Figure 4.1)

### 4.2.3 External Factors Affecting Caregivers

#### 4.2.3.1 Grants

The caregivers of twenty-one (61.8%) of the children were receiving a Care Dependency Grant, whilst a further eight (23.5%) were receiving another form of state subsidy (child care or foster care). The caregivers of four children (11.8%) had applied and were still waiting for the grant. Only one (2.9%) child was not eligible for a grant, for unknown reasons.

#### 4.2.3.2 Travelling time and costs to health care and rehabilitation

More than half (19 (55.9%)) of the caregivers spent between 1 to 2 hours and 20.6% (n=7) spent between 30 and 60 minutes travelling to the hospital (Table 4.3).

**Table 4.3: Time and Cost for Travel to Hospital (n=34)**

| | | *n* | Percentage |
|---|---|---|---|
| **Travel Time:** | > 2hr | 3 | 8.8 |
| | 1 - 2 hr | 19 | 55.9 |
| | 30 - 60 min | 7 | 20.6 |
| | < 30 min | 5 | 14.7 |
| **Travel Cost:** | < R10 | 6 | 17.6 |
| | R 10 - R 25 | 15 | 44.2 |
| | R26 - R50 | 10 | 29.4 |
| | R51 - R100 | 3 | 8.8 |

Most (33 (97.1%)) of the caregivers and children travelled by taxi and spent between R10 and R25 on return travel-fare.

#### 4.2.3.3. Characteristics of the Home Environment

The majority of the study sample live in homes constructed from mud (25 (73%)), with corrugated iron roofs (27 (79%)) and soil or mud floors (23 (67%)). In many homes, there are either no ablution facilities (13 (38%)), whilst more than half (19 (56%)) used an outside "pit latrine". Only two (5.9%) of the sample had running water into their homes, whilst the remainder had to fetch water from 50m – 200m away (9 (26.5%)) and in almost a third (11 (32.8%)) of the cases they collected water from further than 200m away. A large portion of the sample use paraffin for lighting (14 (41.2%)) and many people still used paraffin and wood for cooking (12 (35.3%)).

## 4.3 GROSS MOTOR FUNCTION MEASURE

Although the GMFM 88 was also completed at all assessment periods the scores were not analysed as they correlated highly with the GMFM-66 scores (Table 4.4). Therefore only the results obtained from the GMFM-66 which is better suited to research were analysed and are presented in the study.

**Table 4.4: Correlation of scores for the GMFM-88 and GMFM-66 (n=34)**

| GMFM-88 and GMFM-66 | r |
|---|---|
| **Test 1** | 0.927 |
| **Test 2** | 0.937 |
| **Test 3** | 0.915 |
| **Test 4** | 0.933 |

Complete GMFM-66 data (i.e. four assessments) were only obtained for 29 (*n*=29) of the 34 participants whose data was analysed for the study. A loss of a further five participants from the GMFM assessments was due to difficult test taking behaviours, the assessment conditions and in one case seizure activity.

Only slight changes occurred in the scores of the GMFM-66 between the first and second assessment with no significant change setting a baseline for change during traditional monthly therapy received by the participants (Figures 4.2).

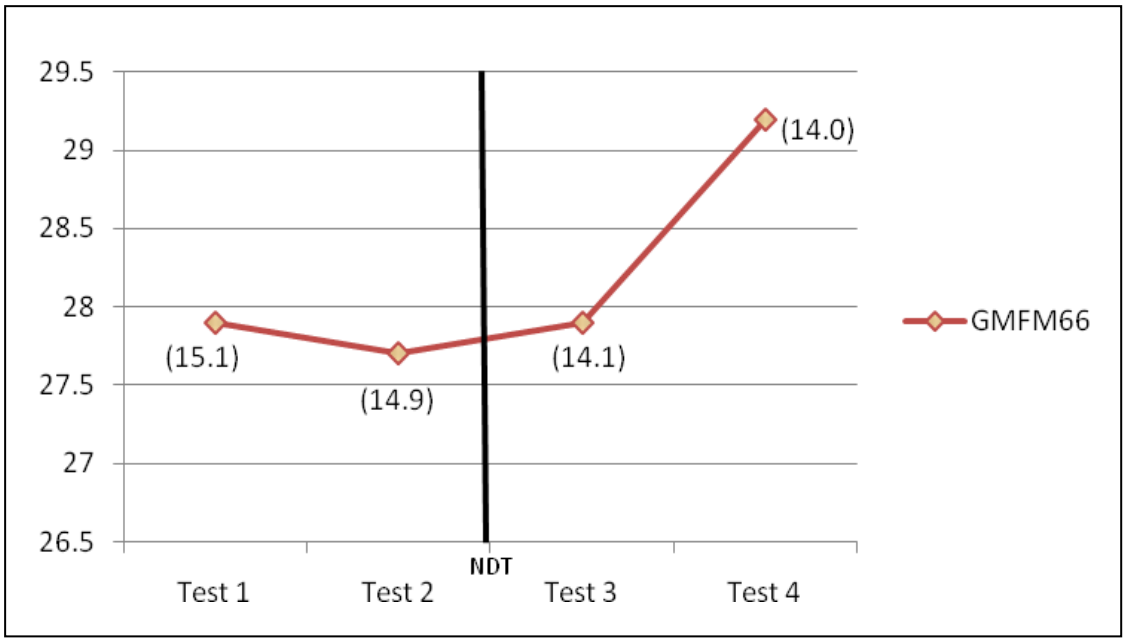



**Figure 4.2: Gross Motor Function Measure - 66 : Group Mean Values and Standard Deviation (SD) (n=29)**

There was no significant improvement (Test 3-1: z= -.91/p= .927 and Test 3-2: z= -.96/p= .923) in the GMFM-66, immediately following the five-day course of NDT treatment (Figures 4.2). Statistically significant improvements (p= .016) were seen in the mean total scores of the GMFM-66 at the eight-week follow-up assessment, when Test 2 and Test 4 where compared (Table 4.5)

**Table 4.5: Gross Motor Function Measure - Wilcoxon's Signed Rank Tests (n=29)**

| | **Wilcoxon's Signed Rank Tests** | | | | | |
|---|---|---|---|---|---|---|
| | *Test 2-1* | | *Test 3-1* | | *Test 4-1* | |
| | *Baseline* | | *NDT Intervention* | | *8 week follow-up* | |
| | *z* | Asymp. Sig. (2-tailed) | *z* | Asymp. Sig. (2-tailed) | *z* | Asymp. Sig. (2-tailed) |
| GMFM-66 | -1.338[b] | .181 | -.091[b] | .927 | -1.206[a] | .228 |
| | | | *Test 3-2* | | *Test 4-2* | |
| | | | *NDT Intervention* | | *8 week follow-up* | |
| | | | *z* | Asymp. Sig. (2-tailed) | *z* | Asymp. Sig. (2-tailed) |
| GMFM-66 | | | -.096[a] | .923 | -1.958[a] | .050[x] |
| | | | | | *Test 4-3* | |
| | | | | | *8 week follow-up* | |
| | | | | | | Asymp. Sig. (2-tailed) |
| GMFM-66 | | | | | | .016[x] |

[a] Based on negative ranks.

[b] Based on positive ranks.

[x] Scores reaching statistically significant levels.

## 4.4 PEDIATRIC EVALUATION OF DISABILITY INVENTORY - (PEDI)-MODIFIED FUNCTIONAL SKILLS SCALES)

Thirty-four (*n*=34) participants completed all four of the PEDI-MFSS assessments and all participants demonstrated positive change in all three PEDI-MFSS domains. There was no significant difference in PEDI-MFSS scores between the baseline and pre-intervention assessments (Test 1 and Test 2) (self-care, p= .761; mobility, p= .687; social, p = .402 (Figure 4.3 and Table 4.6)).

Significant improvement occurred in the mean scores of all three functional skills domains immediately after the five-day course of NDT based intervention (Test 3-1 : self-care, *p* = .000; mobility, *p* = .000; social, *p* = .013 and Test 3-2 : self-care, *p* = .001; mobility, *p* = .002; social, *p* = .001 (Figure 4.3 and Table 4.6)).

Significant improvement was again seen at the eight-week follow-up assessment in all three domains when compared to the baseline assessments (Test 4-1 : self-care, *p* =.000; mobility, *p* = .000; social, *p* = .000 and Test 4-2 : self-care, *p* =.000; mobility, *p* = .001; social, *p* = .000 (Figure 4.3 and Table 4.6)).

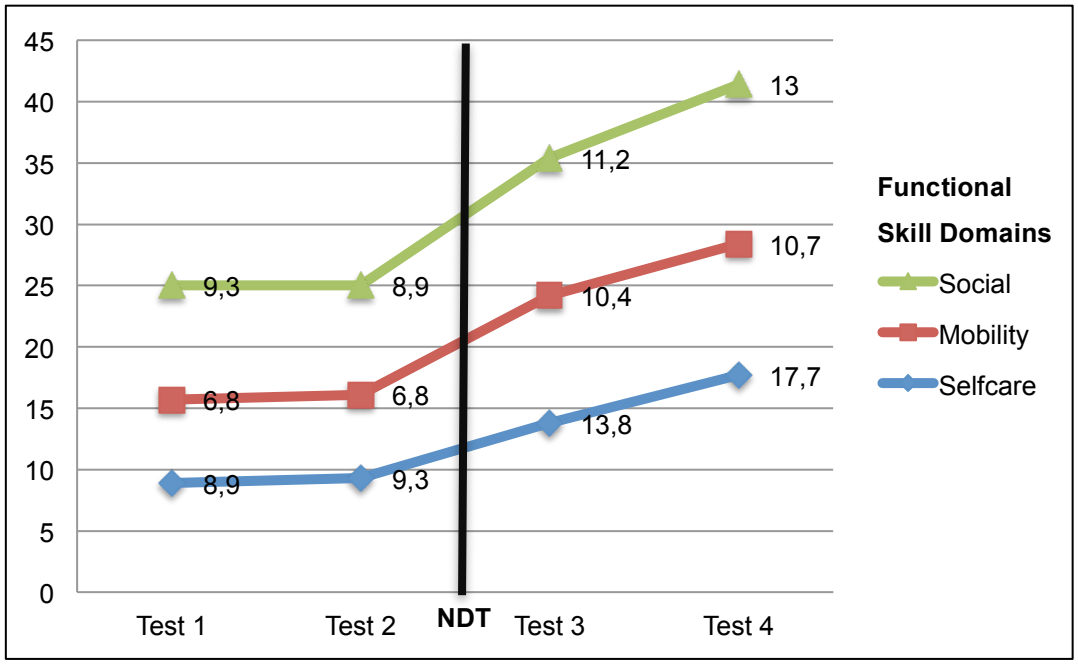



**Figure 4.3: Pediatric Evaluation of Disability Inventory –Modified Functional Skills Scale: Group Mean Values (n=34)**

No significant improvement in the mean scores of the mobility domain was seen at eight weeks follow up (Test 4), when compared to the post intervention assessment (Test 3) ($p$ = .612, Figure 4.3 & Table 4.5). The mean scores of the self-care and social domains showed significant improvement at eight weeks follow-up (Test 4) when compared to the post intervention assessment (Test 3) (self-care, $p$ = .000; social, $p$ = .002, Table 4.6).

**Table 4.6: Pediatric Evaluation of Disability Inventory – Modified Functional Skills Scales: Wilcoxon's Signed Rank Tests (n=34)**

| *Functional Skill Domains* | **Wilcoxon's Signed Rank Tests** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | *Test 2-1 Baseline* | | | *Test 3-1 NDT Intervention* | | | *Test 4-1 8 week follow-up* | | |
| | *Z* | Asymp. Sig. (2-tailed) | *Effect Size d* | *z* | Asymp. Sig. (2-tailed) | *Effect Size d* | *z* | Asymp. Sig. (2-tailed) | Effe Size |
| Self-care | -.304[a] | .761 | .04 | -4.504[a] | .000 [x] | .43 | -5.090[a] | .000 [x] | .78 |
| Mobility | -.404[a] | .687 | -.01 | -3.599[a] | .000 [x] | .38 | -3.953[a] | .000 [x] | .39 |
| Social | -.837[b] | .402 | -.03 | -2.489[a] | .013 [x] | .18 | -3.852[a] | .000 [x] | .35 |

| | *Test 3-2 NDT Intervention* | | | *Test 4-2 8 week follow-up* | | |
|---|---|---|---|---|---|---|
| | *z* | Asymp. Sig. (2-tailed) | *Effect Size d* | *z* | Asymp. Sig. (2-tailed) | *Effe Size* |
| Self-care | -3.404[a] | .001[x] | .39 | -4.901[a] | .000 [x] | .73 |
| Mobility | -3.035[a] | .002[x] | .38 | -3.240[a] | .001[x] | .40 |
| Social | -3.377[a] | .001[x] | .23 | -4.301[a] | .000 [x] | .40 |

| | *Test 4-3 8 week follow-up* | | |
|---|---|---|---|
| | *z* | Asymp. Sig. (2-tailed) | *Effe Size* |
| Self-care | -3.741[a] | .000 [x] | .31 |
| Mobility | -.507[a] | .612 | .02 |
| Social | -3.051[a] | .002 [x] | .17 |

[a] Based on negative ranks.

[b] Based on positive ranks.

[x] Scores reaching statistically significant levels.

The effect size ratios indicate that caregivers reported the greatest change in the self-care domain (.78) (Table 4.6) which is equivalent to a large change on the PEDI-MFSS with medium similar gains in mobility and social domains according to Cohen's d. The effect size indicates that change continued to occur after post intervention assessment (Test 3) to the eight weeks follow-up (Test 4) in the

domains of self-care with medium effect and social with a small effect. Mobility showed no effect size in this period. Thus there was ongoing change in the occupational performance post intervention.

**Table 4.7: Mean Change from Test 1 to Test 4 on the GMFM-66 and the mobility scores for the Pediatric Evaluation of Disability Inventory – Modified Functional Skills Scales (n-29)**

| | | Correlation r |
|---|---|---|
| **Mean change in GMFM-66 scores** | 1.19 | 0.233 |
| **Mean change in mobility PEDI-MFSS scores** | 3.41 | |

When the association of the change in the scores for from Test 1 to Test 4 on the GMFM-66 and the mobility PEDI-MFSS for the participants was analysed, there was a low correlation. Changes assessed on the GMFM-66 were not always reflected on changes in mobility on the PEDI-MFSS (Table 4.7).

## 4.5 PARENT QUESTIONNAIRES

Thirty-four (*n*=34) caregivers completed the questionnaires at all four asessments. Changes reported immediately post intervention (Test 3) and at eight weeks follow-up (Test 4) were recorded and analysed. All of the caregivers reported positive changes in at least one occupational performance area occurring immediately after and again at eight weeks after the five-day course of NDT based therapy.

The most frequently reported changes occurred in dressing (17 (50%)), overall mobility (17 (50%)) and lying/rolling (17 (50%)). Almost half of the caregivers reported positive changes in children's ability to eat (16 (47%)) and drink (15 (44.1%)). More than a third reported positive changes in bathing (13 (38.2%)), grooming (12 (35.3%)) and sitting (12 (35.3%)). To a lesser degree caregivers also reported changes in other areas of motor function (standing (26.5%), crawling/kneeling (23.5%) and walking (8.8%)), self-care (toileting (20%)) and

social function (expressive communication (23.5%), play interactions (14.7%), practical play (8.8%) and receptive communication (5.9%))(Figure 4.4).

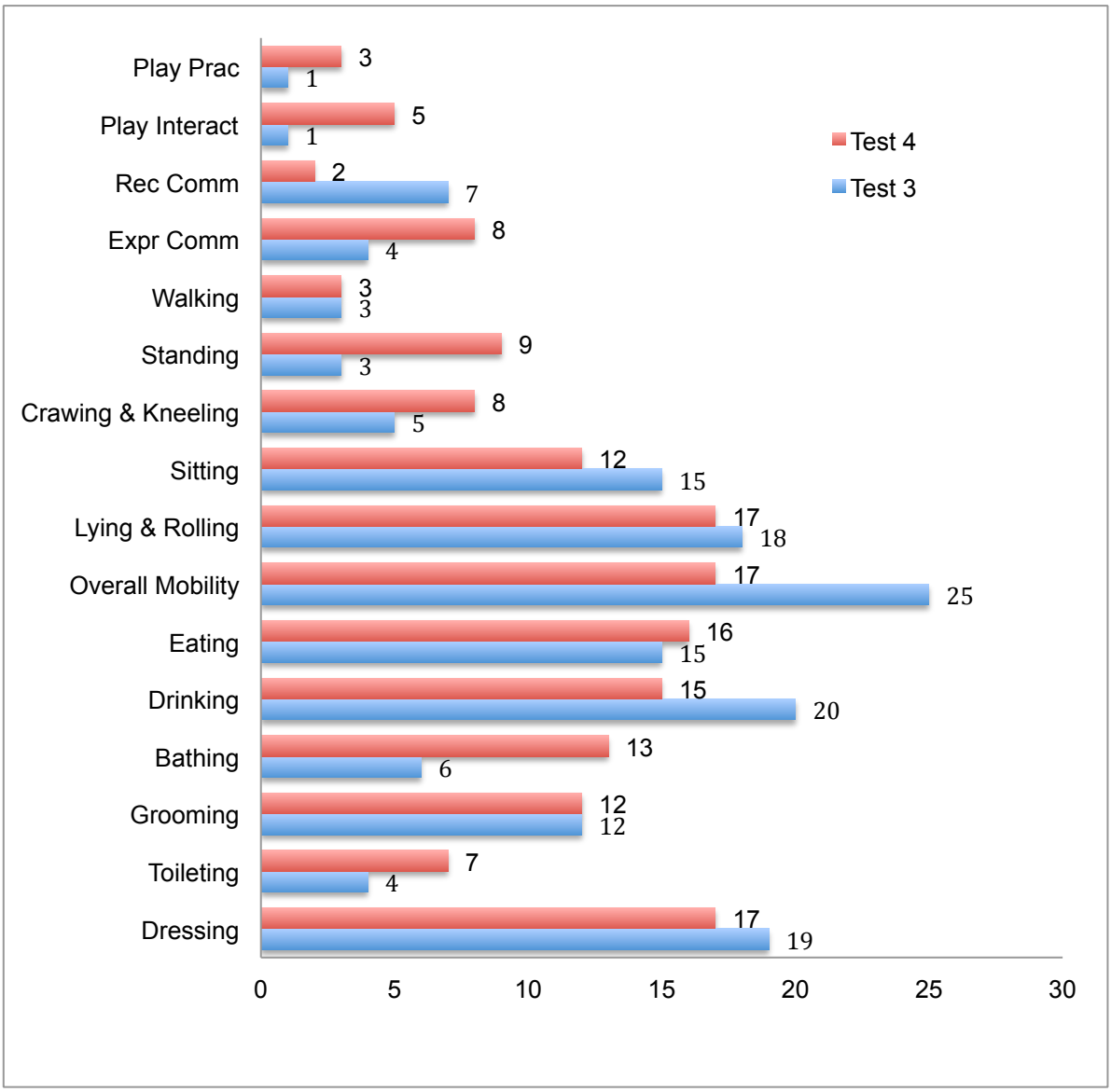



**Figure 4.4: Number of Parents reporting improvements on Parent Questionnaire (n=34)**

## 4.6 SUMMARY OF GROSS MOTOR FUNCTION MEASURE AND PEDI-MODIFIED FUNCTIONAL SKILLS SCALES RESULTS COMPARED TO CAREGIVERS PERCEIVED AREAS OF IMPROVEMENT TABLE (*n*=34)

The Summary of GMFM-66 and PEDI-MFSS results along with caregivers perceived areas of improvement table (Appendix S) reflects the overall change in GMFM-66 and PEDI-MFSS compared to the perceived areas of improvement and comments on the Parent Questionnaire on follow-up (Test 3 and Test 4)) by frequency of response and assistive devices prescribed (Appendix S and Appendix T).

**Table 4.8: Summary of Appendix S (n=34)**

| ***Level*** | ***Summary of Comparative Results*** |
|---|---|
| GMFCS-Level V (*n*=15): | There was a high degree of overlap between the most frequently reported changes by caregivers and the results of the self-care domain of the PEDI-MFSS (86%) and the GMFM-66 (57%). Caregivers' perceived changes were: -<br>• dressing (60%)<br>• overall mobility (60%) |
| | There was also a high degree of overlap between the caregivers' perceived changes and the mobility domain of the PEDI-MFSS (26.6%). Caregivers' perceived changes were: -<br>• lying, rolling (26.6%)<br>• standing (26.6%) |
| | The results of the social domain of the PEDI-MFSS (73.3%) suggest a higher degree of socio-emotional improvement than was reported by the caregivers' perceived changes, which were: -<br>• play interactions (20%)<br>• expressive communication (20%). |
| | The most frequently issued items of equipment: -<br>• a standing box (73%)<br>• Madiba buggies (53.3%)<br>• benches (53.3%) and<br>• wedges (46.6%). |
| GMFCS-Level IV (*n*=10): | There was a high degree of overlap between the caregivers' perceived changes and the self-care domain of the PEDI-MFSS (90%). Caregivers' perceived changes were: -<br>• dressing (80%)<br>• grooming (70%)<br>• eating (70%) |
| | The results of the social domain of the PEDI-MFSS (70%) suggest a higher degree of socio-emotional improvement than was reported by the caregivers' perceived changes, which were: -<br>• play interactions (10%)<br>• expressive communication (10%). |
| | There was also a high degree of overlap between the caregivers' perceived changes and the results of the mobility domain of the PEDI-MFSS (50%) and the GMFM-66 (60%). Caregivers' perceived changes were: -<br>• lying, rolling (60%)<br>• sitting (50%) |
| | The most frequently used items of equipment in this group were: -<br>• a standing box (100%)<br>• benches (60%) |

| *Level* | *Summary of Comparative Results* |
|---|---|
| GMFCS-Level III (*n*=7): | There was a high degree of overlap between the caregivers' perceived changes and the self-care domain of the PEDI-MFSS (100%). Caregivers' perceived changes were:-<br>• dressing (71.4%)<br>• drinking (57.1%)<br>• eating (57.1%) |
| | In this group, the results of the social domain of the PEDI-MFSS (85.7%) suggest a higher degree of socio-emotional improvement than was reported by the caregivers' perceived changes, which were:-<br>• play interactions (28.5%)<br>• expressive communication (42.8%). |
| | Although there was an overlap between the caregivers' perceived changes and the results of the mobility domain of the PEDI-MFSS (85.7%) and the GMFM-66 (75%), the standardised test results suggest a higher degree of change than that perceived by the caregivers. The caregivers' perceived changes occurred in lying and rolling (57.1%) |
| | The most frequently issued items of equipment were<br>• blocks (57%)<br>• AFO's (42.8%)<br>• trolley/rollator's (42.8%)<br>• standing boxes (42.8%) |
| GMFCS-Level II (*n*=1) and GMFCS-Level I (*n*=1): | Of this group, only one had complete GMFM data, which demonstrated improved motor function. These results were also reported by the parents |
| | The Parent Questionnaire responses reflected improved motor function and self-care skills, but no improvement in social function. |
| | Both children reflected improvements in all three domains on the PEDI–MFSS. |

On the Parent Questionnaire, almost all of the participants were perceived by the caregivers to have made positive changes at the 3rd (Test 3) as well as the 4th (Test 4) assessment (Figure 4.4). When the group was divided into the five different GMFCS levels, the following was observed (Table 4.8).

There was a high negative correlation (r = -0.841) between the perceived positive change in the participants on the Parent Questionnaire and a negative moderate correlation (r = - 0.649) to change measured on the PEDI-MFSS, and the number of assistive devices prescribed. The participants at level V received more assistive devices as they required more assistance and compensation than those at level III. Even with the prescription of assistive devices, the negative association with improvement seen after the intervention period, indicates that participants at level III, showed greater improvement even though they received fewer assistive devices.

**Table 4.9: Average change from Test 1 to Test 4 according to GMFCS levels on the GMFM-66 (n=29) and the Pediatric Evaluation of Disability Inventory: Modified Functional Skills Scale correlated with the perceived change on the Parent Questionnaire (n=34)**

| GMFCS | V | IV | III | Correlation r |
|---|---|---|---|---|
| **Mean change in GMFM-66 scores** | 1.81 | 0.56 | 2.16 | 0.322 |
| **Perceived overall change on Parent Questionnaire** | 61.96 | 73.33 | 90.46 | |
| **Mean change in self-care PEDI: MFSS** | 7.53 | 7.6 | 12.14 | 0.243 |
| **% perceived change in self-care on Parent Questionnaire** | 37.73 | 51.66 | 47.56 | |
| **Mean change in Mobility PEDI: MFSS** | 2.26 | 4.1 | 5.85 | 0.619 |
| **% perceived change in mobility on Parent Questionnaire** | 13.28 | 57.5 | 40.41 | |
| **Mean change in Social PEDI: MFSS** | 4 | 1.2 | 5 | 0.782 |
| **% Perceived change in social on Parent Questionnaire** | 13.3 | 10 | 35.65 | |

Participants at Level III on the GMFCS showed the greatest positive change between Test 1 and Test 4 for all aspects of the GMFM-66 and the PEDI-MFSS with participants at Level V showing greater improvement on the GMFM and for social aspects on the PEDI-MFSS than those on Level IV (Table 4.9).

The correlation between the caregiver's perceived changes and the results of the PEDI-MFSS and the results of the GMFM-66, post-intervention were analysed for GMFCS Levels III to V as there were sufficient participants in these groups. There was a low correlation between perceived positive change overall by the caregivers on the Parent Questionnaire and the GMFM-66.

Positive changes in self-care, mobility and social as measured by the Parent Questionnaire and the PEDI-MFSS show a low to high correlation and Level of

association, indicating caregivers perception of change in these aspects were similar for mobility and social but not for self-care.

## 4.7 SUMMARY

Information from the descriptive data has been used to form a profile of the children and caregivers, who comprised the study sample of 45. The study experienced a dropout of 22% (11 children) and a sample of 34 children formed the sample for analysis.

The participants in the study were young as the average age was under five years (4.75 years) and more than 90% were under the age of 9 years. Most of the participants were functioning in GMFCS Levels IV and V (73%), suggesting that they demonstrated very limited independent motor function. Most of the participants presented with spastic CP (47%) but a large proportion also presented with dyskinetic CP (38%).

Although the average age of the caregivers was 38 years, most of the caregivers (70%) were under the age of 45 years. The majority of caregivers had either not completed their high school education (41%) or had very limited primary school levels of education (29%). The majority of caregivers were unemployed (79%) and of the remaining caregivers only 9% were in full-time employment, the remaining 12% had “piece” jobs. The majority (85%) were reliant on some form of state subsidy to supplement the household income.

A baseline of no significant change during usual monthly therapy received by the participants was set in the first two test scores of the GMFM-66 and the PEDI–MFSS (mobility, social and self-care scores).

No significant improvements were observed in the mean total scores of the GMFM-66 immediately post intervention, but statistically significant improvements were seen in the mean total scores of the GMFM-66 at the eight-week follow-up assessment, when comparing Test 2 and Test 4. Significant improvements were

also observed in the mobility scale of the PEDI–MFSS immediately post intervention and at the eight-week follow-up assessment.

There was little association between the GMFM-66 results and the overall perceived improvement observed by caregivers and reported on the Parent Questionnaire. The GMFM-66 results suggest a lower degree of change than that perceived by the caregivers especially in overall mobility in the GMFCS Level IV. The results of the GMFM-66 support positive change after a five-day "block" of intensive NDT, therefore the treatment is effective in improving gross motor function of children with CP, living in a rural area of South Africa and the null hypothesis for this aspect is rejected.

Significant improvements were also seen in the mean total scores of the social, mobility and self-care scales of the PEDI–MFSS immediately post intervention and at the eight-week follow-up assessment. The effect size indicates that change continued to occur after the post intervention assessment (Test 3) to the eight weeks follow-up (Test 4) in the domains of self-care with medium effect and social and mobility with a small effect. According to the Parent Questionnaire, the changes most frequently described by caregivers were in dressing, overall mobility, lying and rolling, eating and drinking. The PEDI-MFSS results were highly correlated with the caregivers' perceived changes in the area of social participation, but had a low to moderate correlation in the areas of self-care and mobility respectively.

Participants at level III showed the greatest positive change with those at Level IV benefitting more in the self-care and mobility areas of occupational performance than the participants at Level V.

The results of the PEDI-MFSS support positive change after a five-day "block" of intensive NDT and indicate that NDT is effective in improving the occupational performance of children with CP, living in a rural area of South Africa in self-care, mobility and social participation and the null hypothesis for this aspect is rejected.

# CHAPTER 5
# DISCUSSION

This chapter describes the key findings of the study and offers discussion and review with relevant findings from other published studies. Limitations of the present study are discussed, along with a summary of the clinical and research implications of the findings.

## 5.1 DEMOGRAPHICS AND CONTEXT

The demographics of the 34 participants included in the study indicated that the majority were below four years of age, male and had spastic CP. The participants presented with severe motor deficits with 73.5% falling into Level V and IV on the GMFCS levels. All participants were scheduled to attend therapy on a monthly basis and received the medication they needed.

Although 51 participants were recruited for the study initially 5 participants were excluded, as they did not meet the inclusion criteria. Thereafter, a further 11 participants were lost for comparative analysis, due to relocation, illness and transport/communication issues. Although this loss of 22% is higher than the accepted 10% and may have resulted in bias in terms of the results, the final sample size of 34 was acceptable at a power of 80% and therefore the results are considered valid at this level.

The high loss to follow up was not unexpected in this longitudinal study and was accommodated for by recruiting enough participants to provide the sample needed.

Of the 11 participants lost for comparative analysis, five participants did not attend the second assessment and therefore did not establish a baseline for comparison. Of these five participants, three were GMFCS Level V and the other two were Level III and IV. All five received treatment and attended the post treatment assessments. The other six participants were treated but did not attend the final assessment to establish the long-term effects of intervention. Of these six, four

were classified, as GMFCS Level V and the other two were Level III. Considering that 63.6% of the total dropouts were classified as GMFCS Level V it is possible that the socio-economic, medical and body function and structure deficits as well as the wellbeing of a child with this level of disability, may have an impact on access to services and rehabilitation outcomes in rural disadvantaged areas of South Africa.

These aspects may also be impacted on by the demographic factors and external environment that present challenges to the caregivers in this study as they are from disadvantaged backgrounds and have few resources. The caregivers in this study face financial burden, and the high nearly 80% unemployment rate amongst them is higher than the reported rate of 68% for the Mnquma municipal district. Home environment factors such as homes constructed of mud (73%), with corrugated iron roofs (79%) and soil or mud floors (67%), no ablution facilities (38%) or the use of outside "pit latrine" (56%) and limited availability of fresh running water add to the burden of caring for a disabled child and indicate the extensive lack of resources in the area. The level of poverty is reflected in the type of dwelling in which they live and their access to services is poor due to the situation in this rural area of the Eastern Cape where water, electricity and sanitation, as well as to health services are limited.

Other factors that may have affected attendance at therapy and loss to follow up of participants other than the monthly household income of less than R1000 (47.1%), are the lengthy travel times of up to two hours (55.9%) along with travel costs of up to R25 (44.2%) for participants to reach rehabilitation services. Thus these families experience major problems accessing services because they have to travel far distances in order to reach appropriate centres[158] and are further disadvantaged by the lack of finances and the time needed to travel.[158] This results in added difficulties for the caregiver of a disabled child especially when as Portfield & McBride (2007)[75] found the family lives far from the hospital services and the children they care for are dependent on them for activities of daily living.[75]

Caring fell in the majority of cases to the mothers of the participants and although more caregivers in this study had achieved matric than the reported rate of 16.5% for this area, their poor education levels may also affect their ability to attain knowledge and information on how to provide the children in their care with the correct assistance. The results of this study highlighted that many of the participants live with single caregivers (61.8%) who have to deal with very difficult everyday living conditions as well as deal with the multifaceted challenges of caring for a child with CP.

As literature suggests these caregivers of children with CP face unique stressors,[69] more challenges,[70] additional emotional problems,[42] and considerable personal, familial and societal burden.[55] The burden of care is exacerbated in the face of poverty when there are inadequate financial resources to meet daily living needs, poor housing, nutritional problems, neighbourhoods that fail to offer a safe environment for play and poor social support structures.[73,74] According to the ICF and OTPFII, the child's ability to participate in activities can also be affected by the context or environment.[6]

From the discussion above the problem presented as to the role of these factors in the dropout of participants for comparative study as well as the access to services and rehabilitation outcomes for children with CP in rural disadvantaged areas of South Africa may be of particular interest for future studies since Rosenbaum and Stewart (2004)[66] emphasised that contextual factors may influence and modify the many of the components of dysfunction in CP.[47,53] With socio-economic and health care resources of the participants in this study being so limited, the objectives of this study were to assess the improvement in performance skills of gross motor function and the occupational performance in activities of daily living in self-care, mobility as well as the social function of children with cerebral palsy (GMFCS levels I to V), following an intensive five-day course of NDT therapy compared to the current rehabilitation available to them.

## 5.2 CURRENT REHABILITATION

In South Africa, although the prevalence of CP may be as high as 10 per 1000[44] services for children with CP living in rural areas are extremely limited and there is little evidence on which to base practice and to achieve best outcomes.

The researcher was unable to obtain documentation describing current services in the public sector for children with CP, but experience and observation suggests that although services vary throughout the country the trend where services are available in rural areas, is that children with CP receive monthly rehabilitation from the available staff. Information pertaining to the effectiveness of current intervention practices in rural areas was not available, as no South African studies have been conducted. It is known that only about 30% of children with disabilities in South Africa are being reached by the current public sector services.[44]

The participants in this study had access to monthly rehabilitation sessions generally offered by a physiotherapy assistant who was intermittently assisted by community service physio, speech and occupational therapists.

In order to establish the change over a eight week period when attending current treatment a baseline of change was measured using assessments at Test 1 and Test 2 (pre-intervention), whilst the participants continued to receive their regular therapy. The motor performance skills and occupational performance areas were measured using the PEDI-MFSS, the GMFM-66 and the perceptions of their caregivers were obtained through a Parent Questionnaire.

Although there were slight changes in the scores of the GMFM-66 between the first and second assessment (in a negative direction), this was not statistically significant (Figures 4.2 & 4.3). On the PEDI-MFSS no significant change was seen in the mobility, self-care and social scores between assessment one and two (Figure 4.4 & Table 4.6) with an effect size of between 0.01 and 0.04. Therefore, the first two assessments over eight weeks set a baseline of no significant change during monthly outpatient programme received by the participants when measured with the GMFM-66 and the PEDI-MFSS. Caregivers did not report any change

during this period on the Parent Questionnaire either. Although these results might support Mayo's findings (1991)[130] that a regime of weekly NDT (intensive) was substantially better than a once a monthly regime, they may also reflect some of the many contextual factors that affect access to rehabilitation and the quality of services offered in a rural area in South Africa.

Given the quality of limited services, the shortage of staff with experience in NDT and the monthly treatment sessions offered to these participants at the site for this study, at the most they only received two treatment sessions in this baseline period, the lack of change was not unexpected.

## 5.3 INTENSIVE THERAPY AND FOLLOW UP

Intensive therapy for children with cerebral palsy has been described in different ways in other studies[21,28,29] and can vary from five sessions a week over four to six months or more than one session daily over these months. There is no agreement as to what is the best routine and given the distances travelled to reach the research sites, the context the participants and their caregivers come from and the limited availability of volunteer, trained NDT therapists to implement the treatment, one week of intervention was considered a realistic, sustainable strategy for this situation.

Therefore the intensive therapy programme for this study resulted in, the participants receiving five-days of daily treatment (90 minutes), during which each participant received individual NDT treatment. This was a realistic time for therapists volunteering to treat the participants and accommodation could be arranged for caregivers and participants for this period at the hospitals. Caregivers were prepared to be away from home if necessary for this amount of time. The five days also allowed for the participant to be issued with and fitted for appropriate adaptive equipment.

During this time caregivers were present throughout the therapy sessions during which they were trained to handle their children more effectively and they had time to practice and understand what was required of them. They were also trained in

the use and maintenance of the adaptive equipment or furniture and they were provided with home programmes.

The post intervention change was measured immediately after the five-day intervention period (Test 3) and then again eight weeks later (Test 4) to establish if initial change was maintained and if the continued intervention by caregivers over this period had an effect. Positive change was seen in the participants' gross motor functioning at Test 3 with further change occurring at Test 4 supporting research which has shown that intensive blocks of therapy may be effective in improving gross motor function, but this cannot be directly compared to monthly rehabilitation sessions as the skill level of the therapists providing the interventions are different.[29]

### 5.3.1 Gross Motor Functioning

The first objective of this study was to investigate the effects of a five-day "block" of intensive NDT on the motor performance skills related to gross motor function of participants with CP, living in a poor rural area.

Of the 34 participants in the study five participants were excluded from the comparative study sample of the GMFM for various reasons, including behavioural issues, assessment conditions and medical factors. In this study, the participants who were unable to complete all the sets of GMFM-88 and GMFM-66 data were excluded from the comparative analysis, thus data from the GMFM was completed on 29 participants. Four participants who were not completely tested because of behavioural issues were classified at higher Levels on the GMFCS at Level III and I. It seems possible that the structure of the GMFM and the assessment conditions may have influenced their test taking abilities and since they functioned on a higher level it was difficult to get them to perform the lower level skills that needed to be scored. The fifth child excluded from the GMFM comparative analysis was classified as GMFCS Level V, experienced seizure activity during the fourth assessment.

Since both the GMFM-88 and GMFM-66 were used in all the assessments in the study, the large number of test items made the test long and difficult to complete for many of the participants and when dealing with participants with behaviour difficulties and low intellectual capacity the requirement that every item must be observed to receive a score can be problematic. According to Russell et al (1989),[115] whilst it may save time in terms of administering and scoring the test to omit some items, there is evidence that the reliability and validity of the dimension scores are not as high as when the measure is used as a whole.

A high correlation between the GMFM-88 and GMFM-66 scores was found in this study (Table 4.4). Even though the majority of participants in this study were more severely involved at Level V and IV on the GMFCS, and the GMFM-66 is potentially less sensitive to change for these participants, these findings indicate that in future for research purposes it would be possible to use only the GMFM-66 with this population, to obtain valid results when measuring change in gross motor function. Since participants were under the age of four years the sensitivity of the GMFM-66 to change in children over five years was not a consideration.[60]

The GMFM results suggest that after one week of intensive NDT based therapy there was a small non-significant positive change on the functional motor skills of the participants (Test 3) when compared to Test 1 at baseline. Although motor function changes were reported by the caregivers during the five-days of therapy, these gains were not reflected in the GMFM-66 results immediately after the intervention (Table 4.5). At the eight week follow-up assessment (Test 4) there was a significant improvement when scores on the GMFM-66 were compared with the initial baseline assessment (Test 1). This supports the findings of Knox and Evans (2002)[21] and Tsorlakis et. al., (2004)[28] that intensive NDT results in significant improvement in gross motor function.[28]

During this study, motor skills may not have been mastered within the initial treatment period of five days, but as the children and caregivers were appropriately prepared for function then skills would be mastered over time through practice and participation at home. The follow up change on gross motor

function after eight weeks reflects the need to practice the emerging skills in a functional setting, especially in GMFCS Level IV and V children. In a similar study in Norway, where the intensive therapy was offered three times a week for three weeks, there was a significant improvement immediately after intensive training on the GMFM-66 and further improvement after another three weeks.[169] When compared to the present study with five days of intensive NDT, the same time to practice skills was not available to caregivers and participants, and the effect of practice resulting in significant change was only seen after eight weeks. The participants in the Norwegian study were mostly GMFCS Level I and II children making it difficult to compare to the children at level IV and V in this study in terms of actual gains in gross motor function scores.

Although the groups of participants in each GMFCS Level was small the average improvement in the GMFM-66 scores from Test 1 to Test 4, for participants at Levels III-V were analysed. Since there was only one participant at Level II and none at Level I with GMFM-66 scores these levels could not be considered. The greatest gain in the average GMFM-66 score was made by participants at GMFCS Level III (Table 4.9) followed by those at GMFCS Level V. The small numbers in the groups and various demographic and diagnostic differences in the Levels may have affected the small average change seen for participants at Level IV. Scores of some participants at Levels IV and V remained static on the GMFM-66 (*n*=3) and some regressed (*n*=5)). It should be noted that even a lack of change in motor function might have clinical significance for children with CP.[170] Often there is a levelling off, or even regression in motor development, especially in children with severe spasticity (GMFCS IV & V) and older children (over four years), where movement patterns have become fixed and little or no more improvement can be expected.[170]

The gains in motor function changes reported by the caregivers on the Parent Questionnaire after the five-days of therapy were not reflected in the GMFM-66 results after the intervention, particularly for participants at GMFCS Level IV where little change was seen in the GMFM-66 scores. This results in a low correlation between the caregiver's perception of change and the scores on the GMFM-66.

Thus while these results confirm that although significant changes in motor function can be expected following intensive NDT treatment they need to be interpreted with caution as the internal validity may be affected by the small sample size resulting in a Type I error.

It is clear that other factors influenced the effectiveness of intensive NDT in improving gross motor functioning including the period of intensive treatment, the context which affects how and when intensive treatment can be made available as well as the GMFCS Level of the participants.

Historically the focus of NDT therapy was quality of movement and management and effectiveness was assessed by measuring gross motor functioning, but the focus has more recently shifted towards greater participation in activities of daily life.[13,138] In line with occupational therapy practice children are now encouraged to practise daily living activities at home and with their caregivers, who are trained during treatment to assist the child, use assistive devices and adaptive equipment and implement home treatment programmes.[13,138]

### 5.3.2 Occupational performance

The second objective of this study was therefore to investigate the effects of a five-day "block" of intensive NDT on the occupational performance areas of self-care, and social participation of children with CP, living in a poor rural area.

Similar findings to those reported above on the GMFM-66 indicate that the intensive block of therapy had an effect on the participant's occupational performance. The results of the PEDI-MFSS indicate however that the participants made significant positive changes in their self-care, mobility and social participation immediately following five-days of NDT based therapy (as measured by PEDI-MFSS) (Test 3) with effect size between 0.39 to 0.23) There was continued significant change in self-care and social participation at the eight weeks follow-up (Test 4) with effect size of between 0.31 to 0.17 indicating that this group has between 21%-14% - improvement over the 21 weeks.

These results support those of Knox and Evans (2002)[21] who showed NDT significantly improved both gross motor functioning and occupational performance skills, in children with CP.[21] They found significant improvement in self-care skills and mobility skills, as measured by the PEDI, following a six-week course of NDT therapy. Similarly to this study, the children acted as their own controls and it was a repeated measures study, but the therapy they received was for a significantly longer period (6-weeks) on fewer participants (n=15). Comparable results were obtained on the PEDI (and PEDI-MFSS), which supports the hypothesis that intensive NDT based therapy is effective in improving the occupational performance of children with CP and that the influence of NDT may extend beyond motor function.

The significant improvement in occupational performance areas of self-care, mobility and social participation in this study also confirmed the use of current NDT based therapy principles in incorporating more normal motor activity for use in daily activities with all treatments, which were directed towards working on activities of daily life.[138] This was facilitated by an individual goal setting approach for each child.[138,140] The aims of treatment were to achieve active participation in specific, relevant, functional skills.[13,136,138]

The need for providing a longer period to practice was not as important in achieving results for occupational performance and the significant effect on caregiver training regarding the ways to assist the child to achieve their best performance and carry-over of skills into the home was seen sooner than changes in gross motor function.[13,136] This may have been influenced by the added assistive devices, adaptive equipment and caregiver training in their use, as an integral part of the treatment.[138,139] The incorporation of these compensatory methods supports the importance of Bobath (1984)[95] recommendations that treatment “incorporate systematic preparation for specific functions” and that children should be treated in functional situations.[95]

Continued practice over eight weeks resulted in further significant gains in self-care and social participation as measured on the PEDI-MFSS but these results did not always correlate with the improvement reported by caregivers on the Parent Questionnaire (Table 4.9). Although both the PEDI-MFSS and the Parent Questionnaire are caregiver report measures caregivers reported greater improve particularly for participants at GMFCS Level IV than was measured on the PEDI-MFSS for self-care and mobility. This is similar to the findings of the GMFM-66 and Parent Questionnaire comparison.

The results of this study therefore support both the importance of incorporating an emphasis on occupational performance in NDT therapy as well as the need to measure functional outcomes when establishing the effectiveness of an intensive NDT programme.

According to the PEDI-MFSS scores, the participants in this study demonstrated significantly improved self-care skills immediately following the five-day course of NDT and again eight weeks post intervention. The greatest improvement was seen in this occupational performance with an effect size of 0.78 from Test 1 to Test 4 and the highest mean change on the PEDI-MFSS. The effect size was large with the mean score at Test 4 being a 0.78 standard deviation above that at Test 1. Thus significant improvement in self-care including dressing, grooming, eating, drinking, bathing and toileting was found after a period of intensive NDT therapy and this change was sustained and continued to show significant improvement after an eight week period.

Changes in the scores on the PEDI-MFSS were the highest for participants at GMFCS Level III who achieved the greatest gains in this area. Caregivers perceived change in self-care indicated more than half (57.1%) having improved drinking and eating skills. These participants had the greatest motor ability and required the least number of assistive devices, and therefore improvements seen were as a result of active participation of the participants themselves in becoming more independent in completing their own self-care activities.

While the PEDI-MFSS results identified a small difference between the improvement in self-care for participants at GMFCS Levels IV and V, 51.66% of caregivers of participants at Level IV perceived improvement and 37.75% of Level V perceived improvement. The change in self-care for these participants was related more to the ease with which the caregivers could carry out the activities for the child.

The participants in this study also made significant gains in the mobility dimension as measured by the PEDI-MFSS immediately following the NDT treatment, and although they maintained these gains for the eight-week follow-up there was no further significant gains. The effect size from Test 1 to Test 4 was 0.39, which is a medium effect.

These results for mobility on the PEDI-MFSS differ from those found for the GMFM-66 where the significance difference was not reflected immediately but at eight weeks after intervention. Greater improvement for participants at GMFCS Level IV than was measured on the PEDI- compared to the other levels. As with the GMFM, the participants at GMFCS Level III scored the greatest improvement on the mobility section of the PEDI-MFSS. Participants at Level IV however showed greater improvement than those at Level V, which differs from the results of the GMFM-66. Again greater improvement was reported by caregivers for participants at GMFCS Level IV than those at level III resulting in a moderate correlation between the mean scores on the PEDI–MFSS mobility and the Parent Questionnaire (Table 4.9).

The results of the mobility domain of the PEDI-MFSS suggest that whilst new functional skills where achieved immediately post intervention, the children in this study were able to maintain and improve their abilities over time.

Of the three occupational performance areas the participants in the study made their smallest gains in social participation measured on the PEDI–MFSS (social domain) with an overall effect size of 0.35 or a 27% improvement. This is

congruent with the study by Knox and Evans (2002)[21] where they found no significant change in this occupational performance area.

The results of the social domain of the PEDI–MFSS suggest positive change in socio–emotional improvement that was then reported by the caregivers on the Parent Questionnaire as play interactions and expressive communication. There was a high correlation between the mean change on the PEDI-MFSS and the changes perceived by parents for social participation (Table 4.9).

Again the greatest change was seen in participants at GMFCS Level III with the smallest improvement occurring in participants at Level IV. Caregivers reported a similar level of change with a high correlation between the PEDI-MFSS social participation scores and the Parent Questionnaire.

### 5.3.3 Caregiver Involvement and Assistive Equipment

The inclusion of caregivers was an integral part of the intervention phase of this study. Caregivers were included in the goal setting, the therapy sessions, and were trained in handling their children and use of adaptive equipment. They were encouraged to actively participate in the treatment; they were given opportunity to practice the skills needed that assist their children. Previous studies by Knox and Evans (2002)[21] and Odman, et al (2009)[134] concluded that the involvement of parents[146, 147] may have a positive effect on the outcome of intervention.

This is also true for another aspect of NDT that is integral to the intervention, the provision of appropriate adaptive equipment encouraging mobility to prevent or slow down the development of secondary deformities.[98,101,144,145] The greatest number of assistive devices in this study were provided to participants at Level V and most of these assisted with mobility, positioning and attaining sitting and standing postures. This was not unexpected as these are participants that are most likely to develop secondary deformities. The number of assistive devices provided also correlated negatively with improvement found after the intervention. In the GMFCS V and IV groups 96.7% of the children received supported standing equipment and 95% received supported sitting equipment.

The significant change at eight-weeks follow up (Test 4), as measured by the GMFM-66, and the PEDI-MFSS self-care and social provides evidence that the caregiver involvement, home programmes and adaptive equipment used in this study played a role in the continuing to improved motor skills and occupational performance areas of children with CP once they were at home with a trained caregiver. A limitation of this study however was that the use of the equipment and the caregiver involvement were not directly measured or observed, therefore the extent to which these played a role in the intervention is unknown.

## 5.4 EFFECTS OF INTENSIVE NEURODEVELOPMENT THERAPY

The findings of this study indicate that the intensive five-day treatment period was effective in improving the gross motor function and the occupational performance of the participants. While other studies including Tsorlakis et. al., (2004)[28] have shown significant improvement in gross motor function after intensive NDT, this has only been linked to improvement in mobility measured on the PEDI in one other study by Knox and Evens (2002)[21]. While it is clear that these two factors may be linked as both fall under performance skills in the OTPF II, the assessments used to evaluate change in these factors differ. Therefore although the GMFM-66 and the PEDI-MFSS (mobility dimension) both assess movement, they rely on different sources of information and focus on different aspects of function.[109] The GMFM-66 was developed specifically for children with CP, therefore the test items included were specifically relevant to the disordered movement common to CP.[60] The GMFM-66 measures the specific performance skills related to motor functions needed for everyday life and the PEDI-MFSS mobility domain assesses functional mobility or movement from one position or place to another during performance of everyday activities. Furthermore, the source of information for the GMFM-66 is provided by qualified therapists, whereas the PEDI–MFSS relies on parent observation and reporting of the child's mobility in various positions and indoors and outdoors.

When comparing the two measures, both Nordmark et. al.,[110] and Han et. al.,[111] concluded that the GMFM-66 and the PEDI mobility domain are complementary

assessments that could be used interchangeably. This study could not be directly compared to these studies as the PEDI was modified. The results of this study suggest that although the PEDI-MFSS results and the GMFM-66 results demonstrated significant gains a low correlation between the results of the two measures (Table 4.7) indicated that they probably measure different components of function.

Furthermore, although the caregivers were able to identify the emerging functional gross motor skills as reported on the Parent Questionnaire, they did not perceive improved quality of the skilled movement patterns. They were able to report more accurately on changes in the mobility of the participants than changes in their gross motor function, but the change for participants at GMFCS Level IV was overestimated for both gross motor function and mobility when compared to the GMFM-66 scores and the PEDI-MFSS (Table 4.9).

Significant increase in the occupational performance areas of self-care and social participation as found in this study can be seen as congruent with the intensive NDT based therapy, as aspects of these occupational performances areas are also dependent on the performance skills of movement. The large effect size in self-care may have been due firstly to the significant change in the participants' ability to position themselves and to move allowing assistance with dressing like straightening of the arms or the lifting of a mug.

Secondly as pointed out by Knox and Evans (2002)[21] when specific self-care goals are part of NDT based treatment they are likely to be focussed on and achieved. When using an NDT based therapy, all treatment should be directed towards working on activities of daily life[138] in functional positions and for those participants who could not achieve this assistive devices were provided allowing them to achieve both sitting and standing which are important functional positions for occupational performance, particularly self-care. It is also possible these participants in their current therapy programme had not had access to occupational therapy. The limited number of therapists in the site of this study

means they may not have had any input in relation to self-care and assistive devices before their involvement in this study.

Although social participation did increase significantly at both assessments post intervention the effect size was small. This occupational performance area was not part of the directed targeted goals in the intervention programme. The changes that were recorded and reported were all in relation to improved mobility and movement like the ability to interact with toys by reaching for them or the turning of the head to look at the mother when she called his name. Perhaps because this aspect was not emphasised as part of the intensive NDT based programme and therefore caregivers did not expect or report as many changes as those for self-care were goals they assisted in setting for the intervention and were the expected outcomes of the intervention.

The results of this study provide evidence that the model of providing therapy combined with the use of an NDT based approach may be effective in the management of CP in poor rural areas of South Africa. Furthermore, caregivers of children with CP need to be recognised as an integral part of the management team, with the ability to integrate and implement strategies for sustained management of their children.

While it is possible that five-days may have been too short a period to significantly affect the motor functions as measured by the GMFM-66, and there may have been insufficient opportunity to practice within functional tasks, the improved GMFM-66 scores at eight weeks follow-up along with the PEDI-MFSS significantly improved scores post intervention (Test 3 – Test 4), suggest that after the children had opportunity to practice their skills at home their motor function improved. Motor learning can be maximized if functionally relevant tasks are practised under wide ranging conditions, preferably within the home environment for skill transference.[171] The results of this study support those of Knox and Evans (2002)[21] in that the children with CP can improve significantly in the occupational areas of mobility and self-care as measured by the PEDI-MFSS after intensive NDT.

## 5.5 LIMITATIONS OF THE STUDY

### 5.5.1 Measurement tools

Due to the ordinal nature of the GMFM-66 and GMFM-88 the large number of items in the test, it is likely to be less responsive for children functioning at the extremes of the scale, i.e. those children with very low GMFM scores or those with very high GMFM scores.[60] These “floor” and “ceiling” effects may affect the overall sensitivity of the test to detect change, as for example in the case of Child 2 (GMFSC - V) who remained static on both GMFM scales. This child’s scores were very low and possibly reflect a “floor” effect, whilst in the case of Child 11 (GMFCS - II), whose scores very high this may reflect a “ceiling” effect. Both these children were perceived to have made motor function changes by their caregivers and Child 11 improved in the mobility dimension on the PEDI-MFSS. The movement changes that were made however were reported to be within the movement from one place to another, which would not be measured by the GMFM.

Two aspects of both the GMFM assessments that affect the sensitivity of the test were the large number of items to be administered and the necessity that every item be observed in order to receive a score.[60] Therefore, if an examiner cannot get a child to perform a particular item for any reason (developmentally the child has progressed passed those items or the child was cognitively or otherwise challenged), the child has to receive a score of zero, which artificially reduces their score. A number of children in this study demonstrated problems with this aspect of testing, for example children 3, 5, 6, 13, 17, 19 and 22. In some cases (child 5 and 19) use of the GMFM-66 was helpful in alleviating the problem, but in others particularly where cognitive impairment was the primary problem, use of the GMFM-66 did not assist with observation of all of the items. It was a limitation of the study that the examiners were very restricted in terms of time and were unable to allow for avoidant or troublesome behaviours, therefore a number of these children were excluded from the GMFM analysis due to incomplete data.

Additional factors related to the GMFM-66 and pertaining to this study were the test's reduced sensitivity for change in more severe children (GMFCS V & IV)[118] and the older child (over 4 years). In this study most (73%) of the children were either Level V (44%) or Level IV (29.4%) children, in which the changes made may have been related more to quality of movement. As for example in the case of Child 13 where her caregiver reported that "she used to spill, but is now much better with feeding" and "her arm was very tight, she is now able to grasp for objects." Furthermore, 38% of the children in this study were over 4 years old when it has been found that the skills measured by the GMFM-66 start to "flatten" and eventually "plateau" by 7 years. At this age, successful performance of gross motor function should be within the context of daily living tasks and outcome measures that reflect this are likely to more successfully reflect change in intervention,[170] as reflected in this study by the results of the PEDI-MFSS.

Although the PEDI-MFSS had been translated into Xhosa for the purposes of the study, it was evident that the African languages do not have words that describe some of the subtle behaviours asked for in the questionnaire. The lack of validity and reliability studies on the PEDI-MFSS could also have affected the results of this study and research to test these aspects on South African populations is recommended.

### 5.5.2 Assessment procedure

The assessors who administered the GMFM assessments were also initially inexperienced, with limited skills in administering this test. This presented as a challenge for test-retest reliability. Furthermore, the assessors who administered the GMFM were not from and same cultural, ethnic or language background as the participants and this presented as a challenge in understanding the subtleties of motivating the children and understanding stress responses.

The interviewer used for the PEDI-MFSS was a local interpreter with limited experience in interviewing, disability or research. Although his command of English and Xhosa was required to administer the questionnaire, his lack of experience presented as a challenge to the data collection phase because the

accuracy and reliability of the data largely depended on his interviewing skills and ability to extract information from caregivers. Despite the challenges though, he shared similar cultural and ethnic backgrounds with the caregivers, compared to the researcher who was from a different cultural and ethnic group.

The reliability and validity of the PEDI-MFSS was not established in this study and would limit and interpretation of these results.

### 5.5.3 Intervention Procedures

For the purposes of this study, the intensive five-day NDT based therapy was individualised and varied according to the needs of each child with CP. Taking into account the heterogenous nature of the CP population, it was not possible to administer a standardised, quantifiable set of interventions that can be administered in discrete units.

The use of equipment and the caregiver involvement were not directly measured or observed as they form part of the holistic NDT based therapy. The extent to which these played a role in the overall results of the intervention is unknown. It is possible that the training of caregivers or the provision of assistive device alone may have a similar effect.

## 5.6 SUMMARY

The overall results support the efficacy of intensive five-day NDT based therapy for improving the functional motor skills and occupational performance of children with CP in under resourced areas of South Africa. Of the 34 children whose scores were analysed, only one remained static at the final follow-up (child 37) on the PEDI-MFSS and the GMFM-66 measures (Appendix S). The measures used in this study, while complimentary show low correlation for most mean change found and therefore at present it would appear that they cannot be used interchangeably with this population. Further research into the validity and reliability of the PEDI-MFSS and the Parent Questionnaire with caregivers in rural areas of South Africa is suggested.

The results of this study also support evidence that caregivers should form an integral part of the management team and that the provision of caregiver training, practice and adaptive equipment should form part of the strategies for improved intervention outcomes. Results from this study add to the body of literature that indicates that the treatment of CP involves management in which clients should be encouraged to practice activities at home and with their caregivers. Therefore, the premise that home programmes, assistive devices, adaptive equipment and caregiver training should form an integral part of the treatment,[138,139] was supported in this study.

The PEDI-MFSS results, the GMFM-66 results and the Parent Questionnaire results support the hypothesis that a five-day "block" of intensive NDT based therapy is effective in improving gross motor function of children with CP, living in a rural area of South Africa. Therefore, the null hypothesis is rejected and a five-day "block" of intensive NDT does have an effect on the gross motor function and the occupational performance of children with CP, living in a rural area of South Africa. Furthermore, the results indicate that there may be an ongoing effect in the occupational performance of the children post intervention.

# CHAPTER 6
# CONCLUSION

This chapter concludes the main findings of this study, summarises the clinical implications and recommendations and the recommendations for further study.

## 6.1 INTRODUCTION

The main aim of this study was to investigate the effects of an intensive five day "block" of NDT based therapy on the motor skills and occupational performance of children with CP in a poor rural area. Thirty-four participants with CP (GMFCS levels I to V) were assessed twice prior to intervention to obtain a baseline of change; they received a five-day "block" of NDT based therapy and were then assessed immediately post intervention and eight weeks later. During the five-day "block" of NDT therapy based on specific motor and occupational performance goals set by the principle researchers and in conjunction with the caregivers. The caregivers also received individual training, practice in handling and home programmes, whilst the participants received hands-on NDT based therapy and were issued with appropriate adaptive equipment and assistive devices. The motor skills and occupational performance areas were measured using the PEDI–modified, the GMFM-66 whilst the perceptions of the parents/caregivers were obtained through a Parent Questionnaire.

The period of five-days of NDT based therapy offered in this study was dictated by the context in which the study took place. This period was shorter than that offered in other studies, but accommodated various factors including: the availability of suitably trained and experienced therapists who had to be transported to the rural site used; the availability to suitable venues; and distance and transport costs for the participants and their caregivers as most were offered accommodation at the hospital for the treatment period.

## 6.2 MAIN FINDINGS

A range of benefits of a relatively short, intensive “block” of five-days of NDT therapy, as practised in South Africa has been demonstrated in this study. Within this sample of children with CP, the majority of whom were less than four years old, presenting with spastic quadriplegia and function at GMFCS Levels III-V, significant improvements were observed in the occupational performance areas of self-care, social function and mobility as measured by the PEDI—MFSS immediately after the intervention with continued significant improvement in self-care and social participation eight weeks later. Although significant changes were observed in the motor skills of the participants at eight weeks these were not as clearly measured by the GMFM-66 for reasons both inherent to the test itself as well as limitations of the study. This study provided evidence for a model of hands-on NDT based intervention, with caregiver involvement, practice, home programmes and adaptive equipment that is effective in improving the gross motor functioning and occupational performance of children with CP in a rural area of South Africa.

This study highlighted the efficacy of a five-day “block” of intensive NDT therapy in improving the functional motor skills and mobility of children with CP living in a rural area who had had little access to regular therapy. The immediate effect of intervention was confirmed by the results of the PEDI–MFSS mobility domain whilst the sustained effect was confirmed by both the GMFM-66 and the PEDI-MFSS results. The GMFM-66 results provide support for previous research that the GMFM-66 may be less sensitive to the motor skills changes and the PEDI maybe more sensitive to slight changes in motor function in children classified as GMFCS levels IV and V. A comparison of the immediate (Test 3) and follow-up (Test 4) GMFM-66 results indicate the need for motor learning to occur for the acquisition of functional motor skills to be meaningful and significant. The five-day intensive NDT based therapy alone in this study allowed insufficient repetition for children with more severe impairment to show significant improvement immediately after the treatment. This study added support for the assumption that the PEDI-MFSS and the GMFM-66 are complementary assessments but that they

measure different aspects of mobility and therefore cannot be used interchangeably.

This study also highlighted the positive effect of a five-day “block” of NDT based therapy on the self-care skills and social participation of children with CP living in rural areas of South Africa. The immediate and sustained effect of NDT based therapy was confirmed by the results of the PEDI–MFSS, social skills domain and self-care domain, particularly for self-care skills that were targeted as goals in therapy along with aspects that were improved as a result of better mobility and gross motor function. The greatest improvement was found for self-care and this was related to the provision of adapted equipment that provided better stability and position for the severely affected participants as well as occupational therapy input that was not previously available to all participants.

Social participation while showing significant improvement had a low effect size with changes seen being related to the participant’s mobility, which resulted in better play and communication.

During this study the caregivers were included in the goal setting, the therapy sessions and were trained in handling their children and the use of adaptive equipment. The caregivers were also given opportunity to practice their skills and provided with photographs of the individualised home programme for their children. The intervention also included the provision of adaptive equipment for the children. Both the immediate and the follow-up results of the PEDI-MFSS and the GMFM-66 provide evidence that caregiver involvement and adaptive equipment are important aspects of successful NDT treatment.

The Parent Questionnaire is complementary to the scores on the GMFM-66 and The PEDI-MFSS but caregivers were inclined to overestimate the change in motor function, self-care and mobility, particularly with participants at GMFCS level IV. This assessment should be used in conjunction with the other assessments but not interchangeably.

## 6.3 CLINICAL RECOMMENDATIONS

Considering the evidence for improved motor skills and occupational performance when children with CP are provided with a short block of intensive NDT based therapy, service provision should make use of a NDT approach and short intermittent intensive periods of therapy in rural settings. The short blocks of NDT therapy can accommodate the factors in the context, which preclude the possibility of other adequate treatment models. This should form an essential part of the intervention for children with CP.

Of particular importance to occupational therapists working with children with CP are the principles basic to the NDT approach. These include:

- facilitation of postural alignment;
- active participation in appropriate functional daily activities;
- caregiver involvement and training;
- the provision of home programmes; and
- the provision of appropriate adaptive equipment.

## 6.4 RECOMMENDATIONS FOR FURTHER STUDY

A number of factors limited the power of these results, including, the analysis on groups by GMFCS Levels as this was done on small groups that may have affected both the internal and external validity of the study. The lack of a control group studied, the large age range and the variety of diagnoses and GMFCS Levels amongst the participants resulted in a heterogeneous sample that could also have affected the external validity and generalisability of the results.

Additional research on a homogeneous group of children over a longer period to ascertain whether the changes observed in this study are sustainable over time if this type of intervention is implemented in under re-sourced areas should be considered. The effects of the context in which these families' live as well as family centred intervention and caregiver training for the management of children with CP in poorer rural areas should also be considered as should the effects of adaptive equipment and furniture with and without a NDT based intervention.

## 6.5 CONCLUDING REMARKS

This was an evaluative study, which has successfully demonstrated the positive effects of an intensive five-day block of NDT intervention on the gross motor function and occupational performance of children with CP, living in poor rural areas of South Africa. In addition, the study highlighted the importance of a holistic approach within the NDT programme, given the importance of goal setting, caregiver involvement and the provision of adaptive equipment. Further study is now required in order to establish the relative importance of the different aspects integral to the NDT approach, namely: goal setting; hands on therapeutic facilitation; caregiver training and adaptive equipment and the possibility and logistics of achieving this model within the South African health system.

This study has provided support and added to the body of literature that indicates that intermittent intensive blocks of therapy should form part of what is considered "best practice" when treating children with CP living in rural areas. The importance of home programmes, appropriate adaptive equipment and caregiver involvement were highlighted in the study results. Furthermore, the study has highlighted some of the important areas for future study in the quest for answers pertaining to best practice when treating children with CP in the rural areas of South Africa.

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# APPENDIX A

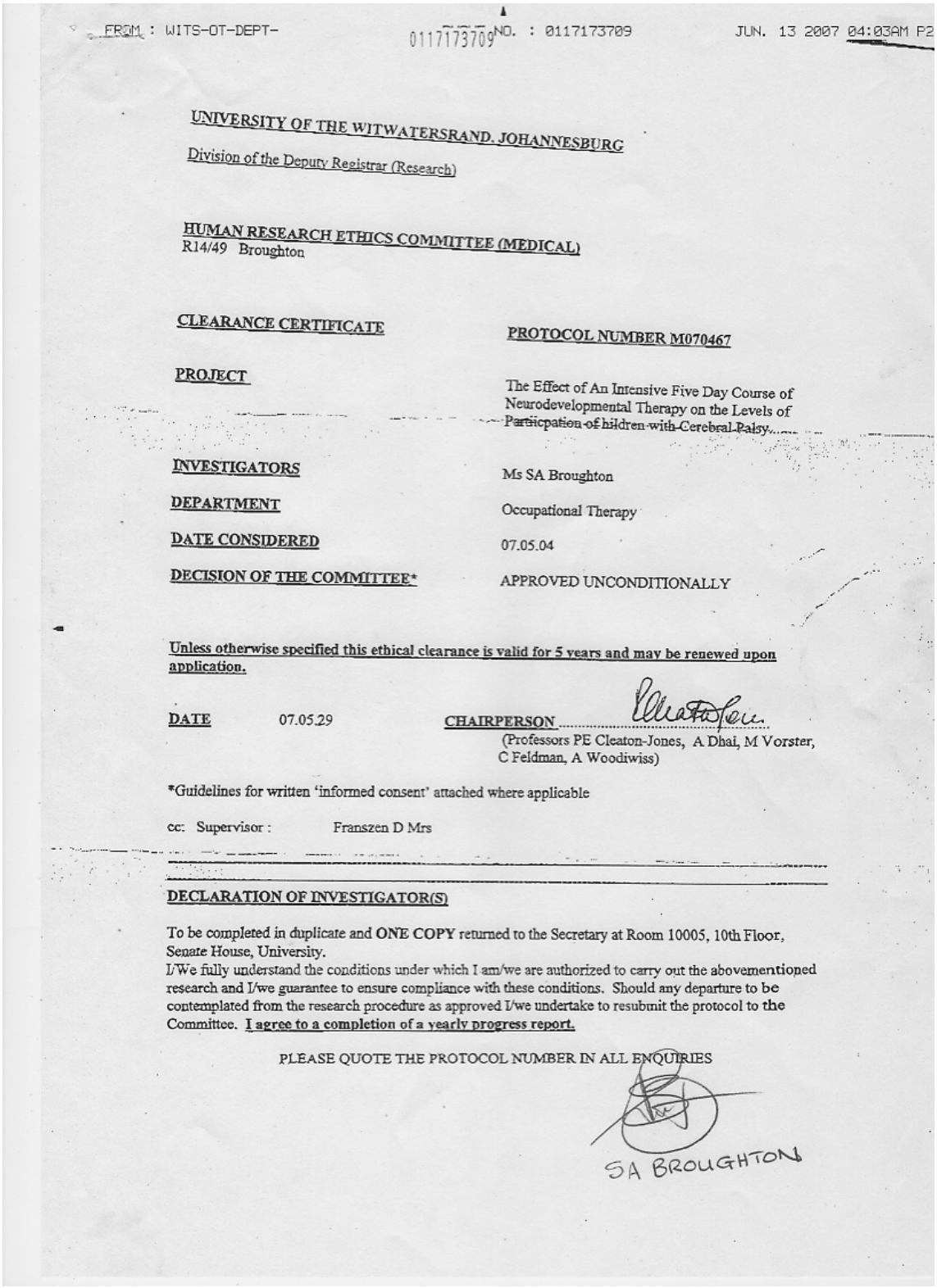
## Gross Motor Functional Classification System

**Overview of Gross Motor Functional Classification System (Palisano et al. 1997)**

| *Level* | *Ability* |
|---|---|
| **Level I** | Walks without assistance |
| **Level II** | Walks without assistive devices, limitations outdoor and in the community. |
| **Level III** | Walks with assistive devices, limitations outdoors and in the community, requiring wheelchair use in these settings. |
| **Level IV** | Self-mobility in wheelchair with limitations, transported all uses power mobility in a community. |
| **Level V** | Very limited self-mobility, even with assistive technology |

# APPENDIX B

## Ethical Clearance Certificate



FROM : WITS-OT-DEPT- 0117173709 NO. : 0117173709 JUN. 13 2007 04:03AM P2

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Broughton

CLEARANCE CERTIFICATE — PROTOCOL NUMBER M070467

PROJECT — The Effect of An Intensive Five Day Course of Neurodevelopmental Therapy on the Levels of Participation of hildren with Cerebral Palsy.....

INVESTIGATORS — Ms SA Broughton

DEPARTMENT — Occupational Therapy

DATE CONSIDERED — 07.05.04

DECISION OF THE COMMITTEE* — APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 07.05.29 CHAIRPERSON .....
(Professors PE Cleaton-Jones, A Dhai, M Vorster, C Feldman, A Woodiwiss)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Franszen D Mrs

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

SA BROUGHTON

## APPENDIX C:

## Permission Letter

Malamulele Onward
Possibilities for Africa's Children with Cerebral Palsy

Section 21 company

registration no. 2006/032287/08

*12 a Rhodes Avenue, Parktown, Johannesburg, 2193. SOUTH AFRICA Tel (011) 726-1555*

2 July 2007

Mr. BL Ntondini
Director: Clinical Health Support Management Directorate
Eastern Cape Department of Health
Dukumbane Building
Bisho

**BY FAX: 040 635 1132 / 040 639 1142**

Dear Mr. Ntondini

**PROPOSAL: REHABILITATION THERAPY FOR CHILDREN WITH CEREBRAL PALSY (CP) IN THE BUTTERWORTH AREA**

I am writing to inform you of the progress of our planned therapy intervention for children with cerebral palsy living in the Butterworth area. Since I met you and Mrs. Joyce Guysman in January this year, there has been much pleasing progress. Funding for the project has been obtained and several volunteer NDT trained therapists have already been recruited to assist with the assessment and intervention.
As I discussed with you in January, research and evaluation forms an important part of any Malamulele Onward intervention project. To this end, two research proposals have been written which cover different aspects of the project. The proposals were submitted to the Ethics Committee of the Faculty of Health Sciences, University of the Witwatersrand and ethical approval has been obtained.

I am attaching the research proposals and the ethical certificate. I am now asking for your assistance in obtaining institutional permission from the Eastern Cape Department of Health in order to do the research aspects of the intervention project.

Please do not hesitate to contact me should you require any further information. I look forward to hearing from you.

**DR. GILLIAN SALOOJEE**
gsaloojee@icon.co.za; 072 483 -5766

## APPENDIX D:

## Caregiver Information Sheet

RESEARCH

THE EFFECT OF AN INTENSIVE FIVE DAY COURSE OF NEURODEVELOPMENTAL THERAPY ON THE LEVELS OF PARTICIPATION OF CHILDREN WITH CEREBRAL PALSY LIVING IN A POOR RURAL AREA: A PILOT STUDY

# CAREGIVER INFORMATION SHEET

**(To be read to the caregiver of the child with cerebral palsy in his or her own language)**

Good morning parent / caregiver

Thank-you for taking the time to read and listen to this information. My name is Shelley Broughton and I am an Occupational Therapist. I am busy doing some research and I would like to invite you to volunteer to take part in this study. Before you agree to take part, it is important for you to understand what the study is about, what it involves and to ask me any questions you may have.

I want to find out whether treating your child for five days in a row will make a difference to your child and whether we will see any improvement in what your child can do. In order to do this, I will need to assess your child first – this will take about 1 hour. Eight weeks after this, I will do the same assessment again - this time the assessment will be a bit quicker. The next day, the therapy will start. A therapist will treat your child for 1 ½ hours every day for five days. I will give you money for transport so that you can bring your child in to the hospital for all these extra sessions.

At the end of these five days, I will assess your child again so that we can see if there has been any progress. I will also ask you some questions to see if you notice any difference in your child. Then eight weeks later, we will ask you the same questions and do the assessment again. This will help us to see if your child continued to improve or not.

In the meantime, you will continue to come to the hospital every month for therapy as you usually do. You must not stop your regular monthly therapy.

The results of this study will help the therapists here at the hospital to see whether this idea of doing daily therapy for five days every few months is a good way of offering therapy to the children and whether this system can work or not.

I have chosen to do this study at Butterworth and Tafolofefe Hospitals, because it is in one of the poorest areas in Amathole Health District, and there are a lot of children who need help. Also for a long time, there were no therapists working at this hospital, only the therapy assistants. We are asking all the mothers of children with cerebral palsy who have been to Butterworth and Tafolofefe Hospitals at least twice, if they would like to take part in this study.

Nothing that we will do will hurt your child and all the information you give us will be kept private. Every child will be given a number, so that your child's name will not be on any of the assessment or questionnaire forms.

If you do not want to be part of this study, you do not have to, and you will still get therapy here at the hospital. If you do decide to join the study, and then you change your mind, you can take your child out of the study at any time without any consequences for you or your child.

If you have any questions, please feel free to ask me.

If you agree for your child to take part in this study, please sign the form.

Thank-you for your help.

*Shelley Broughton*
*Tel number: 082 412 3310*

## APPENDIX E

## Written Caregiver Informed Consent Form

**RESEARCH**

THE EFFECT OF AN INTENSIVE FIVE DAY COURSE OF NEURODEVELOPMENTAL THERAPY ON THE LEVELS OF PARTICIPATION OF CHILDREN WITH CEREBRAL PALSY LIVING IN A POOR RURAL AREA: A PILOT STUDY

**WRITTEN CAREGIVER INFORMED CONSENT FORM**

I, ……..……., confirm that I have been told about the research in a language that I understood. I have also received, read and understood the written information regarding the study.

I am aware that any information I give to the researcher will be kept private and all the results will be anonymously processed.

I understand that at any stage, I may withdraw my child from the study. I understand that if I decide not to take part, or I change my mind, nothing will happen to me and my child. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.

I agree that my child and I will volunteer to take part in this study. I agree that Shelley Broughton can look in the child's file to check the diagnosis and when the child came for therapy.

Parent's / Caregiver's name: _____
(please print)

Parent's / Caregiver's signature: _____

Date: _____

Interviewer's name: _____
(please print)

Interviewer's signature: _____

Date: _____

# APPENDIX F

## Caregiver Information Leaflet - isiXhosa

UPHANDO

UKUHLOLWA KWEFUTHE NOKUKWAZI UKUZIMELA KONYANGO LWEENTSUKU EZINTLANU NGONYAKA ZOKUKHULISWA KOMNQONQO OKUNZULU KUBANTWANA ABANESIFO SOKUNGAKWAZI UKULAWULA IINTSHUKUMO ZABO ABAHLALA KWIILALI EZIHLELELEKILEYO

(*EVALUATING THE IMPACT AND STUSTAINABILITY OF AN ANNUAL FIVE DAY INTENSIVE NEURODEVELOPMENTAL THERAPY FOR CHILDREN WITH CEREBRAL PALSY IN A POOR RURAL AREA*)

# IPHETSHANA LEENKCUKACHA LOMKHATHALELI WOMNTWANA

*Caregiver information leaflet*

(Kufuneka lifundelwe umkhathaleli womntwana ngolwimi lwakhe)

Molo (*igama lomkhathaleli*)

Enkosi ngokuzinika ithuba lokufunda umamele olu lwazi.Igama lam ndinguGillian Saloojee yaye ndingugqirha weengxaki zokungasebenzi komzimba (i*physiotherapist*).Ndixakekile ndenza uphando, yaye ndingathanda ukukumema ukuba uthathe inxaxheba kolu phononongo.Phambi kokuba uvume ukuthatha inxaxheba, kubalulekile ukuba uluqonde ukuba olu phononongo lungantoni na, luquka ntoni na yaye undibuze nayiphi na imibuzo onokuba nayo.

Ndifuna ukuqonda ukuba ngaba ukunika umntwana wakho amayeza – ngale nto ke ndithetha ngokunika umntwana wakho unyango-khathalelo – iintsuku ezintlanu ezilandelelanayo kuya kuba notshintsho na kumntwana wakho kwanokuba siya kubona nakuphi na ukuphucuka kwizinto anakho ukuzenza umntwana wakho.

Ngokuthatha inxaxheba kolu phononongo, ndithetha ukuba ndikucela ukuba uvume ukwenziwa udliwano-ndlebe.Ndiza kukubuza imibuzo ethile malunga nobomi bakho kunye neemvakalelo zakho, ngokunjalo namalunga nonyango alufumeneyo umntwana wakho; kwanokuba ucinga ntoni ngolu nyango, yaye lunokuphuculwa njani.

Le nto siza kuyenza yonke iminyaka kude kuphele iminyaka emithathu. Le nto ithetha ukuba qho ngonyaka kule minyaka mithathu izayo; thina (siliqela loogqirha beentshukumo zomzimba (leetherapisti)) siza kuza kwesi sibhedlele sinike umntwana wakho unyango. Siya kuthi nawe sikuqeqeshe ukuba ungamenzela ntoni na umntwana wakho ekhaya. Ukuba umntwana wakho ufuna naziphi na izixhobo ezinokumnceda ekhaya, siya kukunika ezo zixhobo. Loo nto ayiyi kukufaka kuzo naziphi na iindleko wena nosapho lwakho. Kwakhona, qho ngonyaka siza kukubuza imibuzo efanayo, phambi nasemva kweveki yonyango. Le nto iza kusinceda ukuba sibone ukuba olu nyango nezo zixhobo zinalutshintsho zilwenzayo na emntwaneni wakho.

Iziphumo zolu phononongo ziya kunceda iitheraphisti apha esibhedlele ukuba zibone ukuba olu luvo lokwenza unyango lwantsuku zonke kwiintsuku ezintlanu qho ngeenyanga ezimbalwa

yindlela entle na yokunika unyango kubantwana kwanokuba le ndlela ingasebenza na okanye hayi.

Ndikhethe ukwenza olu phononongo kwisiBhedlele saseGcuwa neTafalofefe, kuba zikwenye yezona ndawo zihlelelekileyo zaseMpuma Koloni, yaye baninzi abantwana abafuna uncedo.Sicela bonke oomama babantwana abanesifo sokungakwazi ukulawula iintshukumo zabo (ic*erebral palsy*) abakhe baya, ubuncinane kabini, kwisiBhedlele saseGcuwa okanye eTafalofefe okanye kwiKlinikhi yaseNgqamakhwe, ukuba bangathanda na ukuthatha inxaxheba kolu phononongo.

Kwizinto esizenzayo akukho nanye eya kumlimaza umntwana wakho, yaye zonke iinkcukacha osinika zona ziya kugcinwa ngokufihlakeleyo.Umntwana ngamnye uya kunikwa inombolo, ukuze wena negama lomntwana wakho ningabikho kuzo naziphi na iifomu zokuhlola okanye zamaphepha-mbuzo.

Ukuba awufuni kuba yinxalenye yolu phononongo, awunyanzelekanga ukuba ungene, yaye umntwana wakho usaza kuqhubeka nokufumana unyango apha kwesi sibhedlele.Ukuba ugqiba ekubeni uzibandakanye nolu phononongo, uze uphinde utshintshe ingqondo, usenokumkhupha umntwana wakho nangaliphi na ixesha kungekho ziphumo zibi uya kujongana nazo wena okanye umntwana wakho.

Ukuba unayo nayiphi na imibuzo, nceda undibuze ngokukhululekileyo.

Ukuba uyavuma ukuthatha inxaxheba kolu phononongo, nceda usayine ifomu.

Enkosi ngoncedo lwakho.

*Gillian Saloojee*
*Umphandi nogqirha weengxaki zokungasebenzi komzimba (Researcher and physiotherapist)*
*Inombolo yomnxeba: 072 483-5766*

# APPENDIX G

## Written Informed Consent – isiXkosa

UPHANDO

UKUHLOLWA KWEFUTHE NOKUKWAZI UKUZIMELA KONYANGO LWEENTSUKU EZINTLANU NGONYAKA ZOKUKHULISWA KOMNQONQO OKUNZULU KUBANTWANA ABANESIFO SOKUNGAKWAZI UKULAWULA IINTSHUKUMO ZABO ABAHLALA KWIILALI EZIHLELELEKILEYO

(*EVALUATING THE IMPACT AND STUSTAINABILITY OF AN ANNUAL FIVE DAY INTENSIVE NEURODEVELOPMENTAL THERAPY FOR CHILDREN WITH CEREBRAL PALSY IN A POOR RURAL AREA*)

IFOMU YEMVUME EBHALIWEYO ESEKELWE ELWAZINI

*Written informed consent*

Mna, ....., ndiqinisekisa ukuba ndixelelwe ngolu phando ngolwimi endiluqondayo.Ndiphinde ndafumana, ndafunda ndaze ndaluqonda ulwazi olubhaliweyo malunga nolu phononongo.

Ndiyaqonda ukuba naziphi na iinkcukacha endizinike umphandi ziya kugcinwa ziyimfihlo yaye zonke iziphumo ziya kusetyenziswa ngendlela enganiki zinkcukacha zomntu.

Ndiyaqonda ukuba nangaliphi na inqanaba, ndingamkhupha umntwana wam kolu phononongo.Ndiyaqonda ukuba xa ndinokugqiba ekubeni ndingathathi nxaxheba, okanye nditshintshe ingqondo, akukho nto iya kwenzeka kum nomntwana wam.Ndilinikiwe ithuba lokubuza imibuzo yaye ndanelisekile ukuba iphendulwe ngokwanelisayo.

Ndyavuma ukuba ndiya kuthatha inxaxheba ngokuzithandela kolu phononongo.Ndiyavuma ukuba uGillian Saloojee angajonga kwifayile yam ukukhangela iziphumo zeemvavanyo (*diagnosis*) naxa umntwana ezele unyango.

Igama loMzali / loMkhathaleli: _____(nceda ungadibanisi)

Ukusayina koMzali / koMkhathaleli: _____ (umhla)

Igama lombuzi-mibuzo: _____ (nceda ungadibanisi)

Ukusayina kombuzi-mibuzo: _____ Umhla _____

# APPENDIX H

## Demographic Questionnaire

STUDY NUMBER: _____ _____

| | QUESTION | RESPONSE |
|---|---|---|
| | | |
| 1 | Date | |
| 2 | Date of birth | |
| 3 | Sex | |
| 4 | Distance from hospital (and how much is the transport) | |
| 5 | Nearest clinic | |
| 6 | Nickname | |
| 7 | Relevant birth and medical history | |
| 8 | Birth weight | |
| 9 | Gestation | |
| 10 | What medication is the child receivng? | |
| 11 | Is the child receiving a CDG? If not, why not? | |
| 12 | CP classification (describe clinical picture) | |
| 13 | GMFCS level | |
| 14 | Caregivers' three main concerns: | |

| | | |
|---|---|---|
| | | |
| 15 | Caregivers' expectations from therapy: | |

## PARENT QUESTIONNAIRE

Child's name: _____ Date: _____

| DOES YOUR CHILD HAVE DIFFICULTIES WITH THE FOLLOWING ACTIVITIES? | Yes | No | Don't know | If the answer is yes, describe the difficulty. | Rate how well your child can do this activity<br>Circle a number 1=able to do it on his own; 2=needs a little help; 3= needs lots of help; 4=can't do it at all |
|---|---|---|---|---|---|
| Un / dressing | | | | | 1 2 3 4 |
| Toiletting | | | | | 1 2 3 4 |
| Grooming – teeth, blowing nose, brushing hair,etc. | | | | | 1 2 3 4 |
| Bathing | | | | | 1 2 3 4 |
| Drinking | | | | | 1 2 3 4 |
| Eating | | | | | 1 2 3 4 |
| Overall mobility (is it easier/harder to move limbs and/or carry child) | | | | | 1 2 3 4 |
| Lying and rolling | | | | | 1 2 3 4 |
| Sitting | | | | | 1 2 3 4 |
| Crawling and kneeling | | | | | 1 2 3 4 |
| Standing | | | | | 1 2 3 4 |
| Walking | | | | | 1 2 3 4 |
| Communication: expression (ability to express feelings or needs, or make choices) | | | | | 1 2 3 4 |
| Communication: level of understanding (e.g. understanding words/pictures/symbols, being able to wait for something) | | | | | 1 2 3 4 |
| Play: Interaction (e.g. child able to make choices, direct play, participate in pretend play) | | | | | 1 2 3 4 |
| Play: practical ability (e.g. using hands differently, playing with new or different toys, looking at toys, can be left in position to play) | | | | | 1 2 3 4 |

What are the 3 most important things in which you would like to see changes Please place them in order of importance, with number 1 being the most important.

1. _____

2. _____

3. _____

## FOLLOW-UP PARENT QUESTIONNAIRE

Study number: _____ Date: _____ Second / third / forth / fifth / sixth assessment

***In the last _____ weeks, have your child's abilities <u>changed</u> in any way?***

The changes may be positive or negative, or none may have taken place. They may include learning new activities, doing activities more quickly / slowly, being more / less consistent, requiring more/less help from a caregiver. Changes may also include the amount of time your child tolerates being in a position, the ease or difficulty with which you can move them; changes in their ability to balance or get in or out of a position and in the distance and speed with which your child moves.

| ACTIVITIES | ANY CHANGE | | | In what way did your child change? | How significant was this change for you and your child? |
|---|---|---|---|---|---|
| | Yes | No | Don't know | | Circle a number 0=very negative and 5=very positive |
| Un / dressing | | | | | 0 1 2 3 4 5 |
| Toiletting | | | | | 0 1 2 3 4 5 |
| Grooming – teeth, blowing nose, brushing hair,etc. | | | | | 0 1 2 3 4 5 |
| Bathing | | | | | 0 1 2 3 4 5 |
| Drinking | | | | | 0 1 2 3 4 5 |
| Eating | | | | | 0 1 2 3 4 5 |
| Overall mobility (is it easier/harder to move limbs and/or carry child) | | | | | 0 1 2 3 4 5 |
| Lying and rolling | | | | | 0 1 2 3 4 5 |
| Sitting | | | | | 0 1 2 3 4 5 |
| Crawling and kneeling | | | | | 0 1 2 3 4 5 |
| Standing | | | | | 0 1 2 3 4 5 |
| Walking | | | | | 0 1 2 3 4 5 |
| Communication: expression (ability to express feelings or needs, or make choices) | | | | | 0 1 2 3 4 5 |
| Communication: level of understanding (e.g. understanding words/pictures/symbols, being able to wait for something) | | | | | 0 1 2 3 4 5 |
| Play: Interaction (e.g. child able to make choices, direct play, participate in pretend play) | | | | | 0 1 2 3 4 5 |
| Play: practical ability (e.g. using hands differently, playing with new or different toys, looking at toys, can be left in position to play) | | | | | 0 1 2 3 4 5 |

What were the 3 most important changes that occurred during the last week /6 weeks. Please place them in order of importance, with number 1 being the most important.

1. _____
2. _____
3. _____

## IPHEPHA-MBUZO LOKUQALA LOMZALI
## *INITIAL PARENT QUESTIONNAIRE*

INombolo yophando: _____ Umhla: _____
*Study number:* _____ *Date:* _____

| **NGABA UMNTWANA WAKHO UNEENGXAKI NGEZI ZENZO ZILANDELAYO?** ***DOES YOUR CHILD HAVE DIFFICULTIES WITH THE FOLLOWING ACTIVITIES?*** | Ewe *Yes* | Hayi *No* | Andazi *Don't know* | **Ukuba impendulo ngu-ewe, cacisa obo bunzima.** ***If the answer is yes, describe the difficulty.*** | **Beka ngokokukwazi kakuhle komntwana wakho ukwenza esi senzo** ***Rate how well your child can do this activity*** Rhangqa inani u-1 = uyakwazi ukuzenzela; u-2 = ufuna uncedo oluncinci; u-3 = ufuna uncedo kakhulu; u-4 = akakwazi tu ukuyenza *Circle a number 1=able to do it on his own; 2=needs a little help; 3= needs lots of help; 4=can't do it at all* |
|---|---|---|---|---|---|
| Ukukhulula / ukunxiba<br>*Un / dressing* | | | | | 1 2 3 4 |
| Ukuya ngasese<br>*Toileting* | | | | | 1 2 3 4 |
| Ukuzilungisa – amazinyo, ukufinya, ukukama, njl. njl.<br>*Grooming – teeth, blowing nose, brushing hair,etc* | | | | | 1 2 3 4 |
| Ukuhlamba<br>*Bathing* | | | | | 1 2 3 4 |
| Ukusela<br>*Drinking* | | | | | 1 2 3 4 |
| Ukutya<br>*Eating* | | | | | 1 2 3 4 |
| Ukukwazi ukushukuma xa kuphelele (kulula/nzima ukushukumisa amalungu kunye/okanye ukuphatha umntwana)<br>*Overall mobility (is it easier/harder to move limbs and/or carry child)* | | | | | 1 2 3 4 |
| Ukulala nokuguquka<br>Lying and rolling | | | | | 1 2 3 4 |
| Ukuhlala<br>*Sitting* | | | | | 1 2 3 4 |
| Ukugaqa nokuguqa<br>*Crawling and kneeling* | | | | | 1 2 3 4 |

| | | | | | |
|---|---|---|---|---|---|
| Ukuma<br>*Standing* | | | | | 1 2 3 4 |
| Ukuhamba<br>*Walking* | | | | | 1 2 3 4 |
| Unxibelelwano: ukuthetha (ukukwazi ukuxela iimvakalelo okanye iimfuno, okanye ukuzikhethela)<br>*Communication: expression (ability to express feelings or needs, or make choices)* | | | | | 1 2 3 4 |
| Unxibelelwano: inqanaba lokuqonda (umzekelo, ukuqonda amagama/imfianekiso/iisimboli, ukukwazi ukulinda into)<br>*Communication: level of understanding (e.g. understanding words/pictures/symbols, being able to wait for something)* | | | | | 1 2 3 4 |
| Ukudlala: Ukunxulumana nabanye (umzekelo, umntwana akwazi ukukhetha, ukudlala okucacileyo, ukuthatha inxaxheba ekudlaleni okulinganisayo<br>*Play: Interaction (e.g. child able to make choices, direct play, participate in pretend play)* | | | | | 1 2 3 4 |
| Ukudlala: ukukwazi ukwenza izinto eziphathekayo (umzekelo ukusebenzisa izandla ngokwahlukeneyo, ukudlala ngezinto zokudlala ezintsha nezahlukileyo, ukujonga izinto zokudlala, angashiywa ekwazi zidlalela)<br>*Play: practical ability (e.g. using hands differently, playing with new or different toys, looking at toys, can be left in position to play)* | | | | | 1 2 3 4 |

Ziintoni ezona zinto zi-3 zibalulekileyo ongathanda ukuzibona zitshintsha. Nceda uzibeke ngokokulandelelana kokubaluleka kwazo, ekunamba 1 iyeyona ibalulekileyo.

*What are the 3 most important things in which you would like to see changes Please place them in order of importance, with number 1 being the most important.*

1. _____

2. _____

3. _____

# PHEPHA-MBUZO LOKULANDELELA
# FOLLOW-UP PARENT QUESTIONNAIRE

INombolo yophando: _____ Umhla: _____ Olwesibini/ olwesithathu/ olwesine/ olwesihlanu/ olwesithandathu uvavanyo
*Study number:* *Date:* *Second / third / forth / fifth / sixth assessment*

**Emavikini ama _____ adlulile, kungaba kukhona inguquko kwizinto anokuzenza umntwana wakho?**
***In the last _____ weeks, have your child's abilities changed in any way?***

Inguquko kungaba ezinhle okanye ezimbi, okanye zingabikho tu. Zinga bandakanya ukufunda ukwenza into ezintsha, okanye ukuzenza ngokukhawuleza/ kancinci, kukunzenzela kwangokwake, ufuna uncedo oluninsi/ oluncinci kumntu omjongileyo. Inguquko zingatsho ubungako bexesha umntwana wakho angasinyamezela ekwesimo sinye, ubunzima okanye ubulula bokumosusa kwindawo abehleli kuyo; utshintsho olumalunga nokukwazi ukuzimela ngokunokwakhe, ukungena okanye ukuphuma ekuhlaleni ngomumo othile kanye nangebanga anokukhawuleza alihambe umntwana wakho.
*The changes may be positive or negative, or none may have taken place. They may include learning new activities, doing activities more quickly / slowly, being more / less consistent, requiring more/less help from a caregiver. Changes may also include the amount of time your child tolerates being in a position, the ease or difficulty with which you can move them; changes in their ability to balance or get in or out of a position and in the distance and speed with which your child moves.*

| NGEZI ZENZO<br>*ACTIVITIES* | KUKHO INGUQU<br>*ANY CHANGE* | | | Kungeyiphi na indlela umntwana wakho athe watshitsha ngayo?<br>*In what way did your child change?* | Idle ngokubaluleka kangakanani kuwe kanye nakuye umntwana indlela atshintshe ngayo?<br>*How significant was this change for you and your child?* |
|---|---|---|---|---|---|
| | Ewe<br>*Yes* | Hayi<br>*No* | Andazi<br>*Don't know* | | Rhangqa inombolo: 0 = kubi kakhulu okanye 5 = kuhle kakhulu<br>*Circle a number 0=very negative and 5=very positive* |
| Ukukhulula / ukunxiba<br>*Un / dressing* | | | | | 0 1 2 3 4 5 |
| Ukuya ngasese<br>*Toileting* | | | | | 0 1 2 3 4 5 |
| Ukuzilungisa – amazinyo, ukufinya, ukukama, njl. njl.<br>*Grooming – teeth, blowing nose, brushing hair, etc* | | | | | 0 1 2 3 4 5 |
| Ukuhlamba<br>*Bathing* | | | | | 0 1 2 3 4 5 |
| Ukusela<br>*Drinking* | | | | | 0 1 2 3 4 5 |
| Ukutya<br>*Eating* | | | | | 0 1 2 3 4 5 |
| Ukukwazi ukushukuma xa kuphelele (kulula/nzima ukushukumisa amalungu kunye/okanye ukuphatha umntwana)<br>*Overall mobility (is it easier/harder to move limbs and/or carry child)* | | | | | 0 1 2 3 4 5 |

| | | | | | |
|---|---|---|---|---|---|
| Ukulala nokuguquka<br>Lying and rolling | | | | | 0 1 2 3 4 5 |
| Ukuhlala<br>*Sitting* | | | | | 0 1 2 3 4 5 |
| Ukugaqa nokuguqa<br>*Crawling and kneeling* | | | | | 0 1 2 3 4 5 |
| Ukuma<br>*Standing* | | | | | 0 1 2 3 4 5 |
| Ukuhamba<br>*Walking* | | | | | 0 1 2 3 4 5 |
| Unxibelelwano: ukuthetha (ukukwazi ukuxela iimvakalelo okanye iimfuno, okanye ukuzikhethela)<br>*Communication: expression (ability to express feelings or needs, or make choices)* | | | | | 0 1 2 3 4 5 |
| Unxibelelwano: inqanaba lokuqonda (umzekelo, ukuqonda amagama/imfianekiso/iisimboli, ukukwazi ukulinda into)<br>*Communication: level of understanding (e.g. understanding words/pictures/symbols, being able to wait for something)* | | | | | 0 1 2 3 4 5 |
| Ukudlala: Ukunxulumana nabanye (umzekelo, umntwana akwazi ukukhetha, ukudlala okucacileyo, ukuthatha inxaxheba ekudlaleni okulinganisayo<br>*Play: Interaction (e.g. child able to make choices, direct play, participate in pretend play)* | | | | | 0 1 2 3 4 5 |
| Ukudlala: ukukwazi ukwenza izinto eziphathekayo (umzekelo ukusebenzisa izandla ngokwahlukeneyo, ukudlala ngezinto zokudlala ezintsha nezahlukileyo, ukujonga izinto zokudlala, angashiywa ekwazi zidlalela)<br>*Play: practical ability (e.g. using hands differently, playing with new or different toys, looking at toys, can be left in position to play)* | | | | | 0 1 2 3 4 5 |

Zizona ziphi izinto ezintathu zezidle ngokubaluleka qhithi ezithe zenzeka kumaviki asithandathu adlulileyo? Nceda uzibeke ngokokulandelelana kokubaluleka kwazo, ekunamba 1 iyeyona ibalulekileyo.
*What were the 3 most important changes that occurred during the last week /6 weeks? Please place them in order of importance, with number 1 being the most important.*

4. _____

5. _____

6. _____

## APPENDIX K

## Written permission from V. Knox for use of the Parent Questionnaire.

**From:** Virginia Knox [mailto:virginia@bobathlondon.co.uk]
**Sent:** 18 January 2010 11:16 AM
**To:** Shelley Broughton
**Subject:** RE: Parent Questionnaire

Dear Shelley,
I am glad you have been able to complete your study. My details are below. My full title is Consultant Physiotherapist & Bobath tutor. If you need any more details let me know.

Best wishes

**Virginia Knox MSc PGCE MCSP**
**Consultant Physiotherapist**
The Bobath Centre, 250 East End Road, London N2 8AU
Direct dial: 020 8442 2261 / email virginia@bobathlondon.co.uk
Tel: 020 8444 3355 Fax: 020 8444 3399 www.bobathlondon.co.uk
The information transmitted is intended for the person or entity to which it is addressed and may contain confidential and/or other privileged material. Any review, transmission, copying, dissemination or other use of, or the taking of any action in reliance upon this information by persons or entities other than the intended recipient is prohibited. If you have received it in error, please notify us immediately; please do not copy or disclose its contents to any person or body, and delete it from your computer systems.

**From:** Shelley Broughton [mailto:edugro@pixie.co.za]
**Sent:** 16 January 2010 06:42
**To:** Virginia Knox
**Subject:** re: Parent Questionnaire

Dear Virginia

I am an Occupational Therapist who has been working with Gillian Saloojee for a number of years. We recently undertook a study in which we used an adapted version of you're Parent Questionnaire. I was given to understand from Gillian that you were aware that we would be using the questionnaire in our research. I am currently writing up the results of the study and would like to know how I should acknowledge you as the author of the questionnaire.

Kind regards
Shelley Broughton

# APPENDIX L

## The Gross Motor Functional Measure

GROSS MOTOR FUNCTION MEASURE (GMFM)
SCORE SHEET (GMFM-88 and GMFM-66 scoring)
Version 1.0

Child's Name: _____ ID #: _____

Assessment date: _____ year / month /day

Date of birth: _____ year / month /day

Chronological age: _____ years/months

GMFCS Level [1]

☐ I ☐ II ☐ III ☐ IV ☐ V

Testing Conditions (eg, room, clothing, time, others present)

Evaluator's Name: _____

_____

_____

_____

The GMFM is a standardized observational instrument designed and validated to measure change in gross motor function over time in children with cerebral palsy. The scoring key is meant to be a general guideline. However, most of the items have specific descriptors for each score. It is imperative that the guidelines contained in the manual be used for scoring each item.

**SCORING KEY**
0 = does not initiate
1 = initiates
2 = partially completes
3 = completes
NT = Not tested [used for the GMAE scoring*]

***It is now important to differentiate a true score of "0" (child does not initiate) from an item which is Not Tested (NT) if you are interested in using the GMFM-66 Ability Estimator Software.***

*The GMFM-66 Gross Motor Ability Estimator (GMAE) software is available with the GMFM manual (2002). The advantage of the software is the conversion of the ordinal scale into an interval scale. This will allow for a more accurate estimate of the child's ability and provide a measure that is equally responsive to change across the spectrum of ability levels. Items that are used in the calculation of the GMFM-66 score are shaded and identified with an asterisk (*). The GMFM-66 is only valid for use with children who have cerebral palsy.

**Contact for Research Group:**
Dianne Russell, *CanChild* Centre for Childhood Disability Research, McMaster University, Institute for Applied Health Sciences, McMaster University, 1400 Main St. W., Rm. 408, Hamilton, L8S 1C7
Tel: North America - 1 905 525-9140 Ext: 27850
Tel: All other countries - 001 905 525-9140 Ext: 27850
E-mail: canchild@mcmaster.ca Fax: 1 905 522-6095
Website: www.fhs.mcmaster.ca/canchild

[1] GMFCS level is a rating of severity of motor function. Definitions are found in Appendix I of the GMFM manual (2002).

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**Check (√) the appropriate score:** if an item is not tested (NT), circle the item number in the right column

| Item | | A: LYING & ROLLING | SCORE | | | | NT |
|---|---|---|---|---|---|---|---|
| | 1. | SUP, HEAD IN MIDLINE: TURNS HEAD WITH EXTREMITIES SYMMETRICAL | 0☐ | 1☐ | 2☐ | 3☐ | 1. |
| * | 2. | SUP: BRINGS HANDS TO MIDLINE, FINGERS ONE W TH THE OTHER | 0☐ | 1☐ | 2☐ | 3☐ | 2. |
| | 3. | SUP: LIFTS HEAD 45° | 0☐ | 1☐ | 2☐ | 3☐ | 3. |
| | 4. | SUP: FLEXES R HIP AND KNEE THROUGH FULL RANGE | 0☐ | 1☐ | 2☐ | 3☐ | 4. |
| | 5. | SUP: FLEXES L HIP AND KNEE THROUGH FULL RANGE | 0☐ | 1☐ | 2☐ | 3☐ | 5. |
| * | 6. | SUP: REACHES OUT WITH R ARM, HAND CROSSES MIDLINE TOWARD TOY | 0☐ | 1☐ | 2☐ | 3☐ | 6. |
| * | 7. | SUP: REACHES OUT WITH L ARM, HAND CROSSES MIDLINE TOWARD TOY | 0☐ | 1☐ | 2☐ | 3☐ | 7. |
| | 8. | SUP: ROLLS TO PR OVER R SIDE | 0☐ | 1☐ | 2☐ | 3☐ | 8. |
| | 9. | SUP: ROLLS TO PR OVER L SIDE | 0☐ | 1☐ | 2☐ | 3☐ | 9. |
| * | 10. | PR: LIFTS HEAD UPRIGHT | 0☐ | 1☐ | 2☐ | 3☐ | 10. |
| | 11. | PR ON FOREARMS: LIFTS HEAD UPRIGHT, ELBOWS EXT., CHEST RAISED | 0☐ | 1☐ | 2☐ | 3☐ | 11. |
| | 12. | PR ON FOREARMS: WEIGHT ON R FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD | 0☐ | 1☐ | 2☐ | 3☐ | 12. |
| | 13. | PR ON FOREARMS: WEIGHT ON L FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD | 0☐ | 1☐ | 2☐ | 3☐ | 13. |
| | 14. | PR: ROLLS TO SUP OVER R SIDE | 0☐ | 1☐ | 2☐ | 3☐ | 14. |
| | 15. | PR: ROLLS TO SUP OVER L SIDE | 0☐ | 1☐ | 2☐ | 3☐ | 15. |
| | 16. | PR: PIVOTS TO R 90° USING EXTREMITIES | 0☐ | 1☐ | 2☐ | 3☐ | 16. |
| | 17. | PR: PIVOTS TO L 90° USING EXTREMITIES | 0☐ | 1☐ | 2☐ | 3☐ | 17. |
| | | **TOTAL DIMENSION A** | | | | | |

| Item | | B: SITTING | SCORE | | | | NT |
|---|---|---|---|---|---|---|---|
| * | 18. | SUP, HANDS GRASPED BY EXAMINER: PULLS SELF TO SITTING WITH HEAD CONTROL | 0☐ | 1☐ | 2☐ | 3☐ | 18. |
| | 19. | SUP: ROLLS TO R SIDE. ATTAINS SITTING | 0☐ | 1☐ | 2☐ | 3☐ | 19. |
| | 20. | SUP: ROLLS TO L SIDE, ATTAINS SITTING | 0☐ | 1☐ | 2☐ | 3☐ | 20. |
| * | 21. | SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD UPRIGHT, MAINTAINS 3 SECONDS | 0☐ | 1☐ | 2☐ | 3☐ | 21. |
| * | 22. | SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD MIDLINE, MAINTAINS 10 SECONDS | 0☐ | 1☐ | 2☐ | 3☐ | 22. |
| * | 23. | SIT ON MAT, ARM(S) PROPPING: MAINTAINS, 5 SECONDS | 0☐ | 1☐ | 2☐ | 3☐ | 23. |
| * | 24. | SIT ON MAT: MAINTAIN, ARMS FREE, 3 SECONDS | 0☐ | 1☐ | 2☐ | 3☐ | 24. |
| * | 25. | SIT ON MAT WITH SMALL TOY IN FRONT: LEANS FORWARD, TOUCHES TOY, RE-ERECTS WITHOUT ARM PROPPING | 0☐ | 1☐ | 2☐ | 3☐ | 25. |
| * | 26. | SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S R SIDE, RETURNS TO START | 0☐ | 1☐ | 2☐ | 3☐ | 26. |
| * | 27. | SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S L SIDE, RETURNS TO START | 0☐ | 1☐ | 2☐ | 3☐ | 27. |
| | 28. | R SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS | 0☐ | 1☐ | 2☐ | 3☐ | 28. |
| | 29. | L SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS | 0☐ | 1☐ | 2☐ | 3☐ | 29. |
| * | 30. | SIT ON MAT: LOWERS TO PR WITH CONTROL | 0☐ | 1☐ | 2☐ | 3☐ | 30. |
| * | 31. | SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER R SIDE | 0☐ | 1☐ | 2☐ | 3☐ | 31. |
| * | 32. | SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER L SIDE | 0☐ | 1☐ | 2☐ | 3☐ | 32. |
| | 33. | SIT ON MAT: PIVOTS 90°, WITHOUT ARMS ASSISTING | 0☐ | 1☐ | 2☐ | 3☐ | 33. |
| * | 34. | SIT ON BENCH: MAINTAINS, ARMS AND FEET FREE, 10 SECONDS | 0☐ | 1☐ | 2☐ | 3☐ | 34. |
| * | 35. | STD: ATTAINS SIT ON SMALL BENCH | 0☐ | 1☐ | 2☐ | 3☐ | 35. |
| * | 36. | ON THE FLOOR: ATTAINS SIT ON SMALL BENCH | 0☐ | 1☐ | 2☐ | 3☐ | 36. |
| * | 37. | ON THE FLOOR: ATTAINS SIT ON LARGE BENCH | 0☐ | 1☐ | 2☐ | 3☐ | 37. |

| Item | | C: CRAWLING & KNEELING | SCORE | NT |
|---|---|---|---|---|
| | 38. | PR: CREEPS FORWARD 1.8m (6') | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 38. |
| * | 39. | 4 POINT: MAINTAINS, WEIGHT ON HANDS AND KNEES, 10 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 39. |
| * | 40. | 4 POINT: ATTAINS SIT ARMS FREE | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 40. |
| * | 41. | PR: ATTAINS 4 POINT, WEIGHT ON HANDS AND KNEES | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 41. |
| * | 42. | 4 POINT: REACHES FORWARD WITH R ARM, HAND ABOVE SHOULDER LEVEL | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 42. |
| * | 43. | 4 POINT: REACHES FORWARD WITH L ARM, HAND ABOVE SHOULDER LEVEL | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 43. |
| * | 44. | 4 POINT: CRAWLS OR HITCHES FORWARD 1.8m (6') | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 44. |
| * | 45. | 4 POINT: CRAWLS RECIPROCALLY FORWARD 1.8m (6') | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 45. |
| * | 46. | 4 POINT: CRAWLS UP 4 STEPS ON HANDS AND KNEES/FEET | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 46. |
| | 47. | 4 POINT: CRAWLS BACKWARDS DOWN 4 STEPS ON HANDS AND KNEES/FEET | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 47. |
| * | 48. | SIT ON MAT: ATTAINS HIGH KN USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 48. |
| | 49. | HIGH KN: ATTAINS HALF KN ON R KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 49. |
| | 50. | HIGH KN: ATTAINS HALF KN ON L KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 50. |
| * | 51. | HIGH KN: KN WALKS FORWARD 10 STEPS, ARMS FREE | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 51. |
| | | **TOTAL DIMENSION C** | ☐ | |

| Item | | D: STANDING | SCORE | NT |
|---|---|---|---|---|
| * | 52. | ON THE FLOOR: PULLS TO STD AT LARGE BENCH | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 52. |
| * | 53. | STD: MAINTAINS, ARMS FREE, 3 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 53. |
| * | 54. | STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS R FOOT, 3 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 54. |
| * | 55. | STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS L FOOT, 3 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 55. |
| * | 56. | STD: MAINTAINS, ARMS FREE, 20 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 56. |
| * | 57. | STD: LIFTS L FOOT, ARMS FREE, 10 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 57. |
| * | 58. | STD: LIFTS R FOOT, ARMS FREE, 10 SECONDS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 58. |
| * | 59. | SIT ON SMALL BENCH: ATTAINS STD WITHOUT USING ARMS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 59. |
| * | 60. | HIGH KN: ATTAINS STD THROUGH HALF KN ON R KNEE, WITHOUT USING ARMS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 60. |
| * | 61. | HIGH KN: ATTAINS STD THROUGH HALF KN ON L KNEE, WITHOUT USING ARMS | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 61. |
| * | 62. | STD: LOWERS TO SIT ON FLOOR WITH CONTROL, ARMS FREE | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 62. |
| * | 63. | STD: ATTAINS SQUAT, ARMS FREE | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 63. |
| * | 64. | STD: PICKS UP OBJECT FROM FLOOR, ARMS FREE, RETURNS TO STAND | 0 ☐ 1 ☐ 2 ☐ 3 ☐ | 64. |
| | | **TOTAL DIMENSION D** | ☐ | |

| Item | | E: WALKING, RUNNING & JUMPING | SCORE | | | | NT |
|---|---|---|---|---|---|---|---|
| * | 65. | STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO R | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 65. |
| * | 66. | STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO L | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 66. |
| * | 67. | STD, 2 HANDS HELD: WALKS FORWARD 10 STEPS | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 67. |
| * | 68. | STD, 1 HAND HELD: WALKS FORWARD 10 STEPS | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 68. |
| * | 69. | STD: WALKS FORWARD 10 STEPS | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 69. |
| * | 70. | STD: WALKS FORWARD 10 STEPS, STOPS, TURNS 180°, RETURNS | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 70. |
| * | 71. | STD: WALKS BACKWARD 10 STEPS | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 71. |
| * | 72. | STD: WALKS FORWARD 10 STEPS, CARRYING A LARGE OBJECT WITH 2 HANDS | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 72. |
| * | 73. | STD: WALKS FORWARD 10 CONSECUTIVE STEPS BETWEEN PARALLEL LINES 20cm (8") APART | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 73. |
| * | 74. | STD: WALKS FORWARD 10 CONSECUTIVE STEPS ON A STRAIGHT LINE 2cm (3/4") WIDE | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 74. |
| * | 75. | STD: STEPS OVER STICK AT KNEE LEVEL, R FOOT LEADING | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 75. |
| * | 76. | STD: STEPS OVER STICK AT KNEE LEVEL, L FOOT LEADING | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 76. |
| * | 77. | STD: RUNS 4.5m (15'), STOPS & RETURNS | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 77. |
| * | 78. | STD: KICKS BALL WITH R FOOT | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 78. |
| * | 79. | STD: KICKS BALL WITH L FOOT | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 79. |
| * | 80. | STD: JUMPS 30cm (12") HIGH, BOTH FEET SIMULTANEOUSLY | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 80. |
| * | 81. | STD: JUMPS FORWARD 30 cm (12"), BOTH FEET SIMULTANEOUSLY | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 81. |
| * | 82. | STD ON R FOOT: HOPS ON R FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 82. |
| * | 83. | STD ON L FOOT: HOPS ON L FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 83. |
| * | 84. | STD, HOLDING 1 RAIL: WALKS UP 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 84. |
| * | 85. | STD, HOLDING 1 RAIL: WALKS DOWN 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 85. |
| * | 86. | STD: WALKS UP 4 STEPS, ALTERNATING FEET | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 86. |
| * | 87. | STD: WALKS DOWN 4 STEPS, ALTERNATING FEET | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 87. |
| * | 88. | STD ON 15cm (6") STEP: JUMPS OFF, BOTH FEET SIMULTANEOUSLY | 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ | 88. |

**TOTAL DIMENSION E** ☐

Was this assessment indicative of this child's "regular" performance? YES ☐ NO ☐

COMMENTS:

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## GMFM RAW SUMMARY SCORE

| DIMENSION | CALCULATION OF DIMENSION % SCORES | GOAL AREA (indicated with ✓ check) |
|---|---|---|
| A. Lying & Rolling | $\frac{\text{Total Dimension A}}{51} = \frac{\quad}{51} \times 100 = \quad\%$ | A. ☐ |
| B. Sitting | $\frac{\text{Total Dimension B}}{60} = \frac{\quad}{60} \times 100 = \quad\%$ | B. ☐ |
| C. Crawling & Kneeling | $\frac{\text{Total Dimension C}}{42} = \frac{\quad}{42} \times 100 = \quad\%$ | C. ☐ |
| D. Standing | $\frac{\text{Total Dimension D}}{39} = \frac{\quad}{39} \times 100 = \quad\%$ | D. ☐ |
| E. Walking, Running & Jumping | $\frac{\text{Total Dimension E}}{72} = \frac{\quad}{72} \times 100 = \quad\%$ | E. ☐ |

**TOTAL SCORE =** $\frac{\%A + \%B + \%C + \%D + \%E}{\text{Total \# of Dimensions}}$

$= \frac{+ \quad + \quad + \quad + \quad}{5} = \frac{\quad}{5} = \quad\%$

**GOAL TOTAL SCORE =** $\frac{\text{Sum of \% scores for each dimension identified as a goal area}}{\text{\# of Goal areas}}$

$= \quad = \quad\%$

### GMFM-66 Gross Motor Ability Estimator Score [1]

GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

previous GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

change in GMFM-66 = _____

[1] from the Gross Motor Ability Estimator (GMAE) Software

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# APPENDIX Mi

# Table of PEDI Modifications

**Table of PEDI – Part I: Functional Skills**
**Modifications for Local Conditions**

| **Self Care Domain** | | | |
|---|---|---|---|
| The following items were modified either in order to enhance understanding and translation of the question into Xhosa and / or adapt the question to the local environment. | | | |
| ***Original PEDI Items*** | | ***Modifications*** | |
| 9. | Users own knife to butter bread, cut soft foods | 9. | Uses a knife to cut |
| 10 | Holds bottle or spout cup | 10 | Hold bottle or cup |
| 14 | Pours liquid from carton or pitcher | 14 | Pours liquid from carton or bottle |
| 35 | Washes body thoroughly, not including face | 35 | Washes body thoroughly, not including face |
| *I.* | *Pullover/front opening garments* | *I.* | *Dressing (top half)* |
| 39 | Assists, such as pushing arms through shirt | 39 | Assists, such as pushing arms through sleeves |
| 40 | Removes T-shirt, dress or sweater (pullover garment without fasteners) | 40 | Removes T-shirt, dress or jersey (pullover garment) |
| 41 | Puts on T-shirt, dress or sweater | 41 | Puts on T-shirt, dress or jersey |
| *K.* | *Pants* | *K.* | *Dressing (bottom half)* |
| 57 | Puts shoes on correct feet; managers velcro fasteners | 57 | Puts shoes on correct feet |
| 58 | Ties shoelaces | 58 | Can fasten shoes–velcro/buckles |
| *M.* | *Toileting Tasks (clothes, toilet management, and wiping only)* | *M.* | *Toileting* |
| 59 | Assists with clothing management | 59 | Assists with clothing |
| 63 | Wipe's self thoroughly after bowel movements | 63 | Wipe's self thoroughly |
| *N.* | *Management of bladder (score=1 if a child has previously mastered skills)* | *N.* | *Bladder Management* |
| 64 | Indicates when wet in diapers or training pants | 64 | Indicates when wet |
| 65 | Occasionally indicates need to urinate (daytime) | 65 | Occasionally indicates need to pass urine |
| 66 | Consistently indicates need to urinate with time to get to toilet (daytime) | 66 | Consistently indicate time to urinate |
| 67 | Takes self into a bathroom to urinate (daytime) | 67 | Takes itself to toilet to urinate |
| *O.* | *Management of Bowel (score = 1 if child has previously mastered skill)* | *O.* | *Bowel Management* |
| 70 | Occasionally indicates need to use toilet (daytime) | 70 | Occasionally indicates a need to use toilet |
| 71 | Consistently indicates need to use toilet with time to get to toilet (daytime) | 71 | Consistently indicates need to use toilet |
| 72 | Distinguishes between need for urination and bowel movements | 72 | Distinguishes between need to pass urine and bowel movements |
| 73 | Take self into bathroom for bowel movements, has no bowel accidents | 73 | Takes self to toilet for bowel movements |
| | | | |
| The following items were removed, because children in the study area (a rural area in the Eastern Cape) have no frame of reference for these items; or they were considered inappropriate for this population group. | | | |
| *D. Toothbrushing* | | | |
| 15 | Opens mouth for teeth to be brushed | | |

| | |
|---|---|
| 16 | Holds toothbrush |
| 17 | Brushes teeth; but not a thorough job |
| 18 | Thoroughly brushes teeth |
| 19 | Prepares toothbrush with toothpaste |
| | |
| 23 | Managers tangles and parts hair |
| 31 | Turns water on and all, obtains soap |
| 36 | Obtains soap and soaps washcloth, if used |
| *J.* | *Fasteners* |
| 44 | Tries to assist with fasteners |
| 45 | Zips and unzips, doesn't separate or hook zipper |
| 46 | Snaps and unsnaps |
| 47 | Buttons and unbuttons |
| 48 | Zips and unzips, separates and hooks zipper |
| | |
| 61 | Managers toilet seat, gets toilet paper and flushes toilet |

**Mobility Domain**

The following items were modified either in order to enhance understanding and translation of the question into Xhosa and / or adapt the question to the local environment.

| ***Original PEDI Items*** | | ***Modifications*** | |
|---|---|---|---|
| 6 | Sits if supported by equipment or caregiver | 6 | Sits on a chair if supported by equipment or caregiver |
| 7 | Sit unsupported on chair or bench | 7 | Sits unsupported on a chair (i.e. with back support) |
| | | 7a | Sits unsupported on a bench |
| 8 | Gets on and author low chair or furniture | 8 | Gets on and off a low chair or bench |
| 9 | Gets in and out of adult sized chair/wheelchair | 9 | Gets in & out of an adult-sized chair |
| 10 | Gets in and out of chair, not needing own arms | 10 | Gets in and out of chair without needing to use his/her arms to help |
| 12 | Gets in and out of cars with little assistance or instruction | 12 | Gets in and out of a car/taxi |
| 16 | Raises to sitting position in bed or crib | 16 | Can sit up from lying |
| 17 | Comes to sit at edge of bed; lies down from sitting at edge of bed | 17 | Can move to sit on edge of bed |
| 18 | Get in and out of own bed | 18 | Gets in and out of own bed without help |
| 25 | Roles, scoots, crawls or creeps on floor | 25 | Rolls, crawls, creeps, bottom shuffles |
| 26 | Walks, but holds onto furniture, walls, caregivers or uses devices for support | 26 | Walks indoors holding onto furniture |
| 27 | Walks without support | 27 | Walks indoors without support or equipment |
| 32 | Moves indoors 50 feet; opens and closes inside and outside doors | 32 | Moves indoors at least 15 metres and opens and closes doors |
| 40 | Moves 10–50 feet | 40 | Moves 3 – 15 metres |
| 41 | Moves 50–100 feet | 41 | Moves 15 – 30 metres |
| 42 | Moves 100–150 feet | 42 | Moves 30 – 50 metres |

| | | | |
|---|---|---|---|
| 43 | Moves 150 feet and longer, but with difficulty | 43 | Moves 50 metres or more but with difficulty |
| 44 | Moves 150 feet and longer with no difficulty | 44 | Moves 50 metres or more with no difficulty |
| 45 | Level surfaces (smooth sidewalks, driveways) | 45 | Manages level surfaces |
| 47 | Rough, uneven surfaces (lawns, gravel driveway) | 46 | Manages rough & uneven surfaces |
| 49 | Up and down curbs | 49 | Up and down curbs and slopes |
| 50 | Scoots or crawls up partial flight, 1 –11 steps | 50 | Crawls or bottom shuffles up stairs |
| 52 | Walks up partial flight | 52 | Walks up stairs but with difficulty |
| 54 | Walks up entire flight with no difficulty | 54 | Walks up stairs with no difficulty |
| 55 | Scoots or crawls down partial flight, 1–11 steps | 55 | Crawls or bottom shuffles down stairs |
| 56 | Scoots or crawls down full flight, 12–15 steps | 56 | Walks down stairs but with difficulty |
| 57 | Walks down partial flight | 57 | Walks up stairs but with difficulty |

The following items were removed, because children in the study area (a rural area in the Eastern Cape) have no frame of reference for these items; or they were considered inappropriate for this population group.

| | |
|---|---|
| *A* | *Toilet Transfers* |
| 1 | Sits if supported by equipment or caregiver |
| 2 | Sit unsupported on toilet or potty chair |
| 3 | Gets on and off the toilet or potty |
| 4 | Gets on and off adult sized toilet |
| 5 | Gets on and off toilet, not needing own arms |
| | |
| *C* | *Car Transfers* |
| 11 | Moves in car; scoots on seat or get in and out of car seat |
| 13 | Gets in and out of car with no assistance or instruction |
| 14 | Manages seatbelt or chair restraint |
| 15 | Gets in and out of car and opens and closes car door |
| | |
| 19 | Gets in and out of own bed, not needing own arms |
| | |
| *E* | *Tub Transfers* |
| 20 | Sits if supported by equipment or caregiver in a tub or sink |
| 21 | Sits unsupported and moves in tub |
| 22 | Climbs or scoots in and out of tub |
| 23 | Sits down and stands up from inside tub |
| 24 | Steps/transfers into and out of an adult sized tub |
| | |
| 30 | Moves between rooms but with difficulty |
| 31 | Moves between rooms with no difficulty |
| 33 | Changes physical location purposefully |

| | |
|---|---|
| 46 | Slightly uneven surfaces (cracked pavement) |
| 48 | Up and down incline or ramps |
| 51 | Scoots or crawls up full flight, 12–15 steps |
| 53 | Walks full flight, but with difficulty–slow for age |
| 58 | Walks down full flight, but with difficulty–slow for age |
| 59 | Walks down full flight with no difficulty |

**Social Function Domain**

The following items were modified either in order to enhance understanding and translation of the question into Xhosa and / or adapt the question to the local environment.

| ***Original PEDI Items*** | | ***Modifications*** | |
|---|---|---|---|
| 16 | Uses gestures with clear meaning | 16 | Uses gestures/signs with clear meaning |
| 29 | Attempts to imitate adults previous action during a play activity | 29 | Attempts to copy adults previous action during a play activity |
| *G.* | *Peer Interactions: child of similar age* | *G.* | *Interaction with other children* |
| 45 | Can direct an adult to help child return home or back to the hospital room | 45 | Can direct an adult to help child return home |
| 52 | Beginning to help with simple household chores if given constant direction and guidance | 52 | Beginning to help with simple household chores, with help |
| 53 | Occasionally initiates simple routines to care for own belongings; may require physical help or reminders to complete | 53 | Occasionally initiates simple routines to care for own belongings or household chores |
| 55 | Consistently initiates and carries out at least one household task involving several steps and decisions; may require physical help | 55 | Consistently initiates and carries out at least one household chore; may require physical help |
| 65 | Makes transection in neighbourhood store without assistance | 65 | Child can buy things at the local shop without assistance |

The following items were removed, because children in the study area (a rural area in the Eastern Cape) have no frame of reference for these items; or they were considered inappropriate for this population group. Furthermore, some of these items were too abstract for caregivers to follow

| | |
|---|---|
| 8 | Understands directions that describe where something is |
| 10 | Understands two sentences that are about the same subject that have a different form |
| | |
| *E.* | *Problem Resolution* |
| 21 | Tries to show you the problem or communicate what is needed to help the problem |
| 22 | If upset because of a problem, child must be helped immediately or behavior deteriorates |
| 23 | If upset because of a problem, child can seek help and wait if it is delayed a short time |
| 24 | In ordinary situations, child can describe the problem and his/her feelings with some detail–usually does not act out |
| 25 | Faced with an ordinary problem, child can join adult in working out a solution |
| | |
| 30 | During play child may suggest new or different steps, or respond to adult suggestion with another idea |
| 34 | Plans and carries out cooperative activity with other children; play is sustained and complex |
| 35 | Plays activities or games that have rules |
| 39 | Makes up extended pretend play routines involving things the child knows about |

| | |
|---|---|
| 44 | Can state full home address; if in hospital, name of hospital and room number |
| 48 | Has a very simple time concepts |
| 50 | Regularly checks clock or asks for the time in order to keep track of schedule |
| 54 | Occasionally initiates simple household chores; may require physical help or reminders to complete |
| 56 | Shows appropriate caution around stairs |
| 58 | When crossing the street with an adult present, child does not need prompting about safety rules |
| 60 | Crosses busy street safely without an adult |
| 63 | Follows guidelines/expectations of school and community setting |

## APPENDIX Mii

## PEDI-Modified Functional Skills Scales (PEDI-MFSS)

### PEDIATRIC EVALUATION OF DISABILITY INVENTORY (PEDI) MODIFIED VERSION FOR SOUTH AFRICA

STUDY NUMBER : _____

**KEY:** *0 = Unable* *1 = Capable (Able to)*

***Please answer ALL the questions***

| | *QUESTION* | *0* | *1* | | *QUESTION* | *0* | *1* |
|---|---|---|---|---|---|---|---|
| **SELF CARE DOMAIN** | | | | | | | |
| **Food textures** | | | | **Washing body and face** | | | |
| 1 | Eats pureed/blended/strained foods | | | 34 | Tries to wash parts of body | | |
| 2 | Eats ground/lumpy foods | | | 35 | Washes body thoroughly | | |
| 3 | Eats cut up/chunky/diced foods | | | 37 | Dries body thoroughly | | |
| 4 | Eats all textures of food | | | 38 | Washes and dries face thoroughly | | |
| | | | | | | | |
| **Use of utensils** | | | | **Dressing (top half)** | | | |
| 5 | Finger feeds | | | 39 | Assists, such as pushing arms through sleeves | | |
| 6 | Scoops with a spoon & brings to mouth | | | 40 | Removes T-shirt, dress or jersey (pullover garment) | | |
| 7 | Uses a spoon well | | | 41 | Puts on T-shirt, dress or sweater | | |
| 8 | Uses a fork well | | | 42 | Puts on & removes front-opening shirt, not including fasteners | | |
| 9 | Uses a knife to cut food | | | 43 | Puts on & removes front-opening shirt, including fasteners | | |
| | | | | | | | |
| **Use of drinking containers** | | | | **Dressing (bottom half)** | | | |
| 10 | Holds bottle or cup | | | 49 | Assists, such as pushing legs through pants | | |
| 11 | Lifts cup to drink, but cup may tip | | | 50 | Removes pants with elastic waist | | |
| 12 | Lifts open cup securely with 2 hands | | | 51 | Puts on pants with elastic waist | | |
| 13 | Lifts open cup securely with 1 hand | | | 52 | Removes pants with fasteners | | |
| 14 | Pours liquid from a carton or bottle | | | 53 | Puts on pants including fasteners | | |
| | | | | | | | |
| **Hairbrushing** | | | | **Shoes and socks** | | | |
| 20 | Holds head in position while hair is combed | | | 54 | Removes socks and undoes shoes | | |
| 21 | Brings brush or comb to head | | | 55 | Puts on unfastened shoes | | |
| 22 | Brushes or combs hair | | | 56 | Puts on socks | | |
| | | | | 57 | Puts shoes on correct feet | | |
| **Nosecare** | | | | 58 | Can fasten shoes- Velcro/buckles | | |
| 24 | Allows nose to be wiped | | | | | | |
| 25 | Blows nose into held tissue | | | **Toileting** | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 26 | Wipes nose using tissue on request | | | 59 | Assists with clothing | | |
| 27 | Wipes nose using tissue without request | | | 62 | Manages with clothes before and after toileting | | |
| 28 | Blows and wipes nose without request | | | 60 | Tries to wipe self after toileting | | |
| | | | | 63 | Wipes self thoroughly | | |
| **Handwashing** | | | | | | | |
| 29 | Holds hands out to be washed | | | **Bladder management** | | | |
| 30 | Rubs hands together to clean | | | 64 | Indicates when wet | | |
| 32 | Washes hands thoroughly | | | 65 | Occasionally indicates need to pass urine | | |
| 33 | Dries hands thoroughly | | | 66 | Consistently indicates need to urinate | | |
| | | | | 67 | Takes self to toilet to urinate | | |
| **Bowel management** | | | | | | | |
| 69 | Indicates need to be changed | | | | **SELF CARE DOMAIN SUM** | | |
| 70 | Occasionally indicates need to toilet | | | | | | |
| 71 | Consistently indicates need to toilet | | | | | | |
| 72 | Distinguishes between need to pass urine & bowel movement | | | | | | |
| 73 | Takes self to toilet for bowel mvts | | | | | | |
| 68 | Consistently stays dry day & night | | | | | | |
| | | | | | | | |
| **MOBILITY DOMAIN** | | | | | | | |
| **Chair – sitting balance and transfers** | | | | | **Outdoor locomotion / mobility** | | |
| 6 | Sits on a chair if supported by equipment or caregiver | | | 38 | Walks, but holds onto objects, caregiver or devices for support | | |
| 7 | Sits unsupported on a chair ( i.e. with back support) | | | 39 | Walks without support | | |
| 7a | Sits unsupported on a bench | | | 40 | Moves 3 – 15 metres | | |
| 8 | Gets on and off a low chair or bench | | | 41 | Moves 15 – 30 metres | | |
| 9 | Gets in & out of an adult-sized chair | | | 42 | Moves 30 – 50 metres | | |
| 10 | Gets in and out of chair without needing to use his/her arms to help | | | 43 | Moves 50 metres or more but with difficulty | | |
| 12 | Gets in and out of a car/taxi | | | 44 | Moves 50 metres or more with no difficulty | | |
| | | | | 45 | Manages level surfaces | | |
| **Bed mobility** | | | | 46 | Manages rough & uneven surfaces | | |
| 16 | Can sit up from lying | | | 49 | Up and down curbs and slopes | | |
| 17 | Can move to sit over the edge of bed | | | | | | |
| 18 | Gets in and out of bed without help | | | **Stairs** | | | |
| | | | | 50 | Crawls or bottom shuffles up stairs | | |
| **Indoor locomotion / mobility** | | | | 52 | Walks up stairs but with difficulty | | |
| 25 | Rolls, crawls, creeps, bottom shuffles | | | 54 | Walks up stairs with no difficulty | | |
| 26 | Walks indoors holding onto furniture | | | 55 | Crawls or bottom shuffles down stairs | | |
| 27 | Walks indoors without support or equipment | | | 56 | Walks down stairs but with difficulty | | |
| 28 | Moves within a room, but with difficulty | | | 57 | Walks up stairs but with difficulty | | |
| 29 | Moves within a room with no difficulty | | | | | | |
| 32 | Moves indoors at least 15 metres and opens and closes doors | | | | | | |
| 34 | Moves objects along the floor | | | | | | |

| | | | | | | | |
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| 35 | Carries objects small enough to be held in one hand | | | MOBILITY DOMAIN SUM | | | |
| 36 | Carries objects large enough to require two hands | | | | | | |
| 37 | Carries fragile or spillable objects | | | | | | |
| | | | | | | | |
| **SOCIAL FUNCTION DOMAIN** | | | | | | | |
| **Comprehension of word meanings** | | | | **Comprehension of sentence complexity** | | | |
| 1 | Orientates to sound | | | 6 | Understands short sentences about familiar objects & people | | |
| 2 | Responds to "no"; recognizes own name or that of familiar people | | | 7 | Understands 1 step commands with words that describe people | | |
| 3 | Understands 10 words | | | 9 | Understands 2 step commandes, using if/then; before/after, etc | | |
| 4 | Understands when you talk about relationships among people and/or things that are visible | | | | | | |
| 5 | Understands when you talk about time and sequence of events | | | | | | |
| | | | | | | | |
| **Functional use of communication** | | | | **Play with objects** | | | |
| 11 | Names things | | | 36 | Manipulates toys, objects with intent | | |
| 12 | Uses specific words or gestures to direct or request action by someone else | | | 37 | Uses real or substituted objects in simple pretend games | | |
| 13 | Seeks information by asking questions | | | 38 | Puts together materials to make something | | |
| 14 | Describes an object or action | | | 40 | Makes up elaborate pretend sequences from imagination | | |
| 15 | Tells about own thoughts & feelings | | | | | | |
| | | | | **Self information** | | | |
| **Complexity of expressive communication** | | | | 41 | Can state first name | | |
| 16 | Uses gestures/signs with clear meaning | | | 42 | Can state first and last names | | |
| 17 | Uses single word with meaning | | | 43 | Provides names and descriptive information about family | | |
| 18 | Uses 2 words together with meaning | | | 45 | Can direct adult to help child return home | | |
| 19 | Uses 4 – 5 word sentences | | | | | | |
| 20 | Connects 2 or more thoughts to tell a simple story | | | **Time orientation** | | | |
| | | | | 46 | Has a general awareness of time of mealtimes and daily routines | | |
| **Social interactive play** | | | | 47 | Has some awareness of sequence of familiar events in a week | | |
| 26 | Shows awareness and interest in others | | | 49 | Associates a specific time with actions/events | | |
| 27 | Initiates a familiar play routine | | | | | | |
| 28 | Takes turn in simple play when cued for turn | | | **Household chores** | | | |
| 29 | Attempts to copy adult's previous action during a play activity | | | 51 | Beginning to help care for own belongings with constant direction and guidance | | |
| | | | | 52 | Beginning to help with simple household chores with help | | |
| **Interaction with other children** | | | | 53 | Occasionally initiates simple routines to care for own belongings or household chores | | |
| 31 | Notices presence of other children, may vocalize & gesture towards peers | | | 55 | Consistently initiates and carries out household chores; may need | | |

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| | | | | | physical help to do so | | |
| 32 | Interacts with other children in simple and brief episodes | | | | | | |
| 33 | Tries to work out simple plans for a play activity with another child | | | **Self-protection** | | | |
| | | | | 57 | Shows appropriate caution around hot or sharp objects | | |
| **Community function and participation** | | | | 59 | Knows not to accept rides, food or money from strangers | | |
| 61 | Child may play safely at home without being watched | | | | | | |
| 62 | Child can go around familiar environment outside of home with only periodic monitoring | | | **SOCIAL FUNCTION DOMAIN SUM** | | | |
| 64 | Can explore and function in a familiar community setting without supervision | | | | | | |
| 65 | Child can buy things at the local shop without assistance | | | **TOTAL SCORE** | | | |

## APPENDIX N

## PEDI-Modified Functional Skills Scale - isiXhosa

UHLOLO LOLUHLU LOKHUBAZEKO KWIMPILO YABANTWANA
(*PEDIATRIC EVALUATION OF DISABILITY INVENTORY (PEDI)*)

UHLOBO OLULUNGISELELWE UMZANTSI AFRIKA

*PAEDIATRIC EVALUATION OF DISABILITY INVENTORY (PEDI)*
*MODIFIED VERSION FOR SOUTH AFRICA*

INOMBOLO YOPHONONONGO: _____
*STUDY NUMBER :* _____

ISIKHOKELO: *0 = Akwakwazi* *1 = Angakwazi (Uyakwazi)*
***Nceda uphendule YONKE imibuzo***
***KEY:*** *0 = Unable* *1 = Capable (Able to)*
***Please answer ALL the questions***

| | *UMBUZO*<br>*QUESTION* | *0* | *1* | | *UMBUZO*<br>*QUESTION* | *0* | *1* |
|---|---|---|---|---|---|---|---|
| **ICANDELO LOKUZIKHATHALELA**<br>***SELF CARE DOMAIN*** | | | | | | | |
| **Ubunjani (*textures*) bezidlo**<br>***Food textures*** | | | | **Ukuhlamba umzimba nobuso**<br>***Washing body and face*** | | | |
| 1 | Utya izidlo ezicujiweyo/ezixutyiweyo/ezihluziweyo<br>*Eats pureed/blended/strained foods* | | | 34 | Uzama ukuhlama amalungu omzimba<br>*Tries to wash parts of body* | | |
| 2 | Utya izidlo ezigutyiweyo/ezinezigaqa<br>*Eats ground/lumpy foods* | | | 35 | Uzihlamba umzimba ngocoselelo<br>*Washes body thoroughly* | | |
| 3 | Utya izidlo ezisikiweyo/ezinqunqiweyo/ezidayisiweyo<br>*Eats cut up/chunky/diced foods* | | | 37 | Uzosula umzimba ngocoselelo<br>*Dries body thoroughly* | | |
| 4 | Utya zonke iintlobo zokutya<br>*Eats all textures of food* | | | 38 | Uhlamba osule ubuso ngocoselelo<br>*Washes and dries face thoroughly* | | |
| | | | | | | | |
| **Ukusetyenziswa kwezixhobo zokutya**<br>***Use of utensils*** | | | | **Ukunxiba (amantla)**<br>***Dressing (top half)*** | | | |
| 5 | Ukuzityisa ngeminwe<br>*Finger feeds* | | | 39 | Uyancedisa, njengokutyhala iingalo zakhe emikhonweni<br>*Assists, such as pushing arms thorough sleeves* | | |
| 6 | Ukha ngecebe ase emlonyeni<br>*Scoops with a spoon & brings to mouth* | | | 40 | Ukhulula isikipha, ilokhwe okanye ijezi (iimpahla ezikhululwa entloko)<br>*Removes T-shirt, dress or jersey (pullover garment)* | | |
| 7 | Ulisebenzisa kakuhle icephe<br>*Uses a spoon well* | | | 41 | Unxiba isikipha, ilokhwe okanye isikipha esinemikhono emide<br>*Puts on T-shirt, dress or sweater* | | |

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|---|---|---|---|---|---|---|---|
| 8 | Uyisebenzisa kakuhle ifolokhwe<br>*Uses a fork well* | | | 42 | Unxiba akhulule ishethi evulekileyo ngaphambili, zingaqukwanga izinto zokuyiqhobosha (*fastners*)<br>*Puts on & removes front-opening shirt, not including fasteners* | | |
| 9 | Usebenzisa imela ukusika ukutya<br>*Uses a knife to cut food* | | | 43 | Unxiba akhulule ishethi evulekileyo ngaphambili, kuquka nezinto zokokuyiqhobosha<br>*Puts on & removes front-opening shirt, including fasteners* | | |
| | | | | | | | |
| **Ukusetyenziswa kwezinto zokusela**<br>***Use of drinking containers*** | | | | **Ukunxiba (amazantsi)**<br>***Dressing (bottom half)*** | | | |
| 10 | Ubamba ibhotile okanye ikomityi<br>*Holds bottle or cup* | | | 49 | Uyancedisa, njengokutyhala imilenze xa enxiba<br>*Assists, such as pushing legs through pants* | | |
| 11 | Uphakamisa ikomiti ukuze asele, kodwa ikomityi leyo ingagantyaza<br>*Lifts cup to drink, but cup may tip* | | | 50 | Ukhulula ibhulukhwe enesinqe segatha<br>*Removes pants with elastic waist* | | |
| 12 | Uphakamisa ngokukhuselekileyo ikomityi evulekileyo, ngezandla ezi-2<br>*Lifts open cup securely with 2 hands* | | | 51 | Unxiba ibhulukhwe enesinqe segatha<br>*Puts on pants with elastic waist* | | |
| 13 | Uphakamisa ngokukhuselekileyo ikomityi evulekileyo, ngezandla esi-1<br>*Lifts open cup securely with 1 hand* | | | 52 | Ukhulula ibhulukhwe eqhotyoshwayo<br>*Removes pants with fasteners* | | |
| 14 | Ugalela into engamanzi esuka kwikhathuni okanye ebhotileni<br>*Pours liquid from a carton or bottle* | | | 53 | Ukhulula ibhulukhwe kunye naloo nto iyiqhoboshayo<br>*Puts on pants including fasteners* | | |
| | | | | | | | |
| **Ukukama iinwele**<br>***Hairbrushing*** | | | | **Izihlangu neekawusi**<br>***Shoes and socks*** | | | |
| 20 | Umisa intloko kakuhle xa kukanywa iinwele<br>*Holds head in position while hair is combed* | | | 54 | Ukhulula iikawusi nezihlangu<br>*Removes socks and undoes shoes* | | |
| 21 | Usa ibrashi okanye ikama entloko<br>*Brings brush or comb to head* | | | 55 | Unxiba izihlangu ezingabotshwanga<br>*Puts on unfastened shoes* | | |
| 22 | Ubrasha okanye akame iinwele<br>*Brushes or combs hair* | | | 56 | Unxiba iikawusi<br>*Puts on socks* | | |
| | | | | 57 | Unxiba izihlangu kwiinyawo ezifanelekileyo<br>*Puts shoes on correct feet* | | |
| **Ukukhathalela impumlo**<br>***Nosecare*** | | | | 58 | Angabopha iVelcro/amakhonkco ezihlangu<br>*Can fasten shoes-Velcro/buckles* | | |
| 24 | Uyavuma ukosulwa impumlo<br>*Allows nose to be wiped* | | | | | | |
| 25 | Uzifinyisa ngethishyu ayibambileyo<br>*Blows nose into held tissue* | | | **Ukuya ngasese**<br>***Toileting*** | | | |
| 26 | Uzosula impumlo esebenzisa ithishyu xa ecelwa ukuba enze njalo (*on request*)<br>*Wipes nose using tissue on request* | | | 55 | Uyancedisa ekunxibeni<br>*Assists with clothing* | | |
| 27 | Uzosula impumlo esebenzisa ithishyu engacelwanga ukuba makenze njalo<br>*Wipes nose using tissue without request* | | | 57 | Uyakwazi ukulawula iimpahla zakhe phambi nasemva kokuya ngasese<br>*Manages with clothes before* | | |

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| | | | | | *and after toileting* | | |
| 28 | Ufinya azosule imumlo engacelwanga ukuba enze njalo<br>*Blows and wipes nose without request* | | | 56 | Uyazama ukuzosula emva kokuya ngasese<br>*Tries to wipe self after toiletting* | | |
| | | | | 57 | Uyazosulisisa<br>*Wipes self thoroughly* | | |
| **Ukuhlamba izandla**<br>***Handwashing*** | | | | | | | |
| 29 | Unikezela ngezandla ukuba zihlanjwe<br>*Holds hands out to be washed* | | | **Ukulawula isinyi**<br>***Bladder management*** | | | |
| 30 | Uhlikihla izandla ukwenzela ukuzicoca<br>*Rubs hands together to clean* | | | 64 | Uyatsho xa emanzi<br>*Indicates when wet* | | |
| 32 | Uyazihlambisisa izandla<br>*Washes hands thoroughly* | | | 65 | Umane esitsho xa efuna ukuntsontsa<br>*Occasionally indicates need to pass urine* | | |
| 33 | Uyazosulisisa izandla<br>*Dries hands thoroughly* | | | 66 | Usoloko ezixela xa efuna ukuntsontsa<br>*Consistently indicates need to urinate* | | |
| | | | | 67 | Uyaziyela ethoyilethi ukuya kuntsontsa<br>*Takes self to toilet to urinate* | | |
| **Ukulawula ukuya ngasese**<br>***Bowel management*** | | | | | | | |
| 69 | Uyatsho xa efuna ukutshintshwa<br>*Indicates need to be changed* | | | | **AMANQAKU AWAFUMANAYO (*SUM*) KWICANDELO LOKUZIKHATHALELA**<br>***SELF CARE DOMAIN SUM*** | | |
| 70 | Umane esitsho xa efuna ukuya ngasese<br>*Occasionally indicates need to toilet* | | | | | | |
| 71 | Usoloko ezixela xa efuna ukuya ngasese<br>*Consistently indicates need to toilet* | | | | | | |
| 72 | Uyawazi umahluko phakathi kwaxa kufuneka entsontsile naxa kufuneka eye ngasese<br>*Distinguishes between need to pass urine & bowel movement* | | | | | | |
| 73 | Uyaziyela ethoyilethi xa esiya ngasese<br>*Distinguishes between need to pass urine & bowel movement* | | | | | | |
| 74 | Usoloko omile emini nasebusuku<br>*Takes self to toilet for bowel mvts* | | | | | | |
| | | | | | | | |
| **ICANDELO LOKUSHUKUMA**<br>***MOBILITY DOMAIN*** | | | | | | | |
| **Esitulweni – ukuhlala ngokuzinzileyo nokubhekela (*transfers*)**<br>***Chair – sitting balance and transfers*** | | | | | **Ukushukuma kwaphandle (outdoor locomotion / mobility)**<br>***Outdoor locomotion / mobility*** | | |
| 6 | Uhlala esitulweni xa exhaswe ngezinto okanye ngumkhathaleli<br>*Sits on a chair if supported by equipment or caregiver* | | | 38 | Uyahamba, kodwa abambelele ngezinto, umkhathaleli okanye izixhobo zokumxhasa<br>*Walks, but holds onto objects, caregiver or devices for support* | | |
| 7 | Uyazihlalela esitulweni engaxhaswanga nto (oko kukuthi ngokungqiyama ngomqolo)<br>*Sits unsupported on a chair ( i.e. with back support)* | | | 39 | Uyazihambela engabambelelanga<br>*Walks without support* | | |
| 8 | Uyazihlalela ebhentshini engaxhaswanga nto<br>*Sits unsupported on a bench* | | | 40 | Uhamba iimitha ezi-3 - 15*Moves 3 – 15 metres* | | |
| 9 | Uyahlala aphakame kwisitulo okanye ibhentshi emfutshane<br>*Gets on and off a low chair or bench* | | | 41 | Uhamba iimitha ezi-15 – 30<br>*Moves 15 – 30 metres* | | |
| 10 | Ukhwela aphinde ehle esitulweni | | | 42 | Uhamba iimitha ezingama-30 – | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | esilingene ukuhlala umntu omdala<br>*Gets in & out of an adult-sized chair* | | | | 50<br>*Moves 30 – 50 metres* | | |
| 11 | Ukhwela aphinde ehle esitulweni kungakhange kufuneke ukuba azincedise ngokusebenzisa iingalo zakhe<br>*Gets in and out of chair without needing to use his/her arms to help* | | | 43 | Uhamba iimitha ezingama-50 nangaphezulu kodwa ehamba nzima<br>*Moves 50 metres or more but with difficulty* | | |
| 12 | Uyakhwela aphinde ehle emotweni/eteksini<br>*Gets in and out of a car/taxi* | | | 44 | Uhamba iimitha ezingama-50 nangaphezulu ngaphandle kobunzima<br>*Moves 50 metres or more with no difficulty* | | |
| | | | | 45 | Uyakwazi ukuhamba kwiindawo ezithee tyaba<br>*Manages level surfaces* | | |
| **Ukushukuma ebhedini**<br>***Bed mobility*** | | | | 46 | Uyakwazi ukuhamba kwiindawo ezingenamatye nezinamatye<br>*Manages rough & uneven surfaces* | | |
| 16 | Angazivukela ahlale ngeempundu<br>*Can sit up from lying* | | | 49 | Wenyuka ehle iindawo eziziinduli nezehlayo (*curbs and slopes*)<br>*Up and down curbs and slopes* | | |
| 17 | Angaguquka ebhedini<br>*Can turn over in bed* | | | | | | |
| 18 | Angabhekela aye kuhlala kungqameko lwebhedi<br>*Can move to sit over the edge of bed* | | | **Izitephusi**<br>***Stairs*** | | | |
| 19 | Uyazikhwelela azehlele ebhedini ngaphandle koncedo<br>*Gets in and out of bed without help* | | | 50 | Unyuka izitephusi egaqa okanye eshixiza<br>*Crawls or bottom shuffles up stairs* | | |
| | | | | | | | |
| **Ukushukuma kwasendlwini**<br>***Indoor locomotion / mobility*** | | | | 52 | Uyazonyuka izitephusi kodwa nzima<br>*Walks up stairs but with difficulty* | | |
| 25 | Uyaguquka, agaqe, achwechwe, atshitshilize<br>*Rolls, crawls, creeps, bottom shuffles* | | | 54 | Wonyuka izitephsi ngaphandle kobunzima<br>*Walks up stairs with no difficulty* | | |
| 26 | Uhambahamba ngaphakathi endlwini ebambelela kwifanitshala<br>*Walks indoors holding onto furniture* | | | 55 | Wehla izitephusi egaqa okanye eshixiza<br>*Crawls or bottom shuffles down stairs* | | |
| 27 | Uyazihambela ngaphakathi endlwini engabambelelanga ntweni okanye engasebenzisi sixhobo sokuzixhasa<br>*Walks indoors without support or equipment* | | | 56 | Wehla izitephusi kodwa nzima<br>*Walks down stairs but with difficulty* | | |
| 28 | Uhambahamba endlwini, kodwa ngobunzima<br>*Moves within a room, but with difficulty* | | | 57 | Uyazonyuka izitephusi kodwa nzima<br>*Walks up stairs but with difficulty* | | |
| 29 | Uhambahamba endlwini ngaphandle kobunzima<br>*Moves within a room with no difficulty* | | | | | | |
| 32 | Uhambahamba ngaphakathi endlwini ubuncinane iimitha ezili-15 avule, aze avale amacango<br>*Moves indoors at least 15 metres and opens and closes doors* | | | | | | |
| 34 | Uhambisa izinto phantsi emgangathweni<br>*Moves objects along the floor* | | | | | | |
| 35 | Uphatha izinto ezincinci ngokwaneleyo ukuba zingaphathwa ngesandla esinye<br>*Carries objects small enough to be held in one hand* | | | | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 36 | Uphatha izinto ezinkulu ngokwaneleyo ukuba zingaphathwa ngezandla ezibini<br>*Carries objects large enough to require two hands* | | | **AMANQAKU AWAFUMANA KWICANDELO LOKUSHUKUMA**<br>***MOBILITY DOMAIN SUM*** | | | |
| 37 | Uphatha izinto ezophukayo okanye ezinokuchitheka<br>*Carries fragile or spillable objects* | | | | | | |
| | | | | | | | |
| **ICANDELO LOKUSEBENZA ELUNTWINI**<br>***SOCIAL FUNCTION DOMAIN*** | | | | | | | |
| **Ukuqonda iintsingiselo zamagama**<br>***Comprehension of word meanings*** | | | | | | | |
| 1 | Uyaziqonda izandi<br>*Orientates to sound* | | | | | | |
| 2 | Uyeva xa kusithiwa "hayi", uyaliva igama lakhe okanye elo labantu abaqhelileyo<br>*Responds to "no"; recognizes own name or that of familiar people* | | | | | | |
| 3 | Uqonda amagama ali-10<br>*Understands 10 words* | | | | | | |
| 4 | Uyaliqonda ixesha lokuthetha ngeemvano (*relationships*) kubantu kunye/okanye izinto ezibonakalayo<br>*Understands when you talk about relationships among people and/or things that are visible* | | | | | | |
| 5 | Uyaliqonda ixesha lokuthetha ngexesha kunye nolandelelwano lwezehlo<br>*Understands when you talk about time and sequence of events* | | | | | | |
| | | | | | | | |
| **Ukusetyenziswa konxibelelwano ngokusebenzayo**<br>***Functional use of communication*** | | | | **Ukudlala ngezinto**<br>***Play with objects*** | | | |
| 11 | Uxela amagama ezinto<br>*Names things* | | | 36 | Usebenzisa izinto zokudlala, izinto ngenjongo ethile<br>*Manipulates toys, objects with intent* | | |
| 12 | Usebenzisa amagama okanye iintshukumo ezithile ukubonisa okanye acele intshukumo yomnye umntu<br>*Uses specific words or gestures to direct or request action by someone else* | | | 37 | Usebenzisa izinto eziyinyani okanye ezibekwe endaweni yeziyinyani kwimidlalo yokulinganisa elula<br>*Uses real or substituted objects in simple pretend games* | | |
| 13 | Ufuna ulwazi ngokubuza imibuzo<br>*Seeks information by asking questions* | | | 38 | Udibanisa izinto zokwenza into ethile<br>*Puts together materials to make something* | | |
| 14 | Ucacisa into okanye intshukumo<br>*Describes an object or action* | | | 40 | Wakha aze abalise ulandelelwano olulinganiswa ngokwengqikelelo<br>*Makes up elaborate pretend sequences from imagination* | | |
| 15 | Usixelela iingcinga neemvakalelo zakhe<br>*Tells about own thoughts & feelings* | | | | | | |
| | | | | **Ulwazi olungaye l** | | | |
| **Ubunzima bokubeka izimvo zakhe**<br>***Complexity of expressive communication*** | | | | 41 | Angalixela igama lakhe<br>*Can state first name* | | |
| 16 | Usebenzisa izijekulo/iintshukumo ezinentsingiselo ecacileyo<br>*Uses gestures/signs with clear meaning* | | | 42 | Angalixela igama nefani yakhe<br>*Can state first and last names* | | |
| 17 | Usebenzisa amagama amanye anentsingiselo | | | 43 | Unika amagama neenkcukacha ezicacisa usapho lwakowabo | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | *Uses single word with meaning* | | | | *Provides names and descriptive information about family* | | |
| 18 | Usebenzisa amagama ama-2 kunye ngokunentsingiselo<br>*Uses 2 words together with meaning* | | | 45 | Angamcacisela umntu omdala indlela yokunceda umntwana abuyele ekhaya | | |
| 19 | Usebenzisa izivakalisi ezinamagama ama-4 – 5<br>*Uses 4 – 5 word sentences* | | | | | | |
| 20 | Udibanisa iingcinga ezi-2 nangaphezulu, ukubalisa ibali elilula<br>*Connects 2 or more thoughts to tell a simple story* | | | **Ukwazi ixesha**<br>***Time orientation*** | | | |
| | | | | 46 | Uyawaqonda gabalala amaxesha okutya nawezinto azenza qho ngemini<br>*Has a general awareness of time of mealtimes and daily routines* | | |
| **Ukudlala okwenziwa noluntu**<br>**S*ocial interactive play*** | | | | 47 | Unolwazi oluthile lolandelelwano lwemicimbi eqhelekileyo ngeveki<br>*Has some awareness of sequence of familiar events in a week* | | |
| 26 | Ubonisa ukubaqonda abanye nokuba nomdla kubo<br>*Shows awareness and interest in others* | | | 48 | Ixesha elithile ulidibanisa nezenzo/imicimbi<br>*Associates a specific time with actions/events* | | |
| 27 | Uqala indlela yokudlala ayiqhelileyo<br>*Initiates a familiar play routine* | | | | | | |
| 28 | Udlala indima kumdlalo olula xa exelelwe ukuba angene<br>*Takes turn in simple play when cued for turn* | | | **Imisetyenzana yasekhaya**<br>***Household chores*** | | | |
| 29 | Uyazama ukukopa intshukumo ebisenziwa ngumntu omdala xa kudlalwa umdlalo<br>*Attempts to copy adult's previous action during a play activity* | | | 51 | Uqalisa ukunceda ekukhathaleleni izinto zakhe esoloko ekhokelwa exelelwa amakakwenze<br>*Beginning to help care for own belongings with constant direction and guidance* | | |
| | | | | 52 | Uyaqalisa ukuncedisa kwimisetyenzana elula yasekhaya encediswa<br>*Beginning to help with simple household chores with help* | | |
| **Indlela aphathisana ngayo nabanye abantwana**<br>***Interaction with other children*** | | | | 53 | Udla ngokuqala iindlela ezilula zokukhathalela izinto zakhe okanye ukwenza imisetyenzana yasekhaya<br>*Occasionally initiates simple routines to care for own belongings or household chores* | | |
| 31 | Uyabuqonda ubukho babanye abantwana, unokuthetha nokwenza iintshukumo ezijolise kwabo bangangaye<br>*Notices presence of other children, may vocalize & gesture towards peers* | | | 55 | Usoloko eqala aze enze imisetyenzana yasekhaya, unokufuna uncedo lwamandla ukwenza oko<br>*Consistently initiates and carries out household chores; may need physical help to do so* | | |
| 32 | Uyasebenzisana nabanye abantwana kwiimeko ezilula nezimfutshane<br>*nteracts with other children in simple and brief episodes* | | | | | | |
| 33 | Uzama ukwenza amalungiselelo alula omsetyenzana ongumdlalo ekunye nomnye umntwana<br>*Tries to work out simple plans for a* | | | **Ukuzikhusela**<br>***Self-protection*** | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | *play activity with another child* | | | | | | |
| | | | | 56 | Ubonisa ukulumka okufanelekileyo xa ekufutshane nezinto ezitshisayo okanye ezibukhali<br>*Shows appropriate caution around hot or sharp objects* | | |
| **Ukusebenza nokuthatha inxaxheba ekuhlaleni**<br>***Community function and participation*** | | | | 57 | Uyazazi ukuba akufunekanga avume ukukhweliswa, ukuphiwa ukutya okanye imali ngabantu angabaziyo<br>*Knows not to accept rides, food or money from strangers* | | |
| 61 | Umntwana angadlala ngokukhuselekileyo ekhaya kungekho mntu umgadileyo<br>*Child may play safely at home without being watched* | | | | | | |
| 62 | Umntana angahambahamba kwindawo ayiqhelileyo engaphandle kwekhaya emana ekrotywa nje<br>*Child can go around familiar environment outside of home with only periodic monitoring* | | | **AMANQAKU AWAFUMANA KWICANDELO LOKUSEBENZA ELUNTWINI**<br>***SOCIAL FUNCTION DOMAIN SUM*** | | | |
| 64 | Angakhangela asebenze kwiindawo aziqhelileyo zasekuhlaleni engagadwanga<br>*Can explore and function in a familiar community setting without supervision* | | | | | | |
| 65 | Umntwana angathenga izinto ngaphandle koncedo kwivenkile yasekuhlaleni<br>*Child can buy things at the local shop without assistance* | | | AMANQAKU EWONKE<br>*TOTAL SCORE* | | | |

# APPENDIX O

## Letters to Principle Therapists

Malamulele Onward
Possibilities for Africa's Children with Cerebral Palsy

Section 21 company

registration no. 2006/032287/08

*12 a Rhodes Avenue, Parktown, Johannesburg, 2193. SOUTH AFRICA Tel (011) 726-1555*

2 July 2007

**FOR ATTENTION:** Norina Nondudule
Physiotherapist

**Fax: 047 491 0771**

Dear Norina

**SCREENING VISIT: 20 – 24 AUGUST 2007**

As a follow-up to our telephone conversation last week, I am writing to confirm the purpose and the arrangements for the screening week which is the first part of the Malamulele Onward outreach to Butterworth and Tafalofefe. This letter is also being sent to Busi and Misty.

The **purpose** of this visit is to:

2.1 Introduce the project to the children, their caregivers and all the relevant local rehabilitation staff.
2.2 To screen the children to confirm that they will benefit from a week of intensive Bobath/NDT therapy.
2.3 To interview the caregivers to establish their main concerns regarding their children together with their expectations of therapy.
2.4 To complete baseline assessments on all the children who will be participating in the intervention week.
2.5 To ascertain what equipment the children need and to take measurements

The work Malamulele Onward is doing in Butterworth/Tafalofefe will form part of a bigger study, the aim of which is to determine "what works best" with regard to the content and the process of therapy for children with cerebral palsy living in disadvantaged areas. Thus the baseline assessments will done in great detail. These assessments will be repeated immediately prior to the intervention; directly after the intervention and two months later.

A team of six therapists and two field workers (or research assistants) will do all the assessments. These therapists are specially recruited and will need to be trained in how to do the assessments, specifically the Gross Motor Function Measure.

The **programme** for the screening week is thus as follows:

| | | |
|---|---|---|
| Monday 20 August: | am | Introduction<br>Training of therapists in how to do the GMFM<br>Training of field workers in how to do the interviews |
| | Pm | FIVE children to come for the assessments (so here the training will be combined with the pilot study to clarify and solve any problems. |
| Tuesday 21 Aug: | 8 am | 8 children to come in for assessment |
| | 1 pm | 7 children to come in for assessment |
| Wednesday 22 Aug: | 8 am | 8 children to come in for assessment |
| | 1 pm | 7 children to come in for assessment |
| Thursday 23 Aug: | 8 am | 8 children to come in for assessment |
| | 1 pm | 7 children to come in for assessment |
| Friday 24 Aug: | am | Any outstanding work or assessments |

**What needs to be done:**

1. **Caregivers need to be given appointments** to come for the assessments. As outlined above, we will assess five children on the first day and then 15 on the Tuesday, Wednesday and Thursday – eight in the morning and 7 in the afternoon. These appointments need to given by the local rehabilitation staff ie. Busi and Misty.

   The venue for the assessments will depend on where the children are coming from – we could do one day at Butterworth Hospital; one day at Nqamakwe Clinic and one day at Tafalofefe Hospital. Or alternatively, all three days could be done at Butterworth Hospital. I am relying on Norene, Busi and Misty to make the best arrangements for organizing the children and the venue. They will need to let me know what these arrangements are. Malamulele Onward will cover the local taxi fares for caregivers to bring their children in to the hospital or clinic for the assessments.

2. **A local field worker needs to be recruited** to assist with the caregiver interviews. Ideally, this field worker should be a mother or a sibling of a disabled child and he/she needs to speak English and Xhosa well. This person also neIeds to be available for all the assessment dates. The idea of training a local person to assist with the research is part of the process of empowerment and capacity building. This person may become a local resource and be able to assist with any future studies. For this study, they will be paid a small honorarium and their daily transport costs will be covered. I am anticipating the Norene, Busi, Misty or any of the other local therapists will be able to identify and recruit this field worker.

The accommodation and transport costs of the Malamulele Onward therapists and field workers will be covered by Malamulele Onward.

Please let me know if you have any queries.

**DR. GILLIAN SALOOJEE**

gsaloojee@icon.co.za; 072 483 -5766

Section 21 company registration no. 2006/032287/08

*12 a Rhodes Avenue, Parktown, Johannesburg, 2193. SOUTH AFRICA Tel (011) 726-1555*

25 April 2007

**FOR ATTENTION:** Busi and Misty
Physiotherapy and Occupational Therapy Deparments
Tafalofefe Hospitals

**Fax: 047 498 7088**

Dear Busi and Misty

**DATES FOR INTERVENTION**

Please accept my apologies for not getting this information to you earlier. It has been so busy here with NDT basic and advanced courses and I have had also a lot of people staying with me. As promised, here is the letter I sent to Joyce in March.

**To summarize:**
I am anticipating that there will be more than 25 children in the area who would benefit from a week of intervention. We can see maximum of 25 children in one week. So I am making provision for two weeks of intervention – so the children can be divided into two groups.

I will come for the **screening visit the week of 20 – 24 August 2007**. You and the rehab team can decide where we will see the children – whether it is at Nqamakwe, or Butterworth or Tafalofefe. I will let you know how many children we can assess each day and then you can give the mothers appointments.

The **intervention weeks will be from the 22 – 26 October 2007 and the following week 29 October – 2 November 2007.** We can decide in August where the venues will be for each week – either Butterworth, Nqamakwe or Tafalofefe. It will depend on where the children are from, how easy it is for them to get transport and also how much space there is in the hospital or health centre. I know there is a lot of space at Tafalofefe and we also discussed whether it might be possible for the mothers to come and stay at the hospital for the whole week, if transport is difficult.
Please let me know if you have any queries.

**DR. GILLIAN SALOOJEE**
gsaloojee@icon.co.za; 072 483 -5766

# APPENDIX P

# Treatment Goals for Each Participant

**SHORT TERM TREATMENT GOALS FOR BUTTERWORTH OUTREACH 2007**

| NO | TREATMENT GOALS | NO | TREATMENT GOALS |
|---|---|---|---|
| 1 | ▪ Independent standing<br>▪ Walking with assistance<br>▪ Pull to stand | 2 | ▪ Help to reduce stiffness<br>▪ Improve use of vision<br>▪ Positioning, working for symmetry<br>▪ Try to get some interaction and response from the child.<br>▪ Get flex of hips – ness to enable child to be positioned in sitting. |
| 3 | ▪ Standing at a bench<br>▪ Walking with assistance<br>▪ More independence in ADL<br>▪ More interest in play and use of his hands | 4 | ▪ Establish communication / interaction with child<br>▪ Improve use of functional vision |
| 5 | ▪ Reduce spasms & pushing<br>▪ Be able to be placed in sitting and also in standing box<br>▪ Feeding & drinking | 6 | ▪ Facilitate rolling for at least part of the sequence of rolling<br>▪ To be able to sit independently for a brief period<br>▪ Use hands together in midline to play<br>▪ Touch a toy and bring to midline<br>▪ Standing at a table for brief periods<br>▪ Assist with constipation<br>▪ Assist with sleeping |
| 8 | ▪ Independent sitting on bench, taking weight thru hands and feet.<br>▪ Standing in standing frame<br>▪ Communication – be able to indicate 1 or 2 signs<br>▪ Keep her mouth closed and chew | 9 | ▪ Balance in sitting<br>▪ Use of hands for play<br>▪ Use of arms for balance / weightbearing<br>▪ Able to stand in a standing frame & take weight thru legs<br>▪ Self feeding<br>▪ Some basic help with communication |
| 10 | ▪ Independent standing<br>▪ Walking 100m with reverse walker<br>▪ Standing & sweeping | 11 | ▪ Improve dynamic balance in standing<br>▪ Self feeding and dressing – NB chewing |
| 12 | ▪ Find positon where he can be placed and maintained in a more symmetrical position.<br>▪ Use of vision – just to look & then to perhaps follow<br>▪ Eating & drinking – more solids | 13 | ▪ Some active use of R hand for bilateral activities<br>▪ Independent standing<br>▪ Walking with less support and for longer<br>▪ To understand 1 or 2 signs |

| NO | TREATMENT GOALS | NO | TREATMENT GOALS |
|---|---|---|---|
| 15 | ▪ Supported sitting, with forearm support at a table to play<br>▪ Specific sensory stimulation of UL to encourage exploration<br>▪ Standing in standing box<br>▪ Eating and drinking | 17 | ▪ Standing independently, holding on<br>▪ Assisted walking<br>▪ Communication NB – does have words<br>▪ Assist with dressing and undressing |
| 18 | ▪ Supported sitting - forearm support<br>▪ Standing in box<br>▪ Some exploration with hands – possible raking or gross grasp<br>▪ Visual fixation on an object | 19 | ▪ Gen advice, and ideas on stimulating low toned child<br>▪ Feeding – vomits solids |
| 20 | ▪ Tolerate standing in standing box<br>▪ Sitting independently on a block – hands down<br>▪ Exploring/touching a toy with both hands | 22 | ▪ Improve sitting balance<br>▪ R UL weightbearing in preparation for self-propulsion of wheelchair. |
| 25 | ▪ Functional sitting for play<br>▪ Standing in standing box<br>▪ Sustained grasp<br>▪ Self-feeding using R hand<br>▪ Communication – be able to indicate toilet needs<br>▪ Preparation for school | 27 | ▪ Chewing, eating firmer foods<br>▪ To be able to be placed in a standing frame and bat/push/touch a toy<br>▪ Assisted walking (with another person)<br>▪ Few signs to indicate needs |
| 28 | ▪ To be placed in a standing frame and hold his head up<br>▪ To maintain the alignment when positioned for sleeping<br>▪ To get interaction / consistent response with another person | 29 | ▪ Standing independently at a table<br>▪ Sequencing from sitting to standing at a table<br>▪ Use of both hands to hold and explore an object<br>▪ Self feeding (finger feeding) |
| 31 | ▪ Loosening<br>▪ Be able to be positioned without pushing<br>▪ Help mom with handling<br>▪ Look at vision<br>▪ Feeding – lateral finger feeding – encourage chewing, assist with feeding – try to get lip closure | 32 | ▪ Release the arms and enable hands to be open<br>▪ Be able to sit on a block with arms relaxed and at his sides<br>▪ Be able to take some wt through his arms<br>▪ Be able to stand in a standing box with relaxed arms and have a drink |
| 34 | ▪ Be able to keep her head up whilst in the standing frame<br>▪ Sit independently<br>▪ Breathing – enable her to breathe more deeply<br>▪ Watch the kyphosis of her spine<br>▪ Self propulsion in a wheelchair | 36 | ▪ Standing and playing at a table<br>▪ Walking a few steps with the help of a trolley<br>▪ Sequences – getting from lying to sitting by himself<br>▪ Use of hands to explore a large object |

| NO | TREATMENT GOALS | NO | TREATMENT GOALS |
|---|---|---|---|
| 37 | ▪ To be able to be positioned in a standing frame<br>▪ Sitting on a bench for dressing and undressing without becoming stiff<br>▪ Chewing (only eating purity at the moment)<br>▪ Appropriate seating for play and use of hands | 38 | ▪ Independent sitting on a bench for 3 seconds<br>▪ Chewing and lateral finger feeding<br>▪ Be able to explore a toy using both hands<br>▪ Be able to take weight through arms in sitting |
| 39 | ▪ Dynamic sitting balance for play ie. To be able to play in sitting<br>▪ Toilet training – be able to indicate needs<br>▪ Standing alone at a table<br>▪ Self feeding | 40 | ▪ Self feeding<br>▪ Address the drooling<br>▪ Walking independently with a rollater or trolley<br>▪ More purposeful play – understanding a few signs or gestures |
| 41 | ▪ Make her smile<br>▪ Understand why she falls so much, and whether there is anything which can change this<br>▪ Self feeding<br>▪ Basic communication<br>▪ Find positions where there is greater symmetry<br>▪ Reduce flexor hypertonus and increase active extension, so that she stands with a more upright posture | 43 | ▪ Work for symmetry<br>▪ Active extension and elongation of L side of trunk<br>▪ Weight transfer onto L side<br>▪ Active weight bearing through L side<br>▪ Bilateral upper limb activities<br>▪ Try constraint induced therapy |
| 46 | ▪ Help him to be looser<br>▪ Help granny to understand his problems<br>▪ Chewing and lateral finger feeding<br>▪ Find ways of positioning him in better alignment<br>▪ Use of vision for scanning | 52 | ▪ Establish simple communication system<br>▪ Stand symmetrically in standing frame, keeping head in midline and arms forward eg. to look at a book<br>▪ Simple hand function – be able to reach out and explore a toy |

# APPENDIX Q

# Equipment List

**EQUIPMENT NEEDED FOR BUTTERWORTH OUTREACH 2007**

| NO | | | EQUIPMENT | | | | |
|---|---|---|---|---|---|---|---|
| 1 | | | 20 cm block | | AFO - L foot | Soft UL splints | Kiddies trolley |
| 2 | Madiba buggy | | Medium wedges<br>Positioning Foam | | | | Prone stander<br>Side-lyer |
| 3 | Madiba buggy | Med standing box | 22 cm block | | Bilateral AFOs | | Scooter |
| 4 | | Small standing box | 18 cm bench | APT table and chair | | | |
| 5 | | Small standing box | 16 cm bench | APT chair and table | | | |
| 6 | | APT standing box | | APT chair and table | | | |
| 8 | 14" SAM chair and tray | Med standing box | 25 cm bench | | Bilateral AFO | | Low tech AAC |
| 9 | | Med standing box | 16 cm bench | | Footplates | | |
| 10 | | Med standing box | | | | Soft UL splints | Tricycle<br>Reverse Walker |
| 11 | | | 30 cm bench | | | | Tricycle |
| 12 | | | Positioning Foam | APT table and chair<br>Jumbo Bumbo seat | | | Side lyer |
| 13 | | | 25 cm bench | | "rubber" Gaiter | Soft splint - R UL | Low tech AAC |
| 15 | McLaren buggy | Med standing box | 25 cm bench | APT chair | | Soft UL splint | |
| 17 | 26 cm bench | Med standing box | | | Bilateral AFO | | Reverse Walker |
| 18 | Madiba bugggy | Med standing box | | APT table and chair | | | |
| 19 | | Med standing box | 17 cm block | Jumbo Bumbo seat | | | |
| 20 | Madibabuggy | Med standing box | 19 cm block | Jumbo Bumbo seat | Bilateral AFO | | |
| 22 | 14" Sam chair with Monty back | Med standing box | 21 cm bench | | | | |
| 25 | Madibabuggy | Med standing box | 24 cm bench | | | | Adapted pencil grip<br>Books |
| 27 | | Med standing box | | | | Soft UL splints | |
| 28 | Madibabuggy | Med standing box | Two wedges<br>Positioning foam | | | Soft UL splints | |
| 29 | | | 19 cm block | | | | |
| 31 | | Small standing box | Two wedges | | | | APT side lyer<br>APT prone stander<br>Jumbo Bumbo seat |

| NO | | | EQUIPMENT | | | | |
|---|---|---|---|---|---|---|---|
| 32 | Madiba buggy | standing frame | block or bench | | | | |
| 34 | 12" SAM wheelchair with Monty back | Med standing box | 19 cm bench | | | | |
| 36 | | | 17 cm block | | | soft UL splints | rollater / trolley table 38-40cm high for cruising |
| 37 | Madiba buggy | Med standing box | 21cm bench | APT table | Soft LL splints<br>Bilateral AFO | Soft UL splints | Jumbo Bumbo seat |
| 38 | Madiba buggy | Med standing box | 22,5 cm bench | | Bilateral AFO | | |
| 39 | Madiba buggy | Med standing box | Bench | APT table and chair | Bilateral AFOs | | |
| 40 | McLaren buggy | | 20cm block | | | | rollater/trolley |
| 41 | L arm drive paediatric wheelchair | Large standing box | | | Soft LL splints | | AAC – low tech<br>Walking stick |
| 43 | | | | | | | |
| 46 | Madiba buggy | Med standing frame | 29cm bench - make wider | | Soft LL splints | Soft UL splints | Side lyer |
| 52 | Madiba buggy | Med standing box | 27 cm bench<br>Two wedges | | | | AAC – low tech<br>Books |

## APPENDIX R

## Example of Daily Schedule

<table>
<tr><th colspan="3">Morning Sessions</th><th>Lunch</th><th colspan="3">Afternoon Sessions</th></tr>
<tr><td>6 children scheduled for individual NDT</td><td>Tea provided</td><td>7 children scheduled for individual NDT</td><td rowspan="4">1:00 – 1:30</td><td>6 children scheduled for individual NDT</td><td>Tea provided</td><td>6 children scheduled for individual NDT</td></tr>
<tr><td colspan="3">The 13 “morning session” children scheduled for equipment adjustments whilst waiting for their individual NDT session.</td><td colspan="3">The 12 “afternoon session” children scheduled for equipment adjustments whilst waiting for their individual NDT session.</td></tr>
<tr><td colspan="3">The 12 “afternoon session” children scheduled to practice skills and play.</td><td colspan="3">The 13 “morning session” children scheduled to practice skills and play.</td></tr>
</table>

# APPENDIX S

# SUMMARY OF GMFM-66 AND PEDI-MFSS RESULTS COMPARED TO PARENTS PERCEIVED AREAS OF IMPROVEMENT TABLE

**SUMMARY OF GMFM-66 AND PEDI-MODIFIED RESULTS COMPARED TO PARENTS PERCEIVED AREAS OF IMPROVEMENT TABLE (*n*=34)**

| n GMFCS (*n*= 34 ) | PEDI Areas of perceived improvement | | GMFM (*n*=29) | | Parents Perceived Areas Improvement at Follow-up | | Summary of Parent Comments at 3rd & 4th Assessments | Equipment, Assistive Devices and Furniture issued to Participants | |
|---|---|---|---|---|---|---|---|---|---|
| V | ↑ Self-care | 86.6% | ↑GMFM66 | 57.14% | Dressing | 60% | It's easier to dress and undress him now. | Standing box | 73.3% |
| 15 | ↑ Mobility | 26.6% | ↑GMFM88 | 57.14% | Overall mobility | 60% | He can now straighten his arms | Madiba buggy | 53.3% |
| | ↑ Social | 73.3% | | | Drinking | 53.3% | He can drink now without choking. | Bench | 53.3% |
| | | | =GMFM66 | 14.28% | Bathing | 46.6% | Tries to grasp a towel. | Wedge | 46.6% |
| | = Self-care | 6.6% | =GMFM88 | 21.24% | Eating | 40% | It's quicker to feed my child. | APT table and chair | 40% |
| | = Mobility | 33.2% | | | Lying and rolling | 26.6% | He can now roll from side to side. | Soft UL splint | 33.3% |
| | = Social | 20% | ↓GMFM66 | 28.57% | Standing | 26.6% | She likes to stand now, before she was only happy to sit. | Side lyer | 26.6% |
| | | | ↓GMFM88 | 21.42% | Grooming | 20% | She now calls to have her hair combed. | Bumbo seat | 26.6% |
| | | | | | Expressive communication | 20% | He responds now when you're calling him and turns his eyes to look at his mother. | Prone stander | 20% |
| | | | | | Play interaction | 20% | She is reaching out for objects and able to play with them. | Foam blocks for positioning | 13.3% |
| | | | | | Toilet | 6.6% | | Low tech AAC | 13.3% |
| | | | | | Crawling & Kneeling | 6.6% | | Block | 13.3% |
| | | | | | | | | Bilateral AFOs (orthotics) | 13.3% |
| | | | | | Play hand skill | 6.6% | He can now play with toys on the buggy table. | Books | 6.6% |
| | | | | | Sitting | 6.6% | She is no longer crying when you sit her. | SAM wheelchair | 6.6% |
| | | | | | Auditory attention | 6.6% | His hearing has improved as he likes to listen to music | Foam mattress | 6.6% |
| | | | | | | | | "Rubber" gaiter | 6.6% |
| | | | | | | | | Adapted pencil grips | 6.6% |
| IV | ↑ Self-care | 90% | ↑GMFM66 | 50% | Overall mobility | 90% | The arms are no longer as tight as before | Standing box | 100% |
| 10 | ↑ Mobility | 50% | ↑GMFM88 | 60% | Dressing | 80% | He tries to pull of the trousers down to the feet. | Bench | 60% |
| | ↑ Social | 70% | | | Grooming | 70% | He now does his own teeth and you can wipe his nose | Madiba buggy | 50% |
| | | | =GMFM66 | 30% | Eating | 70% | She can eat mashed food now. | AFO | 45% |
| | = Self-care | | =GMFM88 | 10% | Lying and rolling | 60% | He can now roll from side to side. | Soft UL splints | 20% |
| | = Mobility | 20% | | | Sitting | 50% | She is now able to sit without support. | Block | 30% |
| | = Social | | ↓GMFM66 | 20% | Drinking | 30% | He can now lift the mug up to his mouth. | SAM chair and tray | 20% |
| | | | ↓GMFM88 | 30% | Crawling & Kneeling | 30% | She now tries to move from one point to another using her stomach. He is able to wash himself. | Wheelchair adjustment Soft LL splints | 20% 20% |
| | | | | | Bathing | 30% | He is now able to indicate the need and wait for me to take a potty. | APT Chair & table | 10% |
| | | | | | Toilet | 30% | He now cries when he needs something. | Rollater | 10% |
| | | | | | Expressive communication | 10% | He is able to use his hands | Scooter | 10% |
| | | | | | Play interaction | 10% | He can differentiate between a stranger and his mother. | Low tech AAC | 10% |
| | | | | | Play ability | 10% | | Reverse walker | 10% |
| | | | | | Social Awareness | 10% | | Tricycle | 10% |
| | | | | | | | | Bumbo chair | 10% |
| | | | | | | | | Shoes with sole plates | 10% |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| III | ↑ Self-care | 100% | ↑GMFM66 | 75% | Dressing | 71.4% | He helps by pulling on the clothes | Block | 57% |
| 7 | ↑ Mobility | 85.7% | ↑GMFM88 | 75% | Drinking | 57.1% | He now holds the glass although he spilt the contents. | AFO | 42.8% |
| | ↑ Social | 85.7% | | | Eating | 57.1% | He eats what we eat now. | Trolley/ Rollator | 42.8% |
| | | | ↓GMFM66 | 25% | Lying and rolling | 57.1% | Before he was only trying to turn, now he is able to turn himself. | Standing box | 42.8% |
| | | | ↓GMFM88 | 25% | | | He can now take the toothbrush to the mouth. | Soft UL splints | 28.5% |
| | | | | | Grooming | 42.8% | He is now using his limbs much better than before. | Bench | 28.5% |
| | | | | | Overall mobility | 42.8% | He now points to things he wants. To speak some few words | Shoes with sole plates | 14.3% |
| | | | | | Expressive | 42.8% | He can now sit on the bench and count to five without falling | Wheelchair | 14.3% |
| | | | | | communication | | The way she stands has improved. | Reverse walker | 14.3% |
| | | | | | Sitting | 42.8% | | Table | 14.3% |
| | | | | | | | He can now direct other children in the type of play he wants | McLaren buggy | 14.3% |
| | | | | | Standing | 42.8% | He can now feel when he needs the toilet | Wheelchair | 14.3% |
| | | | | | Bathing | 28.5% | She can now kneel to watch, before we put her in a bath. | | |
| | | | | | Play interaction | 28.5% | She walks faster. | | |
| | | | | | Toileting | 28.5% | | | |
| | | | | | Crawling & | 28.5% | | | |
| | | | | | Kneeling | 28.5% | | | |
| | | | | | Walking | 28.5% | | | |
| II | ↑ Self-care | | =GMFM66 | | Dressing | | Now independent with dressing. | Bench | 100% |
| 1 | ↑ Mobility | | =GMFM88 | | Grooming | | He is now able to brush his teeth. | Tricycle | 100% |
| | ↑ Social | | | | Drinking | | | | |
| | | | | | Eating | | He can now hold objects and feed himself. | | |
| | | | | | Walking | | He can now go down stairs. | | |
| | | | | | Standing | | He is now balanced and more consistent. | | |
| I | ↑ Self-care | | | | Dressing | | She helps to undress herself. | Soft UL splints | 100% |
| 1 | ↑ Mobility | | | | | | When her nose is wet she wipes it. | | |
| | ↑ Social | | | | | | She helps when bathing | | |
| | | | | | Grooming | | | | |
| | | | | | Bathing | | The left hand was unable to work, but now it does. | | |
| | | | | | Overall mobility | | The left leg that was affected is also working. | | |

# APPENDIX T

## Individual Summary of Test Results and Parents Perceived Areas of Improvement (*n*=34)

| PEDI | GMFM (*n*=29) | Child GMFCS | Parents Perceived Areas Improvement atFollow-up | Summary of Parent Comments at 3rd& 4th Assessments |
|---|---|---|---|---|
| ↑ Self-care | | 1 | Dressing | He helps by pulling on the clothes |
| ↑ Mobility | | III | Grooming | He can now take the toothbrush to the mouth. |
| ↑ Social | | | Drinking | He can now play with a towel. |
| | | | Eating | He eats what we eat now. |
| | | | Crawling & Kneeling | He now holds the glass although he spilt the |
| | | | Expressive communication | contents. |
| | | | Play interaction | He now points to things he wants. |
| | | | | He throws the ball back if you play with him |
| ↑ Self-care | GMFM66 = | 2 | Dressing | It's quicker to feed my child now after the treatment. |
| = Mobility | GMFM88 = | V | Grooming | It's easier to dress and undress him now. |
| ↑ Social | | | Drinking | |
| ↑ Self-care | GMFM66 ↓ | 3 | Dressing | He tries to pull of the trousers down to the feet. |
| ↑ Mobility | GMFM88 ↓ | IV | Grooming | He can now lift the mug up to his mouth. |
| | | | Drinking | He can now roll from side to side. |
| | | | Overall mobility | |
| ↑ Self-care | GMFM66 ↑ | 4 | Eating | He can now eat food from a spoon. |
| ↑ Mobility | GMFM88 ↑ | V | Overall mobility | He can now straighten his arms. |
| ↑ Social | | | | |
| ↑ Self-care | GMFM66 ↑ | 5 | Drinking | He can now lift his head. |
| ↑ Mobility | GMFM88 = | V | Lying &Rolling | He can now roll from side to side. |
| ↑ Social | | | Expressive communication | He can drink now without choking. |
| | | | Play interactions | He responds now when you're calling him and turns |
| | | | Play: Hand skills | his eyes to look at his mother. |
| ↑ Self-care | GMFM66 ↓ | 6 | Dressing | It is much easier to dress him because he is relaxed. |
| = Mobility | GMFM88 ↓ | V | Bathing | He now plays in the water. |
| | | | Overall mobility | |
| ↑ Self-care | GMFM66 ↑ | 8 | Drinking | She can now hold the glass and take it to her mouth. |
| ↑ Mobility | GMFM88 ↑ | IV | Eating | She can eat mashed food now. |
| ↑ Social | | | Overall mobility | She can now open and close her hand. |
| | | | Lying &Rolling | She now tries to reach out for objects. |
| | | | Sitting | She is now able to turn partially. |
| | | | | She is now able to sit without support. |
| ↑ Self-care | | 9 | Dressing | He helps with upper body undressing now. |
| ↑ Mobility | | III | Grooming | He takes his toothbrush to his mouth and his comb |
| ↑ Social | | | Drinking | to his head. |
| | | | Sitting | He no longer spills when he drinks water. |
| | | | Walking | He is now using his limbs much better than before. |
| | | | | He can now sit on the bench and count to five |
| | | | | without falling. |

| PEDI | GMFM (*n*=29) | Child GMFCS | Parents Perceived Areas Improvement atFollow-up | Summary of Parent Comments at 3rd& 4th Assessments |
|---|---|---|---|---|
| ↑ Self-care | GMFM66 = | 10 | Dressing | He now dresses his upper body himself. |
| ↑ Mobility | GMFM88 ↑ | IV | Grooming | He now does his own teeth and is able to wash |
| | | | Bathing | himself. |
| | | | Overall mobility | The quality of his movement is better than before |
| | | | Lying &Rolling | and his hips are now loose. |
| | | | | He can now sit with his legs crossed without |
| | | | | assistance. |
| ↑ Self-care | GMFM66 = | 11 | Grooming | Now independent with dressing. |
| ↑ Mobility | GMFM88 = | II | Drinking | He is now able to brush his teeth. |
| ↑ Social | | | Eating | He can now go down stairs. |
| | | | Standing | He is now balanced and more consistent. |
| | | | Walking | He can now hold objects and feed himself. |
| ↑ Self-care | GMFM66 = | 12 | Drinking | The child is not as tight as before. |
| ↑ Social | GMFM88 ↑ | V | Eating | The feeding and drinking is much better now as he |
| | | | Overall mobility | can now swallow. |
| ↑ Self-care | GMFM66 ↓ | 13 | Dressing | She used to spill, but is now much better with |
| ↑ Mobility | GMFM88 ↓ | V | Bathing | feeding. |
| ↑ Social | | | Drinking | Her arm was a very tight, she is now able to grasp |
| | | | Eating | for objects. |
| | | | Crawling & kneeling | The way she drinks and eats is faster now. |
| | | | | She now helps when I dress and undress. |
| | | | | Her hand is no longer tight and fisted. |
| ↑ Self-care | | 15 | Bathing | She is no longer spilling as before. |
| ↑ Social | | V | Drinking | She is now chewing food not just swallowing. |
| | | | Eating | She is more relaxed than before. |
| | | | Lying &Rolling | Now rolls from side to side |
| ↑ Self-care | GMFM66 ↓ | 17 | Dressing | The quantity of doing dressing is finer than before. |
| ↑ Mobility | GMFM88 ↓ | III | Expressive communication | He can now direct other children in the type of play |
| ↑ Social | | | Play interactions | he wants. |
| ↑ Self-care | GMFM66 ↓ | 18 | Dressing | He is now helping by pushing the arm when I dress |
| ↑ Social | GMFM88 = | V | Bathing | him. |
| | | | Overall mobility | He can now chew food. |
| | | | Sitting | He can now sit for a few moments without support. |
| ↑ Self-care | GMFM66 ↑ | 19 | Overall mobility | She can now roll one side to the other side. |
| = Mobility | GMFM88 ↓ | IV | Lying &Rolling | |
| ↑ Self-care | GMFM66 ↑ | 20 | Dressing | She is trying to hold a cup now. |
| ↑ Social | GMFM88 ↑ | V | Grooming | She is no longer crying when you sit her. |
| | | | Bathing | She is reaching out for objects and able to play with |
| | | | Drinking | them. |
| | | | Expressive communication | |
| | | | Play interaction | |
| ↑ Self-care | GMFM66 ↓ | 22 | Eating | She can now sit on a chair at her table. |
| ↑ Mobility | GMFM88 ↓ | IV | Crawling & kneeling | She now tries to move from one point to another |
| ↑ Social | | | | using her stomach. |

| PEDI | GMFM (*n*=29) | Child GMFCS | Parents Perceived Areas Improvement atFollow-up | Summary of Parent Comments at 3rd& 4th Assessments |
|---|---|---|---|---|
| ↑ Self-care | GMFM66 ↓ | 25 | Dressing | He tries to help with dressing and undressing. |
| ↑ Mobility | GMFM88 ↑ | V | Bathing | Tries to grasp a towel. |
| ↑ Social | | | Overall mobility | He can roll now. |
| | | | Lying &Rolling | He can now sit for five to 10 minutes which he could |
| | | | Sitting | not before. |
| | | | Standing | He tries to stand against objects. |
| ↑ Self-care | GMFM66 ↑ | 27 | Dressing | He now tries to lift the arm when dressing. |
| ↑ Mobility | GMFM88 ↑ | IV | Grooming | He enjoys putting the toothbrush in his mouth. |
| ↑ Social | | | Eating | He is now able to chew food. |
| ↑ Self-care | GMFM66 ↑ | 28 | Drinking | He is able to drink better. |
| = Social | GMFM88 ↑ | V | Sitting | He can sit and I can count 1 – 10 while he sits. |
| | | | Overall mobility | He is more relaxed now than before. |
| ↑ Self-care | GMFM66 ↑ | 29 | Bathing | He can chew now and swallows easily. |
| | GMFM88 ↑ | III | Eating | My child was tight, but now he is much better. |
| | | | Overall mobility | Before he was only sitting down, but now he can sit |
| | | | Lying &Rolling | on a bench. |
| | | | Sitting | The arm is no longer bent. |
| | | | Standing | The arm was not grasping, but now he can hold |
| | | | | objects. |
| = Self-care | GMFM66 ↑ | 31 | Dressing | It is easier to move the child now. |
| ↑ Social | GMFM88 ↑ | V | Toileting | She responds now when you are touching her. |
| | | | Bathing | It is easier for me to bath my child. |
| | | | Eating | She is interested in bright colors. |
| | | | Overall mobility | She can chew rough food. |
| | | | Lying &Rolling | She can move the limbs and lift the head. |
| | | | Sitting | She can sit now for a few minutes. |
| ↑ Self-care | GMFM66 = | 32 | Dressing | He now helps on dressing and undressing. |
| | GMFM88 ↑ | IV | Grooming | He is now able to indicate the need to coordinate |
| | | | Bathing | and wait for me to take a potty. |
| | | | Eating | He now tries to stand and sit moving from a low chair |
| | | | Overall mobility | to a higher chair. |
| | | | Sitting | The arms are no longer as tight as before. |
| ↑ Self-care | GMFM66 ↑ | 34 | Dressing | The child is helping by lifting the arm and pulling |
| = Mobility | GMFM88 ↑ | V | Grooming | clothes. |
| ↑ Social | | | Drinking | She now calls to have her hair combed. |
| | | | Overall mobility | She can hold a cup and take to the mouth. |
| | | | | She likes to stand now, before she was only happy |
| | | | | to sit. |
| | | | | The child is much stronger in rolling. |

| PEDI | GMFM (*n*=29) | Child GMFCS | Parents Perceived Areas Improvement atFollow-up | Summary of Parent Comments at 3rd& 4th Assessments |
|---|---|---|---|---|
| ↑ Self-care | GMFM66 ↑ | 36 | Drinking | He is now helping when you dress him unlike before. |
| = Mobility | GMFM88 ↑ | III | Eating | He is no longer vomiting after meals. |
| = Social | | | Overall mobility | Before he was only trying to turn, now he is able to |
| | | | Lying & Rolling | turn himself. |
| | | | Sitting | He understands when you're talking to him better |
| | | | Expressive communication | than before. |
| | | | | He is now able to lift his hands and play with both of |
| | | | | them. |
| | | | | He making noises to draw attention to himself. |
| = Self-care | GMFM66 = | 37 | Toileting | No longer constipated |
| = Social | GMFM88 = | IV | Drinking | He used to choke a lot when drinking. |
| | | | Eating | He is now trying to chew food. |
| | | | Lying & Rolling | Can now roll to one side. |
| | | | Other: Social awareness | There is a change in the way he chews food and is |
| | | | | able to swallow. |
| | | | | His ability to move has changed. |
| | | | | He can differentiate between a stranger and his |
| | | | | mother. |
| ↑ Self-care | GMFM66 ↑ | 38 | Toileting | He can now sit perfectly. |
| ↑ Mobility | GMFM88 ↑ | IV | Grooming | He can blow his nose. |
| ↑ Social | | | Overall mobility | He can roll himself from side to side and can move |
| | | | Lying &Rolling | his upper and lower limbs. |
| | | | Sitting | He can sit without support. |
| | | | Crawling & kneeling | He can now crawl. |
| | | | Expressive communication | He now cries when he needs something. |
| | | | Play interactions | Sitting without support. |
| | | | Play ability: hand skills | Rolling from side to side. |
| | | | | He is able to use his hands. |
| ↑ Social | GMFM66 ↑ | 39 | Toileting | No longer constipated. |
| | GMFM88 ↑ | IV | Grooming | You can now wipe his nose. |
| | | | Drinking | No longer spilling when drinking. |
| | | | Eating | He can finger feed himself. |
| | | | Overall mobility | He can now stretch his leg. |
| | | | Lying &Rolling | He can roll from side to side. |
| | | | Sitting | Sitting has improved from five to 20 minutes. |
| | | | Crawling & kneeling | Can now achieve four point kneeling. |
| | | | | It can now say yes and no. |
| | | | | Can sit for longer than before. |
| | | | | Can move from inside to outside. |
| ↑ Self-care | | 40 | Dressing | Can undress himself now. |
| ↑ Mobility | | III | Toileting | He can now feel when he needs the toilet |
| ↑ Social | | | Bathing | He now plays in the bath water. |
| | | | Lying &Rolling | He now turns himself in bed. |
| | | | Standing | He tries to stand objects at home. |
| | | | | To speak some few words. |
| | | | | Tries to move the leg as if he can take a step. |

| PEDI | GMFM (*n*=29) | Child GMFCS | Parents Perceived Areas Improvement atFollow-up | Summary of Parent Comments at 3rd& 4th Assessments |
|---|---|---|---|---|
| ↑ Self-care | GMFM66 ↑ | 41 | Dressing | Helping to undress herself. |
| ↑ Mobility | GMFM88 ↑ | III | Toileting | She can now wipe herself. |
| ↑ Social | | | Grooming | She cleans her nose now. |
| | | | Drinking | She can take a glass to her mouth. |
| | | | Eating | She can spoon feed herself. |
| | | | Overall mobility | She can roll from side to side. |
| | | | Lying &Rolling | She can now kneel to watch, before we put her in a |
| | | | Crawling & Kneeling | bath. |
| | | | Standing | The way she stands has improved. |
| | | | Walking | She walks faster. |
| | | | | Feeding herself with a spoon. |
| | | | | Wiping herself at the toilet. |
| | | | | Her walk and mobility speed has improved. |
| ↑ Self-care | | 43 | Dressing | She helps to undress herself. |
| ↑ Mobility | | I | Grooming | When her nose is wet she wipes it. |
| ↑ Social | | | Bathing | She helps when bathing |
| | | | | The left hand was unable to work, but now it does. |
| | | | | The left leg that was affected is also working. |
| | | | | That she is able to wipe her nose |
| ↑ Self-care | GMFM66 ↑ | 46 | Drinking | He tries to move his hands now. |
| = Mobility | GMFM88 ↑ | V | Overall mobility | He cries to draw attention. |
| = Social | | | Expressive communication | He can move his hands a bit more than before. |
| | | | | His body is no longer stiff. |
| | | | | He can drink with his mug. |
| ↑ Self-care | GMFM66 ↑ | 52 | Eating | He can now chew. |
| | GMFM88 ↑ | V | Play interaction | He can now play with toys on the buggy table. |
| | | | Other: Auditory attention | His hearing has improved as he likes to listen to |
| | | | | music. |