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DEVELOPMENT OF A SELF CARE INVENTORY FOR CHILDREN WITH CEREBRAL PALSY LIVING IN POORLY RESOURCED CONTEXTS IN SOUTH AFRICA

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A dissertation submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

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Declaration

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

12th Day of May 2016

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Dedication

I dedicate my dissertation work to all the children with cerebral palsy, that I have worked with, together with their families. They are an inspiration to me.

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I wish to thank my supervisors, Denise Franzsen and Gillian Saloojee, for their continued knowledge, support and encouragement. I would like to thank my research assistants, Lydia Ngwana and Fundi Ziqubu for their assistance throughout the research process. I would also like to acknowledge and thank Malamulele Onward and Isibindi Project for allowing me access to complete my research, through use of contacts and workspace.

Abstract

Children with cerebral palsy (CP) struggle to participate within activities of daily living (ADLs), especially self-care. Occupational therapists need to consider many factors that influence self-care for intervention to be clinically significant. There is little documentation regarding culturally appropriate assessment tools for African children with CP. The purpose of this study was to determine criteria for items of the Self Care Inventory for Children with Cerebral Palsy (SCICP) against which dysfunction within the CP population can be measured.

The study included initial development of the items and content validity of the SCICP was determined. Field-testing of the items of the SCICP was done to evaluate the administration and the item appropriateness.

Age, hand function and cognition play a role in self-care skills. The SCICP is able to determine what a child's actual self-care performance is and differentiate between a typically developing child and a child with delayed self-care skills.

Table of Contents

List of Tables

List of Figures

Operational Definitions

Activities of daily Living (ADLs) – These are activities which a person does to look after his body**.** ADLs can also be referred to as self-care, personal management, basic activities of daily living and personal activities of daily living. Examples of ADLs include but are not limited to bathing, toileting, dressing, feeding, functional mobility and grooming[1, 2]. For the purposes of this study, the term self-care will be used.

Content validity - The ability of the items within a domain to accurately represent that domain. For example, within an assessment regarding self-care, items within the eating domain adequately represent eating skills and tasks so that conclusions can be drawn regarding the eating skills. In order to establish content validity, the assessment and its items are reviewed by experts of the domain in order to agree that the content of the assessment does represent the domain being measured[3].

Cerebral Palsy - "Cerebral Palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication and behaviour; by epilepsy and by secondary musculoskeletal problems." p9[4]

Item analysis – The evaluation of the items of an assessment tool in order to determine item difficulty and item discrimination, eliminate item bias, modifying the items concerned and re-piloting the items from the assessment tool[5]. Item difficulty is set by the amount of children who complete the item appropriately. Item discrimination highlights whether the item is able to distinguish between different children who complete the item. This may mean distinguishing between differing severities of CP. Item bias is when an item behaves differently when different children perform the item. Once difficulty, discrimination and bias have been addressed, items can be modified in terms of including suitable items and excluding

items that are not suitable for the assessment. Following any modifications, re-piloting of items needs to be completed before further analysis can occur[5].

Functional Mobility in Self-care - The movement from one position or place to another and including moving objects and functional walking needed to carry out self-care activities[3].

Abbreviations

ADLs	Activities of daily living
ABAS-II	Adaptive Behavior Assessment System - Second Edition
ASK	Activities Scale for Kids
Bayley-III	Bayley Scales of Infant and Toddler Development – Third Edition
BSID-II	The Bayley Scales of Infant and Toddler Development – Second Edition
BFMF	Bimanual Fine Motor Function
CFCS	Communication Functional Classification System
CP	Cerebral Palsy
DMC	Developmental Milestones Checklist
EDACS	Eating and Drinking Classification System
GMDS	Griffiths Mental Developmental Scale for Infants
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
KZN	Kwa-Zulu Natal
MACS	Manual Ability Classification System
PEDI	Pediatric Evaluation of Disability Inventory
PDMS-2	Peabody Developmental Motor Scales
SCPE	Surveillance of Cerebral Palsy in Europe
SCICP	Self Care Inventory for Children with Cerebral Palsy
SME	Subject matter expert

WeeFIM Functional Independence Measure for Children

CHAPTER 1
INTRODUCTION

1.1 Introduction to the Subject

Independence in self-care is something all children strive to master during their childhood. Many factors affect how a child participates within this process - culture, family values, environmental contexts, as well as the motivation to engage [1, 6-8]. Participation within activities of daily living becomes a foundation for occupational performance within other contexts of daily life, such as within school, home and the community[9].

Children with Cerebral Palsy (CP) often struggle to participate within activities of daily living, especially those of self-care. Without appropriate intervention, the children may always remain dependent on caregivers for completion of these activities. To determine what intervention is needed for a child with disability needs, occupational therapists often use standardised assessment tools to assist their clinical reasoning skills[3]. These assessment tools allow the therapist to pinpoint where intervention should be focused.

Evidence based practice allows for the application of research findings in addition to an occupational therapist's clinical reasoning in order to provide the most meaningful and useful intervention for the client. Applying evidence based practice to intervention specific to children with CP can aid the achievement of the desired outcomes[3]. The use of an assessment tool that has been standardised using a resource-constrained South African population increases the ability of occupational therapists to apply evidence based practice within South Africa. This is because the evidence base falls within the same population that requires the intervention.

For a measure to be clinically useful it should be appropriate to the context in which it is used and should have sound psychometric properties for the population with which it is used[10, 11]. This includes the reliability and validity of the assessment tool. Currently, there is no self-care tool focusing on children with CP within a South African Context.

1.2 Statement of the Problem

South Africa is an upper middle income country where cultures, contexts and environments of children with disability vary greatly[12, 13]. Hence the psychometric properties of any tool need to be sound if the assessment is to be useful clinically in determining the degree of activity limitations and the changes in a child's activity participation following therapy.

During earlier work to determine the best therapy approach for children with CP within resource-constrained rural areas in KZN the researcher identified the need for an assessment tool to assess self-care, as well as to determine the outcomes following various therapy approaches for these children.

The Pediatric Evaluation of Disability Inventory (PEDI) is widely regarded as the gold standard assessment of occupational performance in the areas of self-care, mobility and social participation in young children with a disability between the ages of 6 months and 7 years 6 months. It would make sense to establish whether this tool was suitable for use in a South African context. However, analysis of the efficacy of this tool within South Africa cannot take place, as the publishers of the PEDI (Trustees of Boston University), refused permission to have it translated into isiZulu. Written refusal was received from Dennis Hart, a representative of Boston University. Reasons for refusal was due to previous translations of the PEDI not being positive. An article by Haley, Coster, Kao, Dumas et al. (2010) reported that at the time the PEDI has been translated into 12 languages aside from English. This demonstrated that the PEDI is widely used across the world. Haley et al. (2010) commented on the main translation challenges being language differences, cultural differences and differing parental expectations within different cultures and communities[14]. As there are no assessment tools measuring self-care that are valid for use within South Africa specifically for children with CP, a new assessment tool was needed.

Various stages of development need to be followed in order to develop a new assessment tool. According to Davis and Morrow (2004), Foster (2006) and Laver Fawcett (2007), test development steps to follow include: defining the test, preparing and planning relevant items, obtaining data through subject matter expert (SME) reviews and item checks, reliability and validity testing and

publishing of results [5, 15, 16]. As completing all of these steps was beyond the scope of this study, only certain steps were completed. Therefore, this was a starting point for the development of a useful and meaningful assessment tool for use within South Africa. This study consisted of initially reviewing of standardsed assessment tools measuring self-care in children with and without disabilities. Items were then included based on this, followed by an analysis of item properties, test definition, construct and item preparation, planning, revision and analysis of the content validity of the items. This allowed the determination of the final items to be used within the assessment tool.

1.3 Purpose of the Study

The purpose of this study was to develop an assessment tool for measuring independence in self-care skills in children with CP living in resource-constrained South African settings. The study was conducted in Nqutu, part of the Umzinyathi District in Kwa-Zulu Natal. The new assessment tool needed to be critically evaluated in terms of its item properties before it could be considered for further research to make it an effective tool to assess and interpret occupational performance and capacity of children with CP in this population in South Africa. The purpose of this study was to establish criteria for items on the test against which the dysfunction within the CP population can be measured, including identification of items and format of the assessment and establishing content validity for the activities of daily living of typically developing children in this area. It was not to develop developmental norms or determine other types of validity and reliability as this was beyond the scope and size of the study. Analysis of content validity, item analysis as well as other properties of validity and reliability is too extensive a study for a Master's degree level.

1.4 Aims and Objectives of the Study

1.4.1 Aims

1. To describe the domains, items and structure of a new self-care assessment tool for children with CP living in resource-constrained urban and rural South African contexts

2. To establish the content validity of a new self-care assessment tool for children with CP living within resource-constrained urban and rural South African contexts.
3. To complete the item analysis of a new self-care assessment tool for children with CP living within resource-constrained urban and rural South African contexts.

1.4.2 Objectives

The objectives of the study are:

- To develop the structure and items of new self-care assessment tools relevant to children with CP living within resource-constrained urban and rural South Africa using existing assessment tools as a guide
- To establish the content validity in terms of the relevance of each item to the overall construct of self-care and cultural adaptation for the new self-care assessment tool for isiZulu speaking children aged between birth and 7 years, living in resource-constrained areas in South Africa.
- To complete an item analysis on the new self-care assessment tool to finalise the items in terms of their difficulty and discriminative level in relation to age and severity of CP based on the GMFCS.
- To determine the final items to be included in the Self Care Inventory for Children with Cerebral Palsy (SCICP)

1.5 Justification for the Study

There is a need for a valid and reliable tool to measure both the level of dysfunction in occupational performance and the change in occupational performance in children with CP living in resource-constrained South African settings. Particularly in resource-constrained areas of South Africa, children have little access to resources and services. Thus if service delivery and evidence based treatment is to be offered a valid outcome measure appropriate to their context is required. The new self-care assessment tool, if validated in South Africa, can be used clinically and for research for children with CP in similar settings. Following completion of this study, further research can be undertaken to ascertain the SCICP's other psychometric properties.

1.6 Organisation of the Dissertation

1.6.1 Layout of the Study

The study consists of six chapters which describe the item selection and content validity development of SCICP. It includes appendices A-S which follow after the chapters.

1.6.1.1 Chapter 1: Introduction

The introduction presents the topic of initial development of a self-care questionnaire for children with CP within resource-constrained areas of South Africa. It highlights the reasons for completing the study by analysing the statement of the problem and justification for the study itself. The introduction includes the aims and objectives for the overall study.

1.6.1.2 Chapter 2: Literature Review

The Literature review describes the literature around CP, occupational performance of children with CP and assessment tool development. It highlights the need for a new tool to be developed based on lack of suitable assessment tools for children with CP, particularly within resource-constrained areas of South Africa.

1.6.1.3 Chapter 3: Methodology

The methodology chapter describes the steps taken to complete the study through both item selection and content validity. The methodology includes description of the development of the items, a subject matter expert survey, translation of the items, discussion groups, field testing of the SCICP and finalization of the items to be included in the SCICP.

1.6.1.4 Chapter 4: Results

The results chapter highlights the results of initial item selection, as well as items selected following the subject matter expert survey and discussion groups respectively. This chapter also highlights the results of the field testing on typically developing children and children with CP.

1.6.1.5 Chapter 5: Discussion

The Discussion chapter presents the reasons for inclusion or exclusion of original items of the SCICP as well as the performance of the SCICP during the field testing. This is then linked to relevant findings within the literature. This chapter comments on the content validity and item appropriateness of current items of the SCICP and also the reliability of the caregiver's responses. This chapter also presents the limitations of the study.

1.6.1.6 Chapter 6: Conclusion

The Conclusion chapter presents the conclusions drawn from the results and discussion chapters. It also presents recommendations for future studies including the SCICP.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

This chapter reviews the available literature on cerebral palsy (CP), the effects of CP on participation in occupational performance, particularly self-care. In addition, information on existing assessments of personal management for children with disabilities and the development of such assessments is discussed. As the context of this study is a resource-constrained area in Kwa-Zulu Natal, the effects of socioeconomic status on CP and occupational performance will also be considered.

The literature search was conducted in the following databases: Medline Plus, Pubmed, BMJ Clinical Evidence, Science Direct, ExLibris, Wiley Interscience, Cochrane Libraries, OvidSP, EBSCO Host (Academic Search Complete), Sage Online. Keywords used were 'cerebral palsy', 'participation', 'occupational performance', 'personal management and self-care', 'assessment', 'development of assessment tools', 'poverty and South Africa', 'functional ability'.

2.2 History and Definition of Cerebral palsy

Cerebral palsy is a condition that has been studied for over 100 years. Although CP was the subject of medical research since the 19th century, it can be found depicted in art works as far back in history as 1190BC[17].

William Little, a British orthopaedic surgeon was the first to describe CP in modern literature in the 19th century. He described CP as spasticity and paralysis caused by brain damage during infancy[18-20]. By the end of the 19th century, Little had described "Little's Disease" which was spastic diplegia which he attributed to premature birth and birth asphyxia. Little was the first person to theorise a direct link between neuromuscular disabilities described in children, children with complications during birth, neonatal asphyxia and prematurity[17]. In 1889, William Osler, a Canadian professor of clinical medicine published "The Cerebral Palsies of Children". Osler worked towards identifying CP as a "specific group of non-progressive neuromuscular disabilities in children" p288[17].

From 1891 to 1897, Sigmund Freud wrote numerous works about “Cerebral Palsy”. During this time Freud began to develop a classification system that is still used today, the basis of which remains unchanged. The classification is based on clinical descriptions of hemiplegia, total cerebral spasticity, paraplegic spasticity, central chorea, bilateral athetosis and bilateral spastic hemiplegia. Each definition, however, emphasised the non-progressive nature of cerebral palsy resulting in motor difficulties[18, 19].

During an international symposium in 2005, Bax, Goldstein, Rosenbaum, Leviton et al. defined Cerebral Palsy as:

> “A group of disorders of the 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 and/or behaviour and/or by a seizure disorder.” p 572[20].

In a follow up article to the 2005 definition, Armstrong (2007), suggested that the second sentence proposed by Bax et al., should be removed in its entirety and replaced by:

> “A full description of the individual with CP requires classification of motor abnormalities, associated impairments, anatomic findings, and definition of function according to the World Health Organization (WHO) International Classification of Function.” p166[21, 22]

By altering the second sentence, Armstrong proposed that the replaced sentence should not become part of the actual definition of CP, but merely a statement which links the definition to broader classification systems. However, Armstrong felt that these classification systems required further definition by the Executive Committee[21]. In 2006, Rosenbaum, Paneth, Goldstein, Bax et al. (2006) adjusted the definition:

> “Cerebral Palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, 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, and behaviour; by epilepsy and by secondary musculoskeletal problems." p9[4]

In a letter to the editor in 2006, Graham highlighted that although children with CP demonstrate a high prevalence of musculoskeletal pathology, sufficient description within the 2005 definition of CP was lacking. Graham (2006) proposed that "Progressive musculoskeletal pathology" was added onto the definition of CP as an additional annotation to the associated disorders and impairments, which follow the definition[23].

In another commentary, Reddy (2005) highlighted that the new definitions addressed issues arising as a consequence of CP and included concepts of activity and functional limitations and participation, which are societal concepts. This is an aspect which is important for all occupational therapists working with children with CP as it highlights the child's occupational performance[22].

The importance of these definitions is the contribution they make towards a collective language on how cerebral palsy is defined, which could be accessed by clinicians, researchers and health officials throughout the world[20, 22]. Another essential part of these definitions is that they take into account the associated impairments, emphasising not only the motor disorders of CP. This is important, as it is often the additional associated impairments that create the biggest exclusions from activity and participation that have detrimental impacts on both the child and family[6, 24].

2.2.1 Prevalence of Cerebral Palsy

Despite an attempt to create a common language with these definitions, there continues to be controversy surrounding what should and should not be included in a definition of CP. Examples of the controversies in terms of the criteria in the definition of CP are hypotonia, CP as a result of post-natal causes (age at the time of the disturbance), developmental coordination disorder (DCD), cytomegalovirus and rubella[21, 22, 25]. For this reason, the incidence and prevalence of CP is hard to establish as different criteria when diagnosing the condition may be used.

Currently it is estimated however that the incidence of cerebral palsy, in the Western world, is between 2 and 3 per 1000 live births[18, 19, 26, 27] while prevalence estimates of CP around the world range from 1.5 to more than 4 per 1,000 live births. Cerebral palsy is the most common disability with related motor skill dysfunction in childhood and therefore a major contributor to activity limitation and participation restriction within activities of daily living[28-31]. The World Health Organisation, 2005 states a high number of new born infants experience birth injury, infection, and complications of preterm birth, all of which are possible causes of cerebral palsy, in poorly resourced areas[32].

There are little data that accurately reports the prevalence of childhood disability of CP within developing countries. Within South Africa, there is a lack of reliable data about the prevalence of disability although records indicate the prevalence of childhood disability falls within 33 and 64 in 1000 live births, depending on the province[33]. The Department of Social Development/Department of Women, Children and People with Disabilities and UNICEF in 2012, reported that the prevalence of children with disabilities has been underestimated. This means that the prevalence of children with CP is likely also to be underestimated. This report determined that there are nearly 2.1 million children with disabilities in South Africa[34].

A study conducted within rural Kwa-Zulu Natal found disability prevalence of 83 in 1000 live births. Of this figure, 10 in 1000 live births accounted for children with CP[35]. This means that a community based study conducted in 2002 in rural resource-constrained setting in KZN suggested that the prevalence of CP could be as high as 10 per 1000[35]. Another study estimated the prevalence of childhood disability with children under 9 years of age at between 5.2% and 6.4% of the population which includes children living with CP. From this percentage it can be inferred that more than one million children are living with disability within South Africa[36].

Donald, Kakooza, Wammanda, Mallewa et al. (2015) suggested that the prevalence of CP was different in African countries to that in Europe and North America. It was suggested that in African and other resource-constrained countries, there was a higher proportion of more severely disabled children with

CP with more comorbidities. The reason for this was due to poor care during birth, delayed presentation to health care services and poor early intervention services[25]. This has not been confirmed as there is a lack of information regarding access to early intervention and other medical services for children with CP in many African, resource-constrained countries [25].

2.2.2 Socioeconomic Status and Cerebral Palsy in the South African Context

It has been recorded that there is a strong correlation between the presence of disability and living in poverty[33, 34, 37]. Poverty tends to make an individual more susceptible to acquiring a disability and in turn, a disability culminates in the poverty, which may exacerbate the disability. When there is a child with a disability within a family, other than the possible negative attitudes from the community and the increased burden of care on the family, a disabled child usually means an increased financial burden on the family. Children with disabilities are less likely to have access to acceptable housing, sanitation and water accessibility than children without disabilities[33, 34, 36].

The South African Integrated National Disability Strategy (INDS): White Paper made integration of children with disabilities an essential part of government work as early as 1997; this is not being achieved for the majority of these children. This occurs particularly in poorly resourced rural areas, where the community is disadvantaged 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 The information reported by the Department of Social Development/Department of Women, Children and People with Disabilities and UNICEF in 2012 and the Integrated National Strategy on Support Services to Children with Disabilities published in 2009, indicated that this is true for children between birth and 10 years, that are born in rural areas, particularly in the Eastern Cape and Kwa-Zulu Natal[13, 33-36].

Many of the children with disabilities living in these areas do not even have adequate access to health care and social grants despite health care for children under the age of 6 years being free and the provision of the care dependency grant for children with disabilities aged between 1 and 18 who require full time

care. Only approximately one third of children with disabilities living within rural South Africa were found to be receiving public sector services[13, 33-36]. The Department of Social Development/Department of Women, Children and People with Disabilities and UNICEF reported that only 42 per cent of children with disabilities are receiving rehabilitation services, while only 33 per cent have access to the correct assistive devices [34]. This was confirmed by Couper (2002), who found that in rural Kwa-Zulu Natal only one third of the children with disabilities were even known to the health services. There is therefore a marked gap between government's legislation regarding integration of people with disabilities into society and the actual implementation of this integration and the need for urgent implementation of services as a priority[35, 36]. This legislation gap reported using the INDS guidelines according to information from the Department of Social Development/Department of Women, Children and People with Disabilities and UNICEF still exists[13, 34].

It has been reported that the key difficulty in accessing the services mentioned above for many families living within peri-urban and rural areas is due to the distance they need to travel in order to reach the service centres. Many of these centres are far from their homes, and transport can cost them around 5% of the family's monthly income for one trip. This is compounded by the fact that the limited means of transport available to these families are not adequately equipped to transport a person with a disability. As a result, families often need to pay more for private transport hire, which can accommodate a child with a disability[13, 33, 34, 36].

Children with CP from poorly resourced areas are also dependent on government services within the health sector for their health and rehabilitation needs. The INDS stated that rehabilitation services have often been neglected in South Africa with no inter-sectorial policy regarding rehabilitation. Rehabilitation services are often not included in the free health care for children under the age of 6 years[38]. Changes in South Africa's policies regarding children with disabilities to models based on the ICF's model have been made. Even so, this is not being implemented at national planning processes. Discrepancies between policies and implementation continue to create barriers for inclusion of children with disabilities in all areas of society[34]. Saloojee, Phohole, Saloojee, Ijsselmuiden (2006) found

that only a quarter of the children in her study in a peri-urban area were receiving rehabilitation therapy, despite 92% of them being judged as eligible for therapy. Thus within the socio-economic and political climate in South Africa, many families or single caregivers have to deal with the challenges of caring for a child with CP without support[13, 34, 36].

In a study by Assis-Madeira Carvalho and Blascovi-Assis (2013), it was found that in children with milder forms of CP, socioeconomic factors were not a risk in functional skill development. However, in children with moderate and severe forms of CP, those with low socioeconomic status demonstrated poorer self-care and mobility performance than those with a high socioeconomic status and tended to be more dependent[39]. Therefore, it is important to consider the severity and the type of CP as well as the context in which the child lives.

Due to the interaction between poverty and accessibility to resources, having an assessment tool, which is specific to children with CP living in resource-constrained areas, will allow for therapists to quickly, cost-effectively and conveniently identify those children who need self-care intervention. This will enable improved independence in self-care for children with CP who would otherwise receive services. A free tool, specific to children with CP in resource-constrained areas, will decrease some of the barriers to assessment of self-care skills.

2.3 Classification Systems of Cerebral Palsy to Complement Assessments

Many attempts have been made to describe CP through classification systems, but due to the many possible phenotypes, classification systems differed from one another and in what they described.

Classification systems categorize a child with CP according to the severity of the condition rather an assessing his functional abilities[40]. An assessment tool measuring self-care independence, specific to resource-constrained areas, will enhance the holistic understanding around this child's classification level. The use of a classification system creates an understanding of which types of CP may be more independent in self-care skills.

2.3.1 Condition based classifications

In 1998, due to the increasing need to standardise the definition and classification of CP, the Surveillance of Cerebral Palsy in Europe (SCPE) was developed from a network of CP registers and population based surveys with the aid of funding from the European Commission. The SCPE developed a condition based classification and established guidelines in order to aid clinicians in including or excluding a child with the diagnosis of CP[41].

The SCPE places children with CP into subcategories of the same type. The three main groups are children with spastic CP, children with dyskinetic CP and children with ataxic CP. Children often present with a mixed clinical presentation and are difficult to group into one classification. For this purpose, children are classified according to the dominant feature within their clinical picture. The SCPE has now set up its central database, which includes information for 6000 children with CP from 13 geographically defined populations within Europe[29, 42].

The definitions and classification tree set up by the SCPE designed in 2000 is now used in many European countries to classify children with CP according to motor abnormalities described in terms of type and distribution[43]. This system classifies CP with the following categories: bilateral spasticity; unilateral spasticity (left or right); dystonia; choreoathetosis; ataxia and not classifiable[18, 26, 44]. This terminology uses of unilateral and bilateral spastic CP, rather than use of the words ‘hemiplegia’, ‘diplegia’ and ‘quadriplegia’. This means there is no delineation between those children with spastic diplegia and spastic quadriplegia. Rather than separating out the number of limbs, the SCPE uses functional classifications and numbers of associated impairments to further describe the child’s functioning. In this manner the child previously described as having spastic quadriplegia will be described as lower functioning and able to participate within less activities than the child previously described as having spastic diplegia[24, 42]. Functional classification systems are therefore included for children diagnosed with CP by the SCPE. Currently the SCPE also includes the Gross Motor Function Classification System (GMFCS) to classify motor function and the Bimanual Fine Motor Function (BFMF) to classify upper limb function[42, 43, 45, 46]. The SCPE classification system was used to classify the children with CP who participated within this study.

The classification system described above is based on the pathophysiology and distribution of CP developed prior to the publication of the World Health Organisation's International Classification of Functioning, Disability and Health (ICF). The classification therefore focuses on aetiology and distribution of abnormal motor patterns, rather than activity limitations participation restrictions [20, 47] which underlie and are related to the occupational performance of the child with CP[18, 19, 26]

2.3.2 Other Classification Systems used in Cerebral Palsy

Neurologically based classifications were initially used and this was extended in 2005, when Bax et al. they suggested a CP classification for children and adults. The classification contained the following components: motor abnormalities in terms of description and type of the motor disorder; associated impairments; anatomic and radiological findings and causation and timing of injury[20].

These classifications include the Gross Motor Function Classification System (GMFCS), a standardised method of classifying the severity of motor impairment with children with CP. The GMFCS consists of five functional levels with level 1 including the most functional and ambulatory child and level 5 including the least functional child who is not able to sit or roll. GMFCS describes the motor ability of children with CP using four age bands, beginning at less than 2 years and ending at 18 years[18, 48-50].

A second classification system is the Manual Ability Classification System (MACS), which measures the ability of the child to use his hands within functional daily activity. The MACS takes both hands and bimanual activity into account, rather than looking at the function of each hand independently. Children between the ages of 4 and 18 can be assessed with the MACS. As with the GMFCS, the MACS consists of 5 functional levels, with level 1 classifying the child who is able to manipulate daily objects independently and level 5 classifying the child who is unable to handle daily objects, requiring complete assistance from a caregiver[18, 26, 47].

When Delhusen Carnahan, Arner and Hägglund, (2007) used the Gross Motor Function Classification System (GMFCS) in conjunction with the Manual Ability

Classification System (MACS), they found they could group children with CP more effectively according to the severity of the motor function loss. They emphasised the need for using both these classification systems for research purposes as well as the clinical assessment and management of CP[24]. Another study by Majnemer, Dagenais, Shevell (2012), which investigated the correlation between gross motor function and manual ability found that in children with spastic hemiplegia, there were greater deficits in fine motor manual ability than gross motor function, which was to be expected. In children with spastic diplegia, the opposite was true with greater deficits in gross motor function and more functional manual ability. Similar levels of function in manual ability and gross motor function was seen in children with dyskinesia while children with intellectual disability tended to fall within more severe levels on both the MACS and GMFCS scales[51].

A third functional classification tool used for children with CP is the Communication Functional Classification System (CFCS). This classifies children with CP according to their ability to communicate during everyday life. Like the GMFCS and MACS, the CFCS consists of five functional levels. Level I on the CFCS indicates a child who is able to send and receive effective communication with both familiar and unfamiliar people within their everyday environment. Level 5 on the CFCS is scored when a child does not send or receive effective communication with familiar people within their everyday environment. The CFCS includes a decision tree that helps the user to classify the child according to current performance[52].

The most recently published functional classification tool for children with CP is the Eating and Drinking Classification System (EDACS). It classifies children with CP according to their eating and drinking abilities in everyday life. As with the previously described classification systems, the EDACS consists of five different functional levels. Level I on the EDACS is indicative of a child who eats and drinks safely and efficiently while at EDACS level V a child is unable to eat or drink safely, and tube feeding may be used for nutrition. The EDACS includes definitions and explanations to help the user efficiently classify a child with CP[53].

The use of a classification system such as the EDACS, which classifies eating and drinking ability, is supported by activity and participation based frameworks

including the International Classification of Functioning, Disability and Health (ICF).

2.3.3 Activity and Participation based Framework

The International Classification of Functioning, Disability and Health (ICF) is based upon a bio-psycho-social framework, rather than a medical model, shifting focus from the consequences of disease and disorders to a focus on functioning and quality of life. It includes classification of functioning and disability with respect to body structure, body function, activities, participation and environmental and personal factors[54, 55].

The ICF-CY is the child and youth version of the ICF framework designed for use with children and adolescents from birth to 18 years. It includes children's activities and participation (learning and play) and also developmental changes which children undergo. The ICF-CY provides a universal language needed for CP rehabilitation, so a multi-disciplinary team can understand the condition and work on integrated goals for intervention[56]. Understanding a child with CP in relation to the ICF model helps to give a better insight into the child's ability to perform in the occupational performance areas of self-care, school, play, and social participation. Based on assessments of these abilities, occupational therapy clinicians are able to determine the child's therapeutic needs when developing intervention programs[47]. This aspect is of particular relevance in the treatment of children with CP[27] where occupational therapists do need to understand the relationship between the severity of the CP, using classifications such as the GMFCS, MACS, CFCS and EDACS and the child's ability to perform everyday activities.

2.3.4 Relationship between Classifications used in Cerebral Palsy and Occupational Performance

Initially, the GMFCS, MACS, CFCS and EDACS were developed independently from each other as valid stand alone tools without the thought of the relationship between them. Three of these tools classify client factors and skills such as mobility, manipulation and hand function and communication while the EDACS classifies the ability to eat and drink which falls into the self-care occupational performance area ability. The relationship between the GMFCS, MACS and CFCS that has been found for most children with CP indicates that the levels for the

different classifications may therefore differ for an individual child. Although the most functional children with CP may score level I or on all three classifications the least functional children may score level V or IV on one classification, while scoring at level II or III on another. The scores depend on the location and severity of damage at the time of the original injury to the brain[57, 58].

In fact, Hidecker, Ho, Dodge, Hurvitz et al. (2012) found that only 16% of the 222 children within their study were classified at the same level on all three classification systems. They also found that when a child was classified as a level IV or V for GMFCS and MACS, fewer than one in three had communication classified as a level V using CFCS. Thus one classification system does not necessarily predict the level on another classification system and individuals with severe mobility limitations (GMFCS level V) classification, cannot be assumed to have severe communication limitations as well[57]. In children with hemiplegia and quadriplegia, Hidecker et al. (2012) did find a correlation between mobility (GMFCS level) and hand function (MACS level)[57].

Ohrvall, Eliasson, Lowing, Odman (2010) and de Brito Brandao, de Cassia Goncalvesc, Carvalhoc, Crepaldia et al. (2012), also found significant correlations between the GMFCS and gross motor skills while the MACS scores correlated with self-care ability. Each functional classification system is essential in highlighting strengths and challenges for each child. All the functional classification systems should be used to make intervention more specific to each child, through the holistic understanding of their functioning. This reinforces the use of classification systems' combination with occupational performance assessments in order to gather complementary information regarding the child's abilities in their occupational performance areas[7, 47].

Thus information needs to be established on the GMFCS, MACS, CFCS and the EDACS with respect to each child with CP to help create a more holistic picture of that child's overall functional performance, and to create a 'functional profile' specific to each child[57]. This information is useful for enhancing participation within their occupational performance[57] by allowing health professionals to point out which areas the child is able to complete with a little bit of help, and which areas the child is unable to complete at all. In doing so, the health professional and other

multidisciplinary team members are able to work together with the child and their family on meaningful goals, in order to improve functioning in challenging areas. In occupational therapy the effect of these challenges on occupational performance is the main concern[1].

Palisano, Cameron, Rosenbaum, Walter et al. (2006) found that the GMFCS classification remains stable over time and a child with CP's GMFCS level is unlikely to change[59]. In the study, Palisano et al. (2006) found that 73 per cent of their sample did not change in their GMFCS classification level[59]. This was supported by the findings of a study by McCormick, Brien, Plourde, Wood et al. (2007). McCormick et al. (2007) demonstrated that the GMFCS classification level at 12 years of age remained unchanged into adulthood[60]. In a similar study, Ohrvall, Krumlinde-Sundholm and Eliasson et al. (2014) demonstrated that the MACS also showed stability over time[61]. Ohrvall et al. (2014) demonstrated that 82 per cent of the children with CP rated using the MACS remained unchanged at their classification level after one year[61]. These studies highlight that the functional classification systems are useful in understanding the child's functional profile and can describe broadly what they can do. It also highlights that assessment tools which evaluate performance over time and change in performance over time are necessary for justification of intervention.

2.4 Occupational Performance in Cerebral Palsy

Occupation, as defined by the American Occupational Therapy Association (2014), is engagement within everyday activities that has purpose and meaning for the person who is performing the activity. Occupational performance is defined by the person's culture and the manner in which they participate in self-care or personal activities of daily living, instrumental activities of daily living, leisure or play, work or academia, and social participation. Participation within these activities allows the individual to contribute to his community in a meaningful manner[1].

For any person occupational performance requires an interaction between the occupation and the environmental context in which it is being performed. For children this includes the need to master basic skills, become competent within these skills in daily life, connect with other people and define the meaning of

activities in their lives[1, 62]. To achieve this meaning, children are taught and strive to master independence in appropriate activities of daily living in all occupational performance areas throughout their childhood. The time at which a child develops and masters different self-care skills is dependent not only on their age but is also influenced by their culture, family values, environmental contexts, and motivation to engage[1, 6-8].

Independence in activities of daily living becomes a foundation for participation within all contexts of daily life including school, home and the community[9]. Activities of daily living (ADLs) are therefore placed in the activities and participation domain of the ICF framework where they are defined as life tasks that are required for self-care and self-maintenance. These can be personal activities of daily living or instrumental activities of daily living. Instrumental activities of daily living are more complex activities that demand a higher motor and process competency than personal activities of daily living[9]. Self-care falls into the category of basic activities of daily living or personal activities of daily living [1] and involves activities which a person participates in daily, in order to care for themselves[1-3, 63]. For a child, self-care activities encompass learning how to take care of their body through toileting, toilet hygiene, bladder and bowel management, washing (bathing, showering), personal hygiene and grooming, eating, feeding, dressing, functional mobility, personal device care and sleep or rest. These activities need to be performed in a socially and culturally appropriate manner and may differ depending on the familial and societal environments in which the child lives[1, 3, 64]. For example, within many Western cultures, early independence is strived for in an attempt for children to have mastered skills for eating, dressing and toileting before they start school[64]. Self-care skill mastery requires many hours of practice but once the child is proficient in these skills they benefit from having more time to engage in play, and more importantly by being less reliant on care givers for daily activities[64].

Development of self-care mastery is linked to the development of fine and gross motor skills. Children with CP often have deficits within these skills and other building blocks including motor control, sensory, perceptual and the cognitive skills needed for self-care skill mastery. Children with CP often demonstrate delay in attaining self-care abilities, and remain dependent on their caregivers for

assistance[7, 64]. It has been suggested the age at which a child is diagnosed with CP may affect the outcome of treatment. Hadders-Algra (2011) describes critical periods of neural plastic changes, which are thought to end at seven years of age. These critical periods have been shown to be important in the treatment of other conditions such as amblyopia and the effectiveness of cochlear implants on improved cortical processing of auditory information and speech development[65].

Early intervention is documented as an important factor in promoting the typical development in children and thus supporting achievement of independence. Engle, Black, Behrman, Cabral de Mello et al (2007) report greater success within school and work roles when early intervention programs for disadvantaged children occur during early childhood[66]. The Integrated National Strategy paper titled The Right to Belong and Participate supports early intervention and recommends all children with disabilities as well as those at risk for disabilities be screened and monitored and where necessary appropriate interventions are implemented[13]. A study by Donald et al (2015) highlighted the need for early recognition of children with CP in resource-constrained countries in order to prevent more severe disabilities and secondary changes as a result of not accessing early intervention[25].

The restriction of independence in children with CP experience in their occupational performance, compared to that of typical children, results in limited satisfaction with their activities, which can affect the child's health and sense of well-being[1]. Therefore, irrespective of their age, occupational therapy aims to help the child with CP develop as much independence as possible to improve their sense of well-being. The occupational therapist's role includes assisting with age appropriate development of self-care skills, such as dressing, grooming, toileting and feeding, as well as fine motor skills, cognitive and perceptual skills and adaptation of equipment and seating to reduce the child's dependence on others. To determine which intervention approach should be used, occupational therapists need to identify the client factors and performance skills as well as the ability of the child with CP to carry out their self-care activities. This will aid holistic clinical decision making in order to set up appropriate individualised intervention. This is important as the severity of the CP affects the outcomes for each child[3, 27, 67].

2.4.1 Factors affecting Occupational Performance of Children with Cerebral Palsy

Ohrvall et al. (2010) compared children with CP to typically developing children in order to determine whether their classification using the MACS and GMFCS was related to their ability in the occupational performance within self-care and mobility areas assessed on the PEDI. Children with CP who were less severely involved and were classified within the MACS level I and II, developed full independence in the self-care areas, but later than their typical peers. Children classified as MACS level I demonstrated mastery of self-care skills at approximately 9 years of age, whereas children classified as MACS level II demonstrated mastery of self-care skills at approximately 12 years of age. Children classified MACS levels III-V did not achieve complete mastery and independence in self-care skills, and often could only complete part of the task, thus remaining reliant on a caregiver for assistance[7]. A similar trend was observed for mobility skills and GMFCS classification. Children classified as GMFCS level I achieved full mobility mastery by 6 years of age, whereas children classified as GMFCS level II only achieved full mastery after 12 years of age. Typically developing children achieve mastery at approximately 4 years of age[7].

These findings were confirmed by Parkes, McCullough, Madden (2010) in their study, which demonstrated reduced levels of participation in children with more severe CP classified as GMFCS levels IV and V[68]. Parkes et al. (2010) found this to be true for all occupational performance areas with a reduction in both the frequency with which activities were done as well as the variety of activities in which the children participated. However, when given assistive devices to facilitate participation and function, these children showed better engagement in activities of daily living than those children classified as GMFCS III. This highlights the importance of removing environmental restrictions and the provision of compensatory methods on the performance of children with severe motor deficits[68].

Despite limited literature about the effects of resource-constrained settings, it would appear however that children with CP, especially those in developing countries, are not achieving expected levels of independence[25, 69]. In a study by Wong, Chung, Hui, Fong et al. (2004) on children with CP living in China, who

were assessed using the Chinese version of the Functional Independent Measure (WeeFIM), more than half of the participants needed assistance or supervision for completion of self-care activities (grooming, bathing, dressing and toileting). This was due not only to factors such as type and severity of CP but also the presence of epilepsy and intellectual disability, which influenced the ability of the child to become independent. Children with ataxia were able to achieve the most independence while children with tri- or tetraplegia were found to be the most dependent[69].

Pain has also been shown to affect participation in occupational performance and according to Ramstad, Jahnsen, Skjeldal, Diseth (2012) pain is a particular problem for children with CP living within resource-poor areas of South Africa[70]. Due to limited access to medical and rehabilitative services, it was assumed that the children are more likely to present with secondary changes as a result of abnormal movement patterns and abnormal muscle tone resulting in contractures, dislocation and scoliosis which are associated with pain and an increased restriction in participation in occupational performance[70]. In the study by Ramstad et al. (2012), recurrent pain of musculoskeletal origin was found to negatively impact on participation in daily activities and on social interaction within the community and schooling as well as within individual relationships[70].

2.4.2 Factors affecting Occupational Performance of Children with Cerebral Palsy in the resource-constrained South African Context

Certain areas in South Africa, particularly rural areas can be described as being resource-constrained. These areas can be defined as having limited resources according to World Bank criteria of low-income areas [12] and are characterised by poor access to public services such as water and sanitation, inferior infrastructure and job opportunities, and poor access to health facilities. The lack of services and finances mean that, particularly in rural areas, people may not be able to “engage in appropriate personal, food and environmental hygiene practices”p4[12].

Studies have shown that personal hygiene is positively affected by the availability of clean water and sanitation[71, 72]. While this may affect the manner in which individuals carry out their self-care it is not only living in differently resourced areas

that affects the way people in South Africa engage in activities of daily living. There are people of many cultures, languages and religions with many living in the rural areas that still adhere strictly to their tribal beliefs and traditions, all of which also have an influence[71, 72]. Since occupational therapy practice must take into account the way people engage in everyday activities, for occupational therapy to be meaningful for children with CP in rural areas of South Africa, it needs to be sensitive to the cultural practices of the child's family and community as well as considering the resources available for the child[3]. This includes both the assessment and intervention phases of occupational therapy.

Children with CP face challenges with independence in occupational performance areas. Living in a resource-constrained area within South Africa creates additional barriers for children with CP, as access to early interventions can be restricted. This highlights the importance of a suitable assessment tool to monitor children with CP and their self-care skills in order to aid access to any intervention as is necessary.

2.5 Occupational Performance Assessment Tools for Children with Disabilities

Many standardised assessment tools that assess occupational performance in children have come into existence following identification of a need within current therapy practice. Therapists need tools that will assist in the identification of a child's dysfunction requiring intervention, will correlate with clinical observations and provide the basis for comparison of evidence-based intervention outcomes[3, 73]. Currently, the assessment tools available for use with children with CP are not able to provide a basis for comparison to the normative population when used with children living in resource-constrained areas.

These tools should be sensitive enough to identify deficits within normal developmental milestones of activities of daily living of younger children, particularly of self-care. The tools should allow for goal setting in conjunction with parents and the children themselves, based on what is most important and meaningful to them. In order to do so, the correct tools to analyse the deficits in skills that are applicable to the child's environment, culture and resources are needed[9].

As Majnemer, Shevell, Law, Poulin et al. (2010) and Chien, Brown, McDonald, Yu (2012) point out, it is important that when assessing a child with a disability, the difference between the child's capacity to complete activities of daily living and the child's actual performance of activities of daily living is identified and understood as they may be different. Capacity is defined as what a child is able to do, whereas performance is what a child actually does during the activity performance[6, 8, 24, 74, 75]. Studies by Young, Williams, Yoshida, Bombardier et al. (1996) and Tieman, Palisano, Gracely, Rosenbaum et al. (2004), demonstrated that there was a difference in capacity and performance in children with disabilities, both in gross motor skills such as mobility and in activities of daily living skills such as dressing[74, 75]. Tieman et al (2004) found that environmental and personal contextual factors within the home, school and community environments influenced the actual performance of mobility of children with CP[74]. Young et al (1996) found that their participants' performance of daily living skills, including certain self-care tasks was 18 percent lower than their capacity of the same tasks[75]. In a more recent study by Holsbeeke, Ketelaar, Schoemaker, Gorter et al. (2009), motor performance, motor capability and motor capacity related to gross motor skills and daily living skills, including self-care, was determined in children with CP using the Gross Motor Function Measure (GMFM) and PEDI. In this study, capability, identified as what a child can do in his environment, was differentiated from capacity, which was identified as what a child can do within a controlled environment[76]. Holsbeeke et al (2009) also found that there was a significant difference when comparing performance to capacity and capability, whereas capability and capacity were more similar[76]. These studies highlight the importance of assessment tools which evaluate performance within the child's actual environments to correctly identify strengths and deficits, in order for optimal goal setting and intervention to take place[6, 8, 74-76].

2.5.1 Assessment tools for occupational performance in Children with Disabilities

There are many assessment tools that have been designed to analyse motor function in children with CP, or children with suspected CP. Assessment tools may be used in order to discriminate, evaluate or to predict specific occupational performance[77]. This section provides a summary of various assessment tools that

are useful in assessing aspects of self-care and may or may not be relevant for children with CP.

Assessment tools designed to measure performance in self-care and other occupational performance areas, include those such as the Pediatric Evaluation of Disability Inventory (PEDI), which is recommended for use with children with disabilities. A number of other standardised assessment tools, which can be used to assess occupational performance in children, are also available commercially, but have expensive licensing restrictions and training requirements. All of the tests have been developed and standardised in developed countries. For a measure to be clinically useful however, it should be appropriate to the context in which it is used and should have sound psychometric properties for the population with which it is used. This includes the reliability and validity of the assessment[3].

2.5.1.1 The Pediatric Evaluation of Disability Inventory (PEDI)

James, Ziviani, Boyd (2014) reviewed assessments related to the evaluation of occupational performance in children and reported that the PEDI is the best measure to investigate activity of daily living competence in young children with physical disabilities and or coexisting physical and cognitive disabilities. It was determined that amongst the eight standardised measures that they analysed, the psychometric properties of the PEDI were the strongest[9].

The PEDI is a standardised assessment measure designed to assess the occupational performance in young children between the ages of 6 months and 7 years, 6 months, developed in United States of America (USA). It is a parent/caregiver questionnaire, which includes a Functional Skills Scale, a Caregiver Assistance Scale, and a Modification Scale. The Functional Skills Scale evaluates children's occupational performance through their performance in various age appropriate activities set out within its self-care, mobility and social function domains. It was developed specifically for children with disabilities in this age group and has been shown to have acceptable psychometric properties. The PEDI's content validity was established using a panel of 31 experts as well as field testing using children with developmental disabilities. The normative sample included 412 children, of which, 120 children had CP. Rasch modelling was used. The construct validity for PEDI's self-care domain in relation to the MACS is

r=0.72. The PEDI's criterion validity is correlated to the Functional Independence Measure for Children (WeeFIM) for self-care (r> 0.88). The PEDI's internal consistency is α=0.98 for the self-care domain. Interrater reliability for the self-care domain of the PEDI is 0.84 and test-retest reliability for the self-care domain of the PEDI is 0.98[9, 78].

Additional training is not required to use the PEDI and the only cost would be for the manual and score forms[9]. It has been used extensively in research internationally where occupational performance contexts are similar to that described in the USA[14, 79, 80]. The PEDI has been translated into 12 languages, some of which include Dutch, Norwegian, Swedish, Spanish, Japanese, Turkish and Hebrew[14]. Overall, the PEDI covers the widest item content with respect to self-care[9].

The PEDI has been reported as a suitable assessment tool for the occupational performance of children with physical disabilities. It is often used with children with CP alongside various classification systems in order to gain sufficient information regarding the children's functional abilities[47]. Despite this, publishers of the PEDI declined permission to translate for use within South Africa.

2.5.1.2 Functional Independence Measure for Children (WeeFIM)

The use of the Functional Independence Measure for Children (WeeFIM) is restricted for resource-constrained settings, due to the prohibitively expensive annual licence. This is a commonly used assessment tool designed to measure the outcomes of rehabilitation for children with developmental, acquired or genetic disabilities, within the hospital (clinical) and research settings. It was based on the WHO disablement model. It assesses activities of daily living through observation and consists of a self-care, mobility and cognition domain. The WeeFIM can be used with children from 6 months of age to 8 years of age but can be used on children with developmental disabilities up to 18 years of age. It has good reliability and validity ratings, however due to ceiling effects, it has limited use with children who have milder forms of CP[9, 69].

The WeeFIM was adapted from the adult Functional Independence Measure (FIM) and content validity was established using 8 experts. Construct validity of the

WeeFIM's self-care domain is r=0.68. Construct validity studies show that the WeeFIM is able to discriminate between different CP presentation patterns. The WeeFIM's criterion validity is correlated with the PEDI within the self-care domain (r>0.88). The reliability of the WeeFIM shows internal consistency of motor domain at α=0.91, interrater reliability of self-care 0.86 and test-retest reliability of self-care 0.92-0.97[9].

Wong et al. (2004) when using the Chinese version of the Functional Independent Measure (WeeFIM), found that in order for the WeeFIM to be a meaningful assessment tool for use in China, it had to be adapted, translated and piloted in the context first[69].

2.5.1.3 Activities Scale for Kids (ASK)

The Activities Scale for Kids (ASK) is a self-report questionnaire that was designed for use with children ages 5 to 15 years old with physical disabilities, in particular musculoskeletal disorders. There are two versions of the ASK. One measures capability and one measures performance, ASK-capability (ASKc) and ASK-performance (ASKp) respectively. The ASK consists of 30 items, which are representative of 9 domains within self-care, play and mobility. Rasch analysis was used to confirm construct validity. Construct validity shows divergence of -0.03 and convergence of 0.43. The reliability of the ASK showed interrater reliability of 0.99[78, 81].

The ASK can be downloaded from the internet and an annual licence fee is paid. Further training to use the ASK is not needed[82]. The annual licence fee and internet requirement create barriers towards the use of the ASK within a resource-constrained area.

2.5.1.4 Life Skills Inventory

The Life Skills Inventory is an independent living skills assessment tool that is a free resource developed by the Washington State Department of Social and Health Services. The tool is a non-standardised checklist that is used to assess the readiness of an adolescent to live independently. The Life Skills Inventory consists of 15 categories that fall within both basic and instrumental activities of

daily living that are required to live independently. The Life Skills Inventory can be downloaded from the internet once, and used multiple times[83].

A free checklist is useful in a resource-constrained setting as it is easily accessible, however as the Life Skills Inventory is non-standardised, comparisons against a normative population cannot be made.

2.5.1.5 Bayley Scales of Infant and Toddler Development – Third Edition (Adaptive Behavior Questionnaire)

The Bayley Scales of Infant and Toddler Development – Third Edition (Bayley III) is a revision of the Bayley Scales of Infant and Toddler Development – Second Edition (BSID-II) and is designed to measure developmental functioning of infants and toddlers. The Bayley-III is designed for use with children aged 1 to 42 months old in order to identify possible developmental delays. The main difference between the Bayley-III and the BSID-II is the inclusion of the Adaptive Behavior Assessment System - Second Edition (ABAS-II) as the Adaptive Behavior Questionnaire. The Bayley-III includes cognition, language, motor, social-emotional and adaptive behaviour subtests[84].

The ABAS-II has standardisation properties independent of the Bayley-III, and includes a sample of 1350 children aged between 0 and 71 months. As the age range differs between the ABAS-II and the Bayley-III, upper age limit of the ABAS-II is changed to reflect the same age range as the Bayley-III. The Adaptive Behavior Questionnaire included a domain of self-care that consists of 24 items. The reliability for the Adaptive Behaviour Questionnaire is taken from the ABAS-II. Internal consistency, using coefficient alpha and Fisher's z transformation ranges from 0.79 and 0.98. Test-retest reliability demonstrates coefficients of 0.80 or higher. Interrater reliability coefficient for the adaptive domain is averaged at 0.79 and for the adaptive skills area, averaged at 0.73. Validity demonstrates a moderate correlation between the ABAS-II and the Vineland Adaptive Behaviour Scale – Interview Edition with a composite score of 0.58-0.70[84].

In order to be able to administer the Bayley-III, training in developmental assessment and interpretation is required[84]. This, in addition to the cost of the Bayley-III makes this assessment expensive to acquire and use, particularly within a resource-constrained setting.

2.5.1.6 Oregon Project - Sixth Edition

The Oregon Project, sixth edition, is a non-standardised checklist for preschool children who are blind or visually impaired. It forms part of a larger curriculum for use with children from birth to 6 years old. In addition to the checklist, the Oregon Project includes teaching activities, skills inventory and a reference section. The domains of the Oregon Project include cognitive, language, socialization, vision, compensatory, self-help, fine motor and gross motor. The self-help section includes self-care items falling within activities of eating, dressing, grooming and toileting[85].

The Oregon Project can be ordered from the Southern Oregon Education Service District, directly or online. No additional training is required to use the Oregon Project[85]. Even though the low cost is more useful in a resource-constrained setting, the use of a non-standardised assessment tool makes it difficult to make comparisons to a larger standardization sample.

2.5.1.7 The Primary Progress Assessment Chart of Social Development

The Primary Progress Assessment Chart of Social Development is a checklist for social development in children and adolescents with intellectual disabilities. The Primary Progress Assessment Chart of Social Development contains domains of self-help, communication, socialisation and occupation. Self-help includes of self-care skills of eating, dressing, toileting and washing. Validity correlation coefficients when compared with the Stanford Binet Test is 0.42 for self-help. Reliability coefficient for self-help is 0.95[86]. As the Primary Progress Assessment Chart of Social Development is an old assessment tool, it is out of print and not easily accessible.

The assessments described above form the starting point for the item review of this study. Some of the assessments described above have been used in research and within clinical settings with children with CP and are considered suitable to evaluate the occupational performance of children with CP. The challenge for using these tools is that they have been developed within Western countries and normed on well-resourced populations. Thus despite the fact that all the

assessments described above measure aspects of self-care in children, they are not specific to CP and appear to be of limited use clinically in South Africa.

This means that if the assessments are used within resourced-constrained South Africa, interpretations a therapist can make from these results are limited and may be invalid.

Cost is another challenging factor that creates a barrier toward the use of these assessment tools within South Africa. Therapists will need to purchase the assessment tool as well as administration and scoring sheets where necessary. In some instances, therapists will need to complete a five-day training course in order to become competent in administering, scoring and interpreting the assessment in another country.

Currently, there are no valid and reliable assessment tools, freely available, that assess self-care in children with CP living in resource-constrained settings such as South Africa. Therefore, it is important that appropriate assessments are developed for the South African context and that these tests are made available in terms of cost to therapists working in resource-constrained areas.

2.6. Development of Standardised Assessments

2.6.1 Factors to be considered in applying an already standardised assessment within an African Context

When developing a standardised assessment within an African context, there is little documentation with respect to the development of culturally appropriate assessment tools for children living in Africa that can be consulted. This is because many assessment tools, standardised elsewhere are used without taking into account cultural relevance[10, 87].

Matafwali, Serpell (2014) reports that use of assessment tools that have been standardised in Western countries in resource-constrained areas is common[10]. Not only is it extremely time consuming to adjust an assessment tool for use within a resource-constrained area, but many biases may be included in the assessment tool if it is not adjusted rigorously[10].

Cross-cultural bias can arise due to the meaning and importance that culture places onto specific activities. These may be different in different cultures. This means that the assessment of the same activity cannot be compared in the same way across different cultures. Matafwali et al. (2014) have identified three types of bias that might be introduced into a test being administered across different cultures, namely construct bias, method bias and content bias. Construct bias appears when test authors use definitions of constructs that do not overlap between cultures. Method bias is introduced when a cultural factor, not relevant to the construct, affects many items within the test. Content bias occur when there is a lack of accommodation for differences between the cultures[10].

If a tool, developed within a well-resourced context is used within a resource-constrained context, the results may not reflect the child's functional ability and in that case, the information generated is not useful to the assessor. For example, when developing the Zambia Child Assessment Tool (ZamCat), the measures of fine motor ability in Zambian children was completed with an adapted set of subtests, using already standardised subtests as a guide, as Zambian children were not as familiar with pencils as Western children. The ZamCat was developed from already standardised assessment tools. This is an example of construct bias[10].

Often items within standardised assessment tools developed in Western countries are not appropriate to children living in the African context. Therefore, if the original standardised test is used, results may be invalid creating misleading results due to differences in language, culture and socioeconomic status between the original normed population and the target population in the African context. Bornman, Sevcik, Romski, Pae (2010) found that during their translation and adaptation of the Mullen Scales of Early Learning and the Ages and Stages Questionnaires (ASQ) into Afrikaans, items including snowmen, coats, applesauce, measurement use of inches and feet and reference to American currency needed to be adapted[11]. These items are examples of content bias[10].

Gladstone, Lancaster, Umar, Nyirenda et al. (2009) gives an example of the concept of intelligence that is defined differently depending on one's culture. The Western concept of intelligence refers to the child's reasoning, memory and

acquisition of knowledge. The non-Western concept of intelligence however is defined as obedience, independence, taking on social responsibility without being requested to, common sense and the ability to deal with socially complicated situations[87]. These observations are based on focus groups run with professionals and with lay people within Malawi[87]. The use of focus groups to understand cultural emphasis on development is a useful tool to understand the culture of the target population and to understand how the culture impacts on parent's expectations for a child's development.

Other biases referred to by Matafwali et al. (2014) include sample, administration and instrument bias. Sample bias results if different samples that should not be compared are compared. Instrument bias refers to the use of tests where aspects of test items are unfamiliar to the child. For example, within South Africa, a coat is called a jacket and jelly is called jam[10, 11].

When it comes to existing standardised assessment tools successfully used with children within the African context, different methods including adoption, adaptation and assembly have been reported[10]. Matafwali et al. (2014) describe adoption as being the use of one tool within another cultural context from which it was developed, with the only changes being around translation. Adaptation involves more modification of the original assessment tool in terms of its items and administration instructions so that it becomes more meaningful within the different cultural context. Assembly is construction of an entirely new assessment tool when all available tools are not appropriate to the cultural context[10]. The biggest difference between these methods is that adoption and adaptation involve use of an already standardised assessment tool, while assembly involves making an entirely new tool. Although many researchers found the PEDI to be a meaningful tool for assessing performance in children with disabilities, if it the adoption method was to be followed, for use within South Africa, all it would need was translation. If the PEDI were adapted, it would need to be modified so that the items and instructions were culturally appropriate and relevant to resource-constrained South Africa. If both of these methods did not give the most meaningful and useful tool to be used, assembly would be needed. This would mean that the PEDI would be set aside and a new assessment tool developed.

Of these methods, assembly of a similar test seems to be the most appropriate and applicable as the resulting tool has less cultural biases and is more meaningful for the target resource-constrained population. Limitations for assembly would include time and financial constraints, as it would take time and financial resources in order to create a usable assessment tool, based on the original tool. Even with these limitations, the resultant assessment tool is likely to yield better results than if an assessment tool standardised in a Western country was used without any changes[10].

The use of adoption, modification and adaptation approaches to transforming an already developed assessment tool, which can be used with another population are methods that involve less time and cost to the researcher. However, in using these methods, biases may still be inherent in the tool from its original form. This runs the risk of creating a tool, which is meaningless to the population it is being changed for. It also risks creating results which are not a true reflection of the child's abilities[10].

In a study by Abubakar, Holding, Van de Vijver, Bomu et al. (2010), the Developmental Milestones Checklist (DMC), was initially developed from the Griffiths Mental Developmental Scale for Infants (GMDS) and the Vineland Adaptive Behaviour Scale. The DMC's construct was to assess developmental outcomes from birth to two years of age. The DMC's domains includes locomotion, fine motor skills, language and personal-social development. Once the construct had been defined and item selected, focus groups were used, and field testing of the selected items was completed in order to determine the reliability and validity of the DMC[88]. In this study, Abubakar et al. (2010) found that parent reports can be an accurate and useful method for use in resource-constrained settings[88].

The abovementioned studies highlight the need for a new assessment tool to be developed within resource-constrained South Africa, rather than relying on assessment tools developed elsewhere. A new assessment tool should eliminate concerns for introduction of biases, language and cultural differences, unreliable and invalid use of the resultant tool.

2.6.2 Steps in the Development of a Standardised Assessment

The development of a standardised assessment needs to move through stages to define the actual tool. Various psychometric tests are conducted in order to establish good psychometric properties. Following testing, if the tool is to be norm-referenced, it would need to be piloted, in order to establish norms or typical scores relevant to the test[3].

Davis et al. (2004) and Lavar Fawcett (2007) identify the following steps necessary for developing an assessment tool: defining the construct, writing test items, reviewing test items, reliability testing, validity testing, item analysis and conduction of norming studies[5]. Foster (2006) gives a similar description of stages in test development with the first 4 parts describing item development, the next two stages describing reliability and validity testing and lastly a stage to publish results[15]. Foster (2006) further breaks down the first stage of item development, defining the test, into steps to determine the type of measure to be used, which domain and context the test will be based in, types of questions or items to be included, testing format, who the test will be used with, test length and item difficulty[15, 16].

Defining the construct is the manner of defining the assessment tool's purpose. It is the initial steps in creating a plan around what will be measured. For example, the PEDI's construct is activities of daily living, more specifically self-care, mobility and social functioning. Along with defining the construct for the assessment tool, identifying the reasons for development, how the tool will measure the chosen construct and the target population, should be determined[5].

Reliability is an indication of how well the test can be administered over and again with the same scores being obtained[3]. The degree to which a test, tests what it intends to test is known as validity. The validity of a test is established while taking into account the purpose for the test development and what it will be used for when it is complete. There are three main types of validity: construct validity, content validity and criterion-related validity[3].

2.6.2.1 Content validity

Content validity is an important measure in that it identifies whether an assessment tool measures the construct it is meant to measure through its items[5]. Davis and Morrow (2004) explain that in order to establish strong content validity, determining a well-defined domain and using experienced subject matter experts (SME) to identify the match between the domain and the items is essential [5]. A subject matter expert (SME) is defined as an individual who has experience based within the context of the assessment tool. The role of the SME is to rate the relevance of each item, in order to determine whether it is measuring the construct it is set out to measure, and whether it is clear and succinct. Any ambiguity or irrelevance to the test construct can be identified through SME reviews. Davis et al. (2004) recommend that having at least two SMEs to review all items is important in creating sufficient comparison of data[5].

2.6.2.2. Item Analysis

Item analysis involves determining the item difficulty, item discrimination, item bias and modification and piloting of the items[5, 15]. Item difficulty is the proportion of items answered correctly by the participants. This is determined through evaluating the piloted sample's responses. Item discrimination is the amount that the item is able to distinguish between different abilities of participants. To have good item discrimination, a new assessment tool will need to be able to distinguish between children with a given condition in terms of severity and age, in comparison to a typically developing child[5, 15].

Item bias is when an item behaves differently for different groups of participants. Within the new self-care assessment tool relevant to children with CP, item bias occurs if children who are more familiar with knives and forks will be able to perform better when completing an item related to eating with a knife and fork than a child with limited experience. 4 The items on a new assessment tool relevant to children with CP should be analysed by SME occupational therapists and SME caregivers from the target population, in order to aid the modification of the items. Following modification, the items can be re-piloted before it can be used in the final tool [5].

2.7 Summary

The current definition of cerebral palsy includes an emphasis on the condition being a motor disorder, with associated impairments. The importance of a universal definition of cerebral palsy allows the use of collective language for all professionals who work with children with cerebral palsy throughout the world.

In South Africa, there is legislation for children with disabilities, where therapy can access health and therapy services. However, there are instances where children who have disabilities are not known to authorities and do not have access to the current legislative provisions. Having an assessment tool, which is able to determine the independence in self-care in children at risk for delays in self-care skills, would aid identification of these children in order for them to access services.

Due to the diverse nature of CP, classification systems have been designed to aid understanding of each child with CP and their functional abilities. Classification systems are meant to be a tool used in addition to assessment tools. Both together contribute to the overall understanding of the level of a child with CP's occupational performance. This understanding allows occupational therapists to determine therapeutic needs with an emphasis on skills required for activities of daily living.

Many areas in South Africa can be defined as low income and resource poor areas. Engaging in self-care activities are affected by the language, culture, and religion of the person completing these activities. Therefore, OT practice, assessment and intervention are also affected by these factors in order for intervention to be meaningful and sensitive to change. This is why having an assessment tool that is developed within the resource-constrained environment, acknowledging the culture of the people living in the area will aid identification of children with CP who need intervention in self-care independence.

Many standardised tools have been developed to assist in the identification of children needing occupational therapy intervention. These tools help occupational therapists to identify deficits within activity performance. In order for assessment tools to be beneficial and effective, they need to be sensitive to the culture,

environment and the resources available to the target population. A large number of standardised assessment tools have been developed in the Western world, based on Western populations in order to assess performance of self-care and other areas of occupational performance. Many of these assessment tools carry licencing restrictions, high cost and training requirements in order to be successfully implemented. Often these factors mean that these assessment tools are not accessible within the South African context and if they are used, they may create biases, incorrect outcomes and misinterpretations.

There has been little documentation with respect to culturally appropriate self-care assessment tools for children with CP, living within Africa. Therefore, it is essential for culturally relevant assessment tools to be developed and documented.

CHAPTER 3
METHODOLOGY

3.1 Introduction to Methodology

This chapter describes the research methods followed to begin the development of the Self Care Inventory for Children with Cerebral Palsy (SCICP). The study used an instrument development and non-experimental, descriptive design as it aimed to describe the steps in the development of the assessment tool in terms of content validity and the finalisation of items for the newly developed self-care inventory. The methodology started by defining the construct and domains of the SCICP and item generation. Two content validity reviews were conducted and allowed the researcher to modify the items. The first content validity review used subject matter expert (SME) occupational therapists and the second content validity review used caregivers living in a resource-constrained area. In between the first and second content validity review, translation of the items occurred. A preliminary field test was conducted using typically developing children and children with cerebral palsy (CP). Finally, items were analysed and modified in order to determine the items to be included, scoring and administration of the SCICP.

3.2 Research Design

The assessment tool developed in this study focuses on the self-care abilities of children with CP living in resource-constrained contexts in South Africa. The steps that were followed in the development of the SCICP were based on those published by Davis et al. (2004), Foster (2006) and Laver Fawcett (2007)[5, 15, 16, 89].

These aspects of instrument development were completed in four stages:

Stage 1: development of items

Stage 2: establish content validity of the questionnaire using SME followed by the translation of the questionnaire

Stage 3: establish content validity of the questionnaire by caregivers and mothers of children in KZN

Stage 4: pilot test of the SCICP to evaluate the administration of the inventory and the appropriateness of the items on a sample of children with and without CP. The final items to be included in the SCICP were determined.

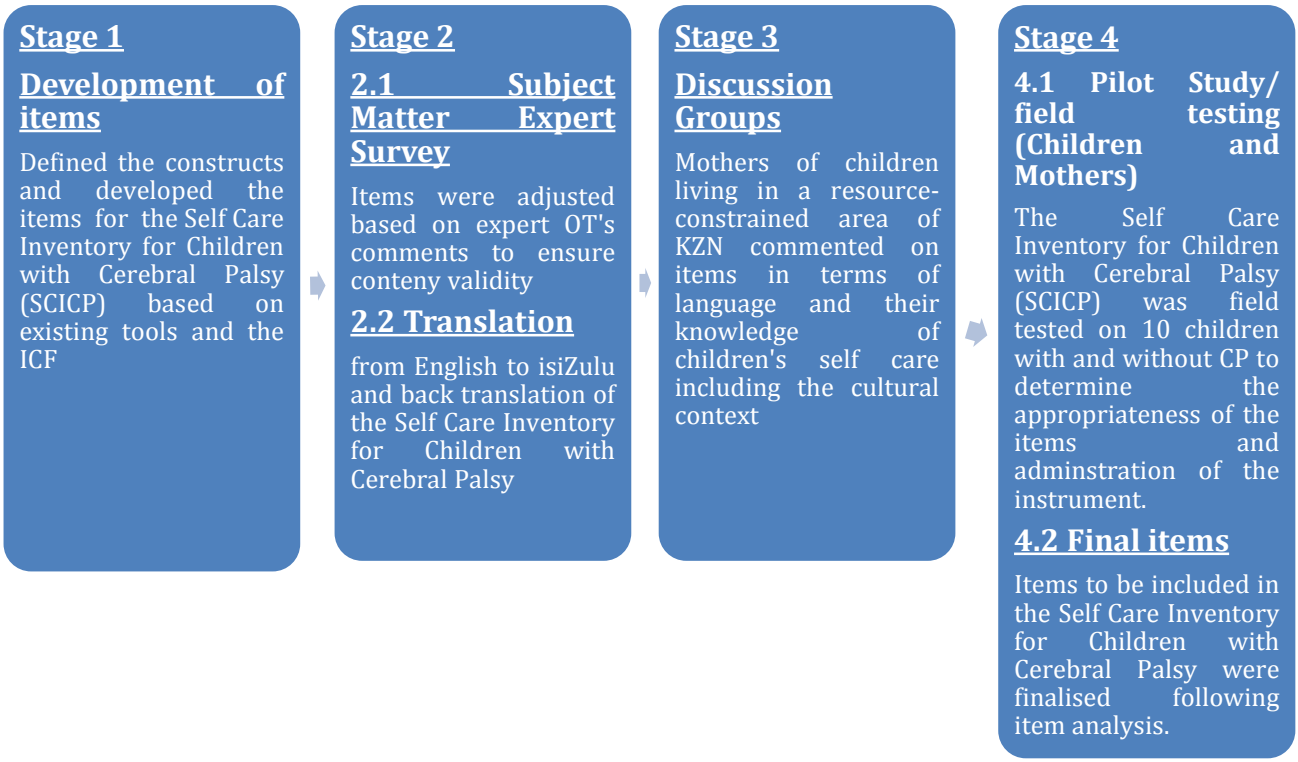


Figure 3.1: Flow Chart depicting order of methodology

3.2 Stage 1

3.2.1 Stage 1.1: Defining the construct and domains of the tool

In this stage the construct as well as the domains of self-care to be included and the context in which the tool would be used was specified. and the appropriate difficulty level for different ages was included.

3.2.1.1. Factors considered in determining the Self-Care Inventory for Children with Cerebral Palsy

Age

The age range for the assessment tool is from birth to 7 years of age. This age range was identified to allow the new assessment tool to be useful for different types of children with CP and to limit the floor or ceiling level irrespective of the differences in functional ability and participation in self-care. Children with severe

CP (GMFCS level V, MACS Level V, CFCS level V), requiring total assistance from caregivers will for instance be able to achieve a similar score as a young typically developing child of 12 months of age or below.

Context and residential conditions and language

Resource-constrained areas are defined as areas within South Africa where there are limited services and infrastructure. This also includes poor accessibility to available resources. The study area, Nquthu, in the Umzimyathi Health District of Kwa-Zulu Natal fits into this definition of a resource-constrained area. The selection of this area was convenient, as the researcher knew the study site from earlier work in the area.

The items on the Self-Care Inventory for Children with Cerebral Palsy needed to be defined for children with CP living in areas where houses are typically a single room, with a thatched roof. These rondavels often lack running water and sanitation in the form of a flushing toilet. The houses lack bathrooms and bathing is done from a bucket, bowl or tin bath. Although some homes have electricity, cooking is usually done over a fire or using a paraffin stove. Meals are often eaten using the right hand or with a spoon sitting on benches or on mats on the floor. Water for drinking, bathing, cleaning and washing needs to be collected from taps situated at various points within the community. Children with CP may also need to travel great distances to access local hospitals and clinics.

Children with CP living in this area speak isiZulu and are being brought up to follow the isiZulu culture. Therefore, it was important that the tool was developed in the language they could understand and items were developed therefore in isiZulu as well as English as most therapists using the tool may not speak isiZulu.

Developmental model

The SCICP is based on the developmental model as it will be used with children developing self-care skills. The inventory will account for the ability to independently engage in self-care as children develop. Cultural differences do play a role in which skills are attained and in what order they are attained. It was important to first ascertain how self-care skills develop in typical children living in

Nquthu, so that the level of function of children with CP can be aligned with the skills acquired in the different age groups[3].

It is important that the SCICP covers all aspects of self-care important for everyday activity, such as eating, washing, toileting, grooming, dressing and sleeping. Each aspect of self-care requires functional mobility necessary to complete the task. Functional mobility for this assessment included the movement from one position or place to another; moving objects; and functional walking needed to carry out self-care activities[3]. Community mobility and transportation were not included. Functional mobility is a key component of many self-care skills. For example, functional mobility in toileting includes walking to the toilet, pulling down clothing, changing position from standing to sitting on the toilet, reaching for toilet paper, changing position of sitting to standing and pulling up clothing. In order to be independent in all self-care skills, a person must also be able to complete all components of functional mobility. Consequently, functional mobility was included as a component in all self-care activities in the assessment tool.

International Classification of Functioning, Disability and Health (ICF)

The SCICP is based on the universal language of the ICF. Selection of domains and items were guided by the ICF codes for self-care, within the section of activities and participation section. The ICF self-care codes allowed for potential items to be included or excluded based on the subcategories for each self-care activity.

To determine the difficulty of the items, and the types of items to include, the International Classification of Functioning, Disability and Health (ICF) was used as a guide for item generation and selection. The World Health Organisation's ICF was originally published as a trial version in 1980 called International Classification of Impairments, Disabilities and Handicaps (ICDH). The current version of the ICF was published in 2002. For the development of this assessment, the self-care activities children of different ages were identified and reviewed from existing questionnaires and adapted to generate the items in the SCICP.

Model of Human Occupation

The SCICP is based on the model of human occupation as it will be used to assess the self-care abilities of children. Understanding of a child's environment, roles and habits and how they influence the performance of self-care will aid the understanding of the increasing independence of self-care as a child develops.

3.2.2 Stage 1.2: Preparing and formatting items

The items for the assessment tool were developed from a review of existing assessments of self-care for children and based on the self-care domains in the ICF. Items were scored on an ordinal scale suitable for parent report or therapist observation of the children for self-care activities. (These items, using four-point scoring, form the initial version of the SCICP).

The type of questions and how they would be answered determined the format in which the items will be presented. The length of the assessment tool was considered in terms of the tolerance of the children for assessment.

3.2.2.1 Format of items

The items were presented within a statement format, to enable them to be used as a self-questionnaire, where a caregiver states whether the child was able to or not able to complete each item. The statement format also enabled the items to be used as an observational tool by the assessor. The assessor was able to ask the child to perform each item and observe and rate his performance. The format of the items that contribute to the length of the entire tool needed to be easily accessible, and quickly administered. Ideally, the SCICP would be an assessment tool that would take approximately 45 minutes to administer. If the tool was any longer, then it would become more time consuming and less cost effective to administer, and would lose some of its usefulness. The format, manner of administration and scoring of the PEDI was used to guide the structure of the SCICP.

3.2.2.2 Item generation

Existing assessment tools focusing on self-care in children were reviewed, to aid item generation for the SCICP.

Before items could be generated, item domain areas were defined within the construct and domains of self-care.

Selection of Item domains

Item domain areas were selected based on the ICF and the codes given to relevant activities relating to self-care. Self-care was coded under the subheading of activities and participation. Item subdomains within the following codes were considered for inclusion: Self-care (d5) – including Washing (d510), Caring for One's Body Parts (d520), Toileting (d530), Dressing (d540), Eating (d550), Drinking (d560); Functional Mobility, Functional Walking and Community Mobility (d410-429), Walking (d450) and Carrying, moving, handling objects (d430-449). For the purposes of this assessment, functional mobility includes the movement from one position or place to another and moving objects[3]. Community mobility includes changing positions, maintaining positions and transferring. A mapping of the SCICP's items and domains to the ICF codes was completed. Functional mobility and community mobility were included for consideration as these aspects are needed in how the self-care tasks are completed.

Item Selection Criteria

To select items, appropriate for different age groups for the SCICP existing standardised assessments were reviewed, viz. The Functional Independence Measure for Children (WeeFIM), Pediatric Evaluation of Disability Inventory (PEDI), the Bayley Scales of Infant and Toddler Development (Adaptive behaviour), Activities for Kids (ASK), the Life skills inventory, the Primary Progress Assessment Chart of Social Development and the Oregon Project for Visually Impaired and Blind Preschool Children. The items in these assessments were analysed for relevance to the above ICF codes for possible inclusion into the development of the new assessment. An item was considered relevant if it was:

- Related to typically developing children below 7 years of age.
- Related to the domain of self-care.
- Related to a functional mobility action needed to complete the self-care task
- Could be mapped to an ICF code within self-care or functional mobility chapters of ICF

All the items from each standardised test were listed under the specific activity and these were combined under the domains of self-care from the ICF.

Once all the relevant items were identified, duplications were excluded and the items were grouped under the domains of Eating, Dressing, Washing, Toileting, Grooming, and Sleeping. Items for functional mobility were grouped under the domains to which they specifically applied e.g. the mobility needed to walk to the toilet was included under toileting. Since some functional mobility items were applicable to more than one self-care domain, an additional general functional mobility domain was also included.

Following the ICF mapping, applicable items were included into the final list of items. The researcher arranged the items into age at which independence is achieved, based on the assessments that the items came from. However, it was assumed that following further analysis through content validity reviews in stage 2 and 3, this would change.

Item Scoring

The scoring was based on either self-report by the parent or therapist observation of the child's participation in these activities to determine independence and level of assistance needed. An ordinal scale was used to identify the different levels of independence of the children through inferences of their ability to complete self-care activities. The scoring on other assessments was reviewed and the limitations like that on the PEDI considered. For example, in the PEDI the functional skills section is scored based on whether the child is able or unable to complete each item. This does not take into account a child who can almost complete an item or whether a child can complete the items with modifications. The modifications section is scored with respect to the amount of modifications the child requires (i.e. no modifications, child orientated modifications, rehabilitative equipment and extensive modifications). This contributes to the clinical picture of the child's overall independence. However, in order to determine this, both ability to complete the item and modifications needed need to be scored. Thus, only one section was included for the SCICP. The items of the SCICP were arranged in order according to age that the child would be expected to complete the activity independently.

The SCICP was finalised and arranged in order for the content validity to be established. Appendix A contains the scoring for the SCICP.

3.3 Stage 2

3.3.1 Stage 2.1: Content Validity – Subject Matter Expert (SME) Survey and Review.

The items selected for the SCICP were reviewed by SME occupational therapists with experience in treating children with CP in resource-constrained areas. Items were adjusted based on their comments.

Content validity needed to be established in order to determine whether the items accurately represented self-care and the chosen domains. This would determine whether the items were applicable to children within resource-constrained areas of South Africa. As with the study by Bornman et al. (2010), the original items analysed contained many words which were not used within South Africa[11]. Words such as “zippers”, “pullover garments”, “closet”, “diaper”, “tub” are examples of words that needed to be changed into the South African equivalent.

As described in the Literature Review, Matafwali et al. (2014) identified certain biases that affect the use of an assessment tool that had not been developed within its target population. They describe cross-cultural bias, method bias, construct bias and sample and administration bias[10]. In order to avoid biases and irrelevant, ambiguous and inappropriate items into the SCICP, content validity needs to be established.

Therefore, a panel of SME were asked to examine and suggest revision of all the items. SMEs are experienced paediatric occupational therapists. These SMEs helped to provide theoretical relevance and input with respect to the content validity of the items. Stage 3 included a second panel of SMEs who were parents and caregivers of children with CP. This panel contributed to the cultural relevance of the content validity of the items.

3.3.1.1. Selection of SME Participants: Occupational Therapists

Population

The population consisted of occupational therapists in South Africa with at least 10 years of experience in paediatrics, specifically with children with CP who have had experience in resource-constrained areas.

Participants

The participants used for the SME survey were selected through purposive selection based on the understanding that they fit the selection criteria[90]. The participants were selected with the assistance of Malamulele Onward, a non-profit organisation providing therapy to children with CP in resource-constrained settings. As such, they have a database of occupational therapists who matched the inclusion criteria.

The selection criteria for participation within the SME survey was:

Inclusion criteria

- An occupational therapist working in the field of paediatrics, specifically with experience in CP
- At least 10 years of experience.
- Experience in working in resource-constrained settings

3.3.1.2 Procedure

Using Survey Monkey (https://www.surveymonkey.com/s/selfcareitems; see Appendix B), the SCICP was e-mailed to 10 occupational therapists who met the inclusion criteria. According to Haynes (1995), the strength of the review increases with the greater the number of SMEs[91]. Survey Monkey allowed the identities of the respondents to remain anonymous to the researcher.

SMEs participants were asked to rate the items selected by the researcher for the SCICP. They were asked to judge according to their knowledge and experience that the item was relevant, ambiguous, simple, or clear, Further, they were asked to indicate whether the item needed clarifications or whether it should be discarded. Following each subsection, there was space for additional comments.

Over eight weeks, two follow-up emails and weekly reminders of the invitation for participation were sent to all 10 participants. Three of the ten SME participants responded. This was the minimum number recommended by Lynn (1986). After review of the SMEs' comments, the researcher adjusted the items. If the items failed to score 75% for the four points participants were asked to comment on, the item was excluded[92]. The inclusion of the ambiguous category created a reversed score. Therefore 75% score indicated that the item was relevant, simple and clear.

3.3.2 Data Analysis for Subject Matter Expert (SME) Survey and Review

The first phase of content validity was determined through SMEs' opinions within the survey. Within the survey, the scores for relevant, ambiguous, simple, clear for each SME were computed. Those questions that scored yes for three out or the four options were accepted at 75% agreement. If the score was lower, then items were reviewed in terms of needing to be edited or discarded. The decision to edit or discard was based on two out of three SME participants agreeing. Ambiguous items that created reversed scores were adjusted.

3.3.3 Translation of the Self Care Inventory for Children with Cerebral Palsy

After the changes suggested by the SME participants were made, a professional translator, with more than 20 years of experience in translation, then translated the SCICP into isiZulu.

The translation was followed by a back translation into English by a Zulu-speaking research assistant. Differences were then discussed and clarified. IsiZulu items were then included in the SCICP with the English translation below.

3.4 Stage 3: Content validity: Content validity - Caregivers of Children Living in a Resource-Constrained Area of Kwa-Zulu Natal (Discussion Groups)

To further ensure content validity, the mothers, fathers, grandmothers, grandfathers and caregivers of typically developing children living in the research site were included in discussion groups to confirm that the items generated reflected the methods their children use to engage in self-care. The mothers, fathers, grandmothers, grandfathers and caregivers were considered experts due

to their experiences raising children within the resource-constrained context. Their opinions contributed to the cultural relevance of the SCICP. They were also asked to confirm at which age they feel the children should achieve independence in each activity, based on their experience of their children's development.

In order to establish content validity with parents and caregivers, the following steps were undertaken:

1. Selection criteria of study participants was established
2. Mothers, fathers, grandmothers, grandfathers and caregivers who fell within the inclusion criteria were invited to attend the discussion groups
3. Two discussion groups were conducted

3.4.1 Study Site

This part of the study took place in Nquthu in Kwa-Zulu Natal (KZN) at Charles Johnson Memorial Hospital in Nquthu and Pilani Drop-In Centre in Nquthu, KZN. This study site was chosen as the researcher has been involved in previous research related to children with CP in the area. Many of the children and their mothers were familiar with the research process and were known to the researcher.

3.4.2 Selection of participants

Population

Mothers, fathers, grandmothers, grandfathers and caregivers of typically developing children living in Nquthu in Kwa-Zulu Natal formed this population.

Participants

The participants for the content validity review in the form of discussion groups were selected through convenience selection. The disability facilitator and parent liaison officer who worked with the mothers of children with CP in the area were asked to invite mothers, fathers, grandmothers, grandfathers and caregivers of typically developing children, within the Nquthu community, to come to the Philani Drop-In Centre in order to participate within the discussion groups.

Inclusion criteria

The selection criteria in order to participate within the discussion group, was for the person:

- To be a mother, father, grandmother, grandfather or caregiver of a typically developing child,
- Living in Nquthu,
- Home language was isiZulu.

3.4.3 Procedure

Training of Research Assistant

The discussion groups were run in isiZulu by a research assistant and translated for the researcher where necessary. The research assistant had experience in translating during other similar research projects, as she is a Parent Liaison Officer. The liaison tasks involved educating, translating for and supporting caregivers of children with CP.

The researcher and research assistant went through each item together, prior to the discussion groups. The research assistant was shown that when presenting each item, she was to ask the group what they thought about the items in terms of the relevance and reasons for this, whether the item was simple, clear or difficult to understand and whether the item's wording in isiZulu needed editing. Finally, the group was to decide whether to keep or discard each item. The research assistant also asked at what age the caregivers felt that their children achieved independence in each item.

Discussion Groups

Two discussion groups took place, with 10 different participants in each group. For research to be useful, the researcher needs to have as many participants within the discussion group as possible. Each group conducted, had a maximum of 10 participants so that the participants felt comfortable enough to speak their thoughts and opinions within the group. This is why two groups of ten participants were held

rather than one group of 20 participants. The research assistant, who is able to speak isiZulu introduced the researcher and explained the purpose of the discussion group to each participant, and asked them to sign the informed consent.

Once the group had 10 members present, the research assistant began the group. The research assistant welcomed the participants, and explained that they would be going through each item on her list and discussing it in terms of the criteria mentioned above. The researcher explained that the item would be discussed until the group reached a consensus about relevance, simplicity, clarity, difficulty in understanding, retaining or discarding the item, its wording and the age at which independence is achieved. Both researcher and research assistant made notes during the discussion group, and the group was recorded for later analysis and confirmation.

The researcher paid for each participant's transportation costs for the day following participation in the discussion group, as an out-of-pocket expense. Arrangements had been made for a caregiver from the Philani Drop-In Centre to look after any children present while their caregivers attended the group, if necessary. None of the children attended the group. Some of them were school age, and were at school. Others, who were younger than school age, attended the children's groups at Philani Drop in Centre, while their caregivers attended the discussion groups.

Following the discussion groups, adjustments were made to the items.

3.4.4 Data Analysis for Content validity - Caregivers of Children Living in a Resource-Constrained Area of Kwa-Zulu Natal (Discussion Groups)

Within the discussion group, the items were analysed according to comments received from the expert caregivers. Items with 100 per cent consensus by the expert caregivers were adjusted. Notes in the form of tick boxes and comments recorded in both of the discussion groups were analysed to determine 80 per cent consensus between each group and then the items were deleted or retained and edited. Items were adjusted for language errors in English and isiZulu at the time

of each discussion group. Items were discarded if they were repetitive or ambiguous, as determined by the consensus of both discussion groups.

3.5 Stage 4.1: Evaluation of the Self Care Inventory for Children with Cerebral Palsy on Child Participants with and without Cerebral Palsy.

The SCICP with Cerebral Palsy was tested on five children with CP and 5 typically developing children to determine the appropriateness of the items of each item for the population it was designed to assess; the ease of administration; the time needed; the scoring and finally to review the items on the tool.

Piloting of the SCICP on a sample of children, for whom it is intended, was essential. This allowed for a preliminary evaluation in order to evaluate the SCICP in terms of the difficulty, discriminative ability and appropriateness of the items, scoring, time taken to administer and ease of administration. Items could then be revised for the final version to be investigated for various psychometric properties[5].

The researcher and research assistant assessed 10 children from the same area, five who were typically developing and five who had various severities of CP, allowed data to be collected for analysis of the SCICP. This field testing of the assessment tool allowed the researcher to evaluate[93]:

- The administration of the items to determine whether any items pose problems
- Standardisation of items needed for the observation of children completing items. This included administration instructions, wording when asking about each item and equipment used for each item
- The difficulty of the items considering the children's age and the severity of their CP
- The ability of the items to discriminate between typically developing children and those with CP
- The ability of the caregivers to answer relevant questions on the Self Care Inventory for Children with Cerebral Palsy in comparison with their child's actual performance
- The scoring and whether this was appropriate when judging the ability of the children with and without CP

- How long it takes when only the child's performance of the items of the Self Care Inventory for Children with Cerebral Palsy are observed
- How long it takes to complete the entire assessment if observation of the child and interviews of the mother were used

3.5.1 Study Site

Children with CP in Nquthu received assistance from a number of projects based in the area. The evaluation of the SCICP was completed in a site where the projects are based and occurred at the Philani Drop-In Centre in Nquthu, as mothers were familiar with the facility and it was close to where they lived. Testing occurs within a discussion room, where chairs were kept for talks and workshops at the centre.

3.5.2 Selection of child participants

Population

Children, between the ages of birth and seven years, who were typically developing and children with Cerebral Palsy between the ages of birth and seven years, living in Nquthu, Kwa-Zulu Natal were recruited into the pilot study.

Child Participants

The facilitators at the Isibindi Project based at the Philani Drop-in Centre in Nquthu helped to identify mothers and children for field-testing the SCICP. Five children with cerebral palsy and five typically developing children, and their mothers or grandmothers were invited to participate in the field-testing. The typically developing children, invited to participate within the study were selected through convenience, as the Isibindi facilitators know them.

The children with CP, recruited for the field-testing have been part of a larger study in the area and therefore known to the facilitators. The Isibindi facilitator was asked to recruit children who were 7 years old or younger and who presented with various levels on the Gross Motor Function Classification System (GMFCS) so that a child at each level from I – V would be represented in the sample. Five children were recruited, one from each GMFCS level. Each child had been classified using the Manual Ability Classification System (MACS). This selection

was to test the SCICP on children functioning at a variety of classification levels to determine whether the SCICP was sensitive to differing levels of severity in CP. This created a stratified sample. GMFCS levels rather than specific ages were also a consideration.

Inclusion Criteria

Children with Cerebral Palsy

- Various levels of severity based on the GMFCS classification confirmed by an experienced physiotherapist.
- A confirmed diagnosis of CP by a doctor at Charles Johnson Memorial Hospital
- Lived within the community of Nquthu
- Home language was isiZulu
- 7 years old or younger
- Known MACS classification confirmed by an experienced physiotherapist or occupational therapist.

Children without cerebral palsy

- No reported illness or disability
- 7 years old or younger
- Lived within the community of Nquthu
- Home language was isiZulu

3.5.3 Research Procedure

Research Assistant Training

The research assistant was asked to read the SCICP, and to ensure that she understood what each item involved. Following this the researcher and research assistant went through each item, and clarified each one as necessary. The researcher physically demonstrated the tasks that needed clarification e.g., peeling a banana, carrying a small object, carrying a large object and opening a drink carton.

The researcher and research assistant checked that all appropriate objects for the assessment were available. All items were to be administered except for sleeping and toileting items. Climbing on and off the toilet was observed in a separate toilet room, next to the discussion room. During the field-testing, the research assistant would be asking each caregiver about whether her child or grandchild was able to complete each item. Following this, the child was asked to demonstrate the performance of each item. Tools needed for each item are found in appendix C.

Preparation of the site

Chairs were moved to the sides of the room, and a blanket was placed on the floor to make room for observation of items. Tools needed for each item was stored to one side for easy access as needed during administration. Tools used for observation of assessment tool items were: cup, spoon, knife, socks, shoes (laces and Velcro fastening), T-shirt, button up shirt, pants (with elastic waist and zip and button), jacket, hat, gloves, belt, serviettes, tissues, face cloth, wash basin, hand towel, soap, comb, brush, tooth brush, tooth paste, toy car, ball. Perishable items such as juice, naartjie, banana, yoghurt, boiled eggs, bread and margarine were also used. For hygiene reasons, the toothbrushes were given to the children following observation of tooth brushing.

Chairs, tea and biscuits were also placed outside the discussion room, for the mothers and children who had arrived, but were waiting their turns to participate with the researcher and research assistant.

3.5.4 Assessment of child participants

During the pilot field-test, the researcher and research assistant used the SCICP with each of the 10 child participants, one at a time, with their primary caregiver present. The research assistant first asked each caregiver about the child's ability to perform each item and if the child needed assistance to complete each item, and then asked the child participant to demonstrate his or her ability to perform it. Discrepancies were recorded in the comments section of the SCICP, and are presented in Chapter 4.

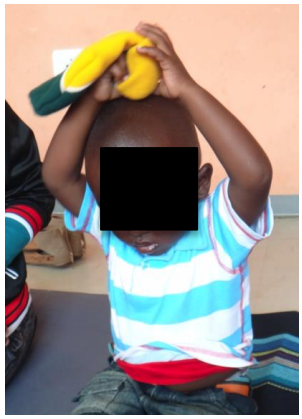
The typically developing child participants were asked to perform every item that their caregiver reported that they could perform as well as all the items for which

the discussion groups had deemed age appropriate. A two-year-old participant was therefore asked to perform all items that the discussion group has decided a child of that age would be able to complete independently such as putting on a hat, drying his hands with a towel, moving an object along the floor and picking an item up off of the floor (Figure 3.2).

Typically developing child picked up an item from the floor

Typically developing child - moved object along the floor

Typically developing child dried his hands with a towel



Typically developing child put on a hat

Figure 3.2: Items observed on typically developing children participant (2 years old) to determine scoring and age of independence for each

The typically developing child participants all demonstrated their ability to complete each appropriate item, with the exception of unobservable items such as sleeps through the night and consistently stays dry day and night.

Appendix D included a list of items that were observed and those that were not observed as well as the reasons for not observing these items. If the caregiver said that the child could not complete the item, the child was asked to attempt the

item. Researcher made notes based on expert caregivers' responses and observation of the child's performance. This same procedure was used with the child participants with CP.

The only difference arose when a child with CP was reported by the caregiver not to be able to complete a task, which according to age of independence, they should be able to complete. The research assistant then asked the child participants with CP to attempt this task. If they were unable to do so they were asked to perform the task with the help of their caregiver. The researcher took photographs of the items demonstrated.

Many child participants used their own clothes to demonstrate dressing, rather than that brought by the researcher, as it is what they were familiar with.

Assessment of each domain

Domain 1: Eating and Functional Mobility Associated with Eating

The eating domain was assessed using both caregiver questionnaire and observation of the child's performance. All eating items were observed (appendix D).

Typically developing child licked food from around his mouth

Typically developing child bit a piece of banana

Figure 3.3: Items observed on typically developing child participant on items for domain Eating and Functional Mobility Associated with Eating

Domain 2: Dressing and Functional Mobility Associated with Dressing

The dressing domain was assessed using both caregiver questionnaire and observation of the child's performance. Appendix D included a list of items which were observed and which were not observed and reasons for not observing. All dressing and functional mobility associated with dressing items were observed for each child.

Typically developing child untied his shoelaces

Typically developing child took off his shoes

Figure 3.4: Items observed on typically developing child participant on items for Dressing and Functional Mobility Associated with Dressing

If the child was wearing an item of clothing that was being asked about in the item, the child used his own clothing. If the child was not wearing that item of clothing, he or she attempted the item using the clothing brought by the researcher.

Domain 3: Washing and Functional Mobility Associated with Washing

Three washing items and two functional mobility associated with washing items were not observed (appendix D).

Typically developing child washed his face

Figure 3.5 Item observed on typically developing child participant on items for Washing and Functional Mobility Associated with Washing

These items included: “Washes body thoroughly, not including face”, “Dries body thoroughly”, “Washes using the basin without help”, “Fill up a basin with water for washing”, “Empty basin after washing, clean the basin”. Time constraints and wasting of resources were the main factors for not observing these items.

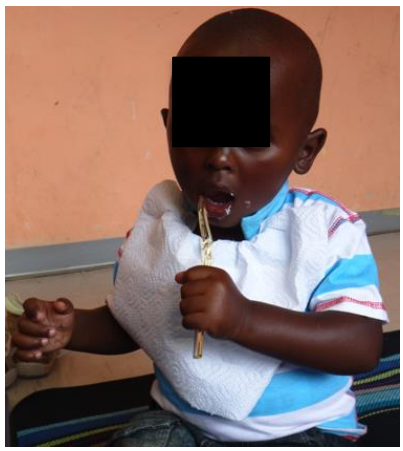
Domain 4: Toileting and Functional Mobility Associated with Toileting

Certain toileting and functional mobility associated with toileting items were observed (appendix D). For this domain, participation occurred within the bathroom opposite the discussion room, as it has an adult sized toilet, and toilet paper.

Domain 5: Grooming and Functional Mobility Associated with Grooming

One grooming item was not observed. All functional mobility items associated with grooming were observed (appendix D). “Washes his or her own hair” was not observed due to time constraints.

Typically developing child blew his nose



Typically developing child brushed his teeth

Figure 3.6: Item observed on typically developing child participant on items for Grooming and Functional Mobility Associated with Grooming

Domain 6: Functional Mobility Associated with Sleeping

All functional mobility associated with sleeping items were observed (appendix D).

Domain 7: General Functional Mobility

All general items were observed (appendix D).

3.6 Stage 4.1 Data Analysis of Items Following Field Test, Administration and Scoring

The results of the field test were analysed. The items were analysed for difficulty in terms of the ages of the typically developing participants, the ability of the items to discriminate dysfunction according to age and the severity of their CP on the GMFCS scale of the participants with CP. The administration and scoring as well as each item's properties in terms of the participants' cultural context was reviewed. Items were adapted accordingly.

Item analysis

To determine if the difficulty level was set correctly in terms of the age that children become independent in that item, the data from the typical children was analysed in the following way: based on the scoring guide of the SCICP, the items were sorted so those that children who were independent for each age level were placed first, followed by those that needed a little help with, then those they needed a lot of help with and finally those they were dependent in. This was done for age two years, three years and five years, which were the ages of the children in the typically developing sample.

All items on the SCICP were sorted, by the researcher, according to difficulty for each age group and percentage scores for each domain was established for each age group in terms of what they should be able to achieve. Those items that could not be easily observed were discarded and those that could not be easily answered by the expert caregivers were edited. In order to determine if the SCICP items discriminated dysfunction in the CP children, a score was calculated for all the children with CP in the pilot sample according to the appropriate age group. Children with CP who were seven years old were compared to the typical five-year-old scores as no typically developing seven-year-old child was assessed in the pilot study. This was done as the seven-year-old had severe CP and was dependent on his caregiver for nearly all of his daily activities, not just self-care. The percentage differences between the typically developing children's scores and those of the children with CP were compared for each domain. Overall Chi

squared tests, at 0.05, were used to determine whether the differences observed within the self-care skills between the typically developing participants and the participants with CP was significant.

The scores obtained when observing the child participants were compared to those obtained from the caregivers' responses to the questions on the SCICP. This helped to determine if the assessment tool could reliably be used as a parent/caregiver self-report.

Finally, the age at which a child achieved independence in each item was compared with the opinions of the expert caregivers from the discussion groups, for the content validity study. The caregivers and researcher observed this in the pilot field test. The mean data from the content validity discussion group study was compared to that observed and ages assigned for the final version of the items on the SCICP.

3.7 Ethical Considerations

3.7.1 Ethical clearance for the study

Ethical Clearance was given by the HREC at the University of the Witwatersrand. – Certificate number M120360 (Appendix E).

3.7.2 Ethical Considerations for SME Content Validity Survey

The SME occupational therapists were invited to participate in the study and provided with an information sheet (Appendix F). Confidentiality was ensured through the use of Survey Monkey and no names could be associated with the data.

3.7.3. Ethical considerations for Content Validity Discussion Groups

Participants for the discussion group were invited to participate in the study and provided with an information sheet (Appendix G) and asked to sign written consent. Participants for the discussion group were advised that participation in this study group cannot be confidential but no names will be associated with the data. Participants' transport costs were paid for by the researcher as an out-of-pocket expense.

3.7.4 Ethical Considerations for Field Test

All caregivers were invited to participate in the field-testing and were given an information sheet (Appendix H) and asked to sign written consent for their participation and that of their child. They were asked to give permission for the child to be photographed. Participants within the field-testing were also advised that participation in this study will be confidential and no names will be associated with the data. Children over the age of four were asked to give verbal assent. Research assistant, speaking in isiZulu, asked for their verbal assent. Participants' transport costs were paid for by the researcher as an out-of-pocket expense.

Information sheets and consent forms had been translated into isiZulu, so that potential participants for the discussion groups and field testing, could read and understand the forms independently. All participants (SME occupational therapists, caregivers and children) were advised that their participation was voluntary and there would be no benefit or harm that will come to them during participation. They were also advised that at any point that they wish to withdraw themselves or their child from the study; there will be no consequences. Results were made available to all participants on request.

CHAPTER 4
RESULTS

4.1 Introduction

This chapter presents the findings in relation to Stage 1, 2, 3 and 4 of the study. This includes the development of the items, item checking and evaluation steps in the development of the assessment tool Self Care Questionnaire for Children with Cerebral Palsy (SCICP). The content validity of the SCICP was evaluated and then confirmed using the results of the SME survey and the discussion groups to determine the appropriateness of all the items. The number and reasons for items being discarded, edited and retained are presented.

The items for the SCICP were further analysed based on the results of the field test of the SCICP on individual children living in an under resourced area of KZN. The appropriate difficulty or level of items in terms of the ages of the typical participants, and the ability of each domain to discriminate the performance of children with CP in terms of the severity of their condition, on the GMFCS scale, was determined. The expected level of performance for different age groups, final scoring and administration criteria were finalised for the domains and total score of the SCICP.

4.2 Development of the items

4.2.1 Mapping to the ICF

Self-care and mobility fall under chapter five and chapter four respectively of the activities and participation section of the ICF. These chapters were reviewed by the researcher, and matched for the domains of the SCICP. There were seven main domains included, six of which included a functional mobility section associated with the self-care task. The final domain included general functional mobility. Table 4.1 shows the mapping of the domains to ICF codes. Appendix I includes the Items prior to ICF Mapping. Appendix J includes ICF mapping for items included in the initial SCICP.

Table 4.1: Construct: Self-care: ICF Mapping

Code	Possible Items	Code	Domain
d510: Washing oneself	Washing body parts	d5100	Washing
	Washing whole body	d5101	
	Drying oneself	d5102	
d520: Caring for body parts	Caring for skin	d5200	Grooming
	Caring for teeth	d5201	
	Caring for hair	d5202	
	Caring for fingernails	d5203	
	Caring for toenails	d5204	
d530: Toileting	Regulating urination	d5300	Toileting
	Regulating defecation	d5301	
d540: Dressing	Putting on clothes	d5400	Dressing
	Taking off clothes	d5401	
	Putting on footwear	d5402	
	Taking off footwear	d5403	
	Choosing appropriate clothing	d5404	
d550: Eating and d560: drinking			Eating
d410: Changing basic body position	Lying down	d4100	Functional mobility associated with eating, washing, dressing, grooming, toileting, sleeping General functional mobility: used in all domains
	Squatting	d4101	
	Kneeling	d4102	
	Sitting	d4103	
	Standing	d4104	
	Bending	d4105	
	Shifting the body's centre of gravity	d4106	
d415: Maintaining a body position	Maintaining a lying position	d4150	
	Maintaining a squatting position	d4151	
	Maintaining a kneeling position	d4152	
	Maintaining a sitting position	d4153	
	Maintaining a standing position	d4154	
d420: Transferring oneself	Transferring oneself while sitting	d4200	
	Transferring oneself while lying	d4201	
d430: Lifting and carrying objects	Lifting	d4300	
	Carrying in the hands	d4301	
	Carrying in the arms	d4303	
	Carrying on the head	d4304	
	Putting down objects	d4302	
d440: Fine hand use	Picking up	d4400	
	Grasping	d4401	
	Manipulating	d4402	
	Releasing	d4403	
d445: Hand and arm use	Pulling	d4450	
	Pushing	d4451	
	Reaching	d4452	
	Turning or twisting the hands or arms	d4453	
d450: Walking	Walking short distances	d4500	

4.3 Content validity

4.3.1 Subject Matter Expert Survey Results

The items selected for the SCICP were reviewed by three SME occupational therapists. Items were adjusted according to their comments. Table 4.1 provides an example of the items discarded and those modified for the domain for eating. Appendix K contains the it.ems validated through the SME Survey.

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Table 4.2: Items for eating adjusted following SME survey

Domain	Total Items changed	Reasons for items being discarded	Item and percentage of agreement of SMEs	Items edited	
Eating	23	Ambiguous 2	Sucks food well (25%) Rubs spoon across plate, puts it to mouth for licking (25%)	9	Swallows without coughing (75%) Eats soft/mushy foods (75%) Feeds himself or herself carrot sticks, biscuits or other finger foods (75%) Drinks from a cup with some help (75%) Drinks from cup without help (75%) Pours a glass of juice (75%) Peels 3 foods (banana, naartjie, boiled egg) (75%)
		Difficult to observe 2	Nurses, drinks or eats willingly with no encouragement (25%) Capable of taking a drink by himself without help (50%)		
		Repetition 4	Uses spoon (may spill some food) (25%) Scoops with a spoon (50%) Drinks from a cup or glass (even if another person must hold it (50%) Holds and drinks from cup using two hands (25%)		
		Culturally in-appropriate 4	Pierces food with fork and brings to mouth (50%) Uses a fork without difficulty (food can be cut and prepared (50%) Eats with a knife and fork, requires no help (50%) Uses napkins when reminded (25%)		
		Not for under 7 years 2	Pours liquids (tea or coffee) from a pot (25%) Uses salt and pepper shakers (0%)		
Functional mobility associated with eating	10	Ambiguous 4	Holds bottle without help while drinking from prone position (25%) Picks up, carries, sets down filled tray (25%) Prepares sack lunch (25%) Made a snack (25%)	4	Prepares sandwich or other snack (75%) Carries a drink or food to the table (75%) Carries cup filled with juice without spilling (75%) Opens milk box (65%) Serves himself food (75%)
		Difficult to observe 2	Clears place at table (25%) Prepares cold cereal (25%)		

Once the surveys were collected, the SMEs' decisions were used to adjust the items. Table 4.1 indicates that within the eating and functional mobility associated

with eating domains, 33 items were discarded. Six of these items were considered ambiguous, four were difficult to observe, four were repeated, four were culturally inappropriate and two were not applicable to children under 7 years of age.

Table 4.3: Items for all domains adjusted following SME survey

Domain	Total Items left	Items discarded	Items edited
Eating	23	14	9
Functional mobility associated with eating	10	7	3
Dressing	31	24	7
Functional mobility associated with dressing	5	5	0
Washing	2	2	0
Functional mobility associated with washing	6	6	1
Toileting	1	1	0
Functional mobility associated with toileting	2	2	1
Grooming	4	4	0
Functional mobility associated with grooming	0	0	0
Sleeping	0	0	0
Functional mobility associated with sleeping	1	1	0
General functional mobility	9	9	0
TOTAL:	94	75	21

The changes to the other domains were listed in Appendix L with the reasoning for each. The main reason for deleting and editing items was due to ambiguity, repetition, irrelevance to age or culture and difficulties in observing the item being carried out. In total, 94 out of a total of 222 (42%) items were adjusted - 75 items were deleted (33%) and 21 were edited (9%) (Table 4.2). Prior to the survey 222 items were included. Following the survey and adjustment of items, 147 items remained.

It could be seen that the majority of the other items discarded were for dressing which were the self-care skills being learnt in the first years of life. No change was made to the sleeping domain, with washing, toileting and grooming having had few changes. The General functional mobility section was reduced to nine items.

4.3.2 Discussion groups with expert caregivers of children living in Nquthu, Kwa-Zulu Natal.

The SCICP items, as adjusted in 4.2.1, was then translated into isiZulu and presented to caregivers of children living in Nquthu, in two discussion groups run over two sessions for each. Items were adjusted again (Table 4.3)

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Table 4.4: Items adjusted for the eating domain following discussion groups

Domain	Total Items changed	Items discarded	Item	Items edited	
Eating	14	Ambiguous: 1	**Does not** Turn head toward nipple when cheek is touched	4	IsiZulu spelling corrected: Ugwinya uketshezi ngaphandle khwehlela IsiZulu word corrected: Udla ukudla okugayiwe/izigaxa IsiZulu word corrected: Uyaliluma iqhuzwana lokudla IsiZulu word corrected: Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe
		Difficult to observe: 1	**Does not** Turn head toward nipple when cheek is touched		
		Repeated: 6	Scoops with a spoon and brings to the mouth by himself or herself Holds and drinks from a sipping cup Uses spoon when eating without requiring help. Feeds self an entire meal using spoon and fork Pours himself or herself a glass or cup of juice Eats independently		
		Inappropriate for under 7 years: 1	Eats with a knife and fork, requires no help		
		Culturally inappropriate: 3	Sucks liquid from a glass or cup using a straw Pierces food with fork and brings to mouth Uses a fork without difficulty		
Functional mobility associated with eating	4	Ambiguous: 1	Locates and picks up own utensils at table	1	Edited item: Opens milk or juice box (Uyalivula ibhokisi lobisi okanye lejusi)
		Culturally inappropriate: 3	Locates and picks up own utensils at table Serves self at table Helps set table		

After the discussion groups, 61 out of a total of 147 (41%) items were adjusted. Of those, 30 items (20%) were deleted and 31 items (21%) were edited. Editing occurred in both English and isiZulu with certain items.

As is indicated in Table 4.4 18 items within the eating and functional mobility associated with eating domains were discarded. Two of these items were considered ambiguous, one was difficult to observe, six were repeated, four were culturally inappropriate and one was not considered applicable to children under seven years of age. The changes to the other domains were listed in Appendix M with the reason for adjustment or deletion.

Table 4.5: Items for all domains adjusted following discussion groups

Domain	Total Items	Items deleted	Itemed edited
Eating	14	11	3
Functional mobility associated with eating	3	3	0
Dressing	9	2	7
Functional mobility associated with dressing	1	1	0
Washing	4	3	1
Functional mobility associated with washing	4	1	3
Toileting	9	1	8
Functional mobility associated with toileting	6	2	4
Grooming	4	3	1
Functional mobility associated with grooming	0	0	0
Sleeping	0	0	0
Functional mobility associated with sleeping	1	1	0
General Functional Mobility	6	2	4
TOTAL:	61	30	31

The items were adjusted in terms of cultural relevance and the wording of certain items in IsiZulu was modified. Examples of items discarded following the discussion groups included: “scoops with spoon and brings to the mouth by himself or herself”; “holds and drinks from a sipping cup”; “pierces food with fork and brings to the mouth”. Following the adjustments made after the discussion groups, the total number of items in the SCICP was 117. The adjustments were verified by the research assistant.

4.4 Item Analysis

4.4.1 Item appropriateness

Those items that were difficult to observe or were repetitive were discarded from each domain - 25 items were consequently deleted, by the researcher. No items were edited. Appendix N contains all items adjusted following this field test.

Following this adjustment, the total number of items in the SCICP was 92.

Within the eating and functional mobility associated with eating domains, three items were discarded (Table 4.6). Appendix N contains the changes to all the other domains with reasons for adjustment or deletion.

Table 4.6: Items adjusted for the eating domain following the pilot field test

Domain	Total Items changed	Items discarded		Items edited
Eating	3	Ambiguous 1	Opens mouth for breast, bottle or spoon (Uyakhamisa khona ezoncela ibele, ibhodlela noma adle ngesipuni)	0
		Repetition 1	Uses spoon when eating without requiring help (Usebenzisa isipuni uma edla ngaphandle kokufuna usizo)	
		Difficult to observe 1	Eats all textures of food (Udla zonke izimo zokudla)	
Functional mobility associated with eating	0	0		0

One of these items was considered ambiguous, one was difficult to observe and one was repeated. There were no items discarded from functional mobility associated with eating and no items were modified. “Opens mouth for breast, bottle or spoon” was thought to be ambiguous as even when the child participants in the pilot study were able to complete this item independently, caregivers said that the child was not able to complete this activity without help. It was also noticed when they were asked at what age did their typically developing child begin to complete this particular item independently, ages of 2 months, 6 months or 12 months were given. Ideally, this item should be independent from birth, or else the child would not get the required nutrition to thrive.

4.4.2 Item difficulty for typical children aged 2 to 5 years

The adjusted SCICP as was piloted on five children with CP and five children without CP to analyse the difficulty level of the items for typically developing children. Following the analysis of the field test, the scoring and administration criteria were reviewed.

4.4.2.1 Participants demographics

The SCICP was field tested on five typically developing children living in an under resourced area of KZN. The age and gender of these five children were listed in chronological order in terms of age in Table 4.7.

Table 4.7: Demographics of typically developing children

Code	Chronological age	Gender
T1	2 years 1 month	Male
T2	2 years 4 months	Male
T3	2 years 9 months	Male
T4	3 years 4 months	Female
T5	5 years 2 months	Male

Four children were male and one was female. The sample represented two, three and five year olds. T1, T2 and T3 were included in the 2-year-old group. T4 was the 3-year-old group and T5 was the 5-year-old group.

4.4.2.2 Percentage Independence of typically developing children according to age

Each item in each domain was analysed to determine the level of independence of typically developing children aged two years, three years and five years. Items were scored on the 4-point scale with 4 indicating independence to 1, indicating dependence. Of the adjusted SCICP (Appendix O) the items for each domain were sorted for each age group according to the scores indicating independent (4) to those they needed a little help (3), a lot of help (2) with and finally those for which

the participants were dependent (1). The researcher completed this using the scoring in appendix A. Table 4.8 indicated that for eating, the difficulty of the items decreased as the participants became older and therefore the difficulty of items for this domain was appropriate for the age groups assessed in this pilot study. As can be seen in Table 4.8, in the eating domain whilst the two years olds needed assistance with or were dependent in the last six items, the 5-year-old was independent for all items except the last four items. The 5-year-old only needed a little help except for the last item, cutting meat in which they remained dependent.

Similar analysis was completed for all domains on the SCICP and reordered to accommodate and organise them according to the item difficulty (Figure 4.8). The score for each age group was converted into a percentage per domain and increasing independence was therefore seen from the 2-year-old group through to the 5-year-old group within each domain of the SCICP and for the total score.

Because the sample sizes were small, statements from the results can only be made tentatively. As a preliminary field test, this small sample size shows that the SCICP has the potential to be useful with a larger sample.

Table 4.8: Reordering of items in the eating domain according to the difficulty for age groups 2-5 years

	Eating Items	2-year-old	3-year-old	5-year-old
2	**Ugwinya uketshezi ngaphandle khwehlela;** Swallows liquids without coughing	Independent (4)	Independent (4)	Independent (4)
3	**Udla ukudla okubushelelezi okuthambile;** Eats smooth soft foods			
4	**Udla ukudla okugayiwe/izigaxa;** Eats **ground/lumpy foods**			
5	**Usebenzisa iminwe uma edla, kodwa akahlafuni;** Uses fingers for eating, but does not chew			
6	**Uyaliluma iqhuzwana lokudla;** Bites off piece of food			
7	**Uphakamisa ibhodlela bese eziphuzela engasizwa muntu;** Picks up bottle and drinks independently			
8	**Uphakamisa inkomishi khona ezophuza, kodwa kungenzeka inkomishi iwe;** Lifts cup to drink, but cup may tip			
9	**Uyakuhlafuna ukudla okuqinileyo;** Chews solid food			
10	**Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe;** Feeds crackers, carrot sticks or other finger foods			
11	**Udla ukudla okusikiwe kwaba yizicucwana/izigaxana/amadayisana;** Eats cut up/chunky/diced foods			
13	**Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni;** Takes spoon filled with food to mouth			
14	**Uphuza ngenkomishi ngaphandle kosizo;** Drinks from a cup without help			
16	**Uyakukhotha ukudla okuzungeze umlomo;** Licks food from around mouth			
17	**Uzithelela yena uqobo ingilazi noma inkomishi yejusi;** Pours himself or herself a glass or cup of juice	Needs a little help (3)	Needs a little help (3)	
22	**Uzidlela konke ukudla esebenzisa isipuni kanye;** Feeds self an entire meal using spoon			
18	**Uhluba ukudla oku-3 (ubhanana, inantshi, neqanda elibilisiweyo);** Peels 3 foods (banana, naartjie, boiled egg)	Needs a lot of help (2)		Needs a little help (3)
19	**Usebenzia ummese khona "ezogcoba" ibhotela, ujamu njll;** Uses a knife for "spreading" butter, jam etc.	Dependent (1)		
20	**Usika ukudla okuthambile ngommese (ubhanana, izambane elibhakiweyo);** Cuts soft foods with knife (banana, baked potato)		Needs a lot of help (2)	
21	**Usika inyama noma okunye ukudla kube izingcucwana ezizolumeka;** Cuts meat or other food into bite-sized pieces		Dependent (1)	Dependent (1)

The major differences between the ages groups were seen in dressing, washing, toileting and grooming and could be attributed to learning how to complete the skill prior to becoming independent in it. Smaller differences were observed in eating, sleeping and general functional mobility. This could be attributed to being already familiar with skills by two years old, or more innate skills such as eating.

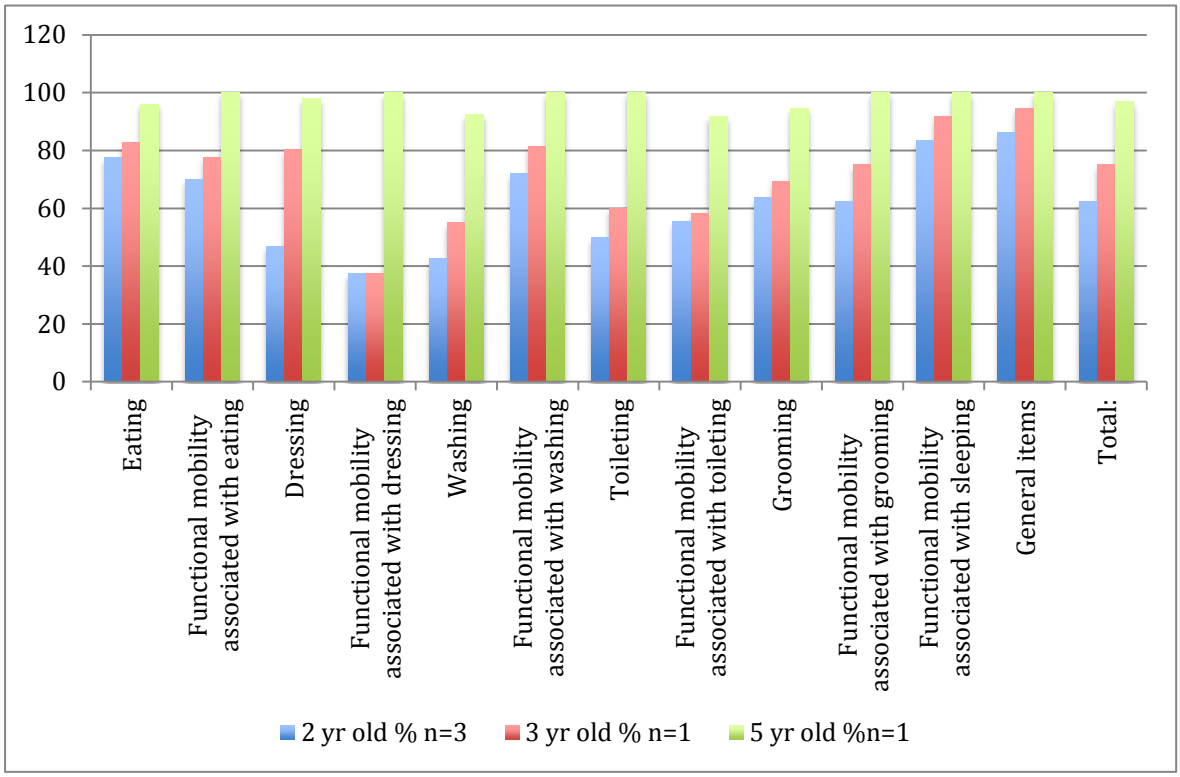

Figure 4.1: Percentage of independence within each domain for typically developing child participants on the Self Care Inventory for Children with Cerebral Palsy

There was a significant difference between the scores obtained for the three different age groups on the SCICP (X^2= 23.56 (df-2) p=0.000) overall on the SCICP. Figure 4.2 indicated a range of independence to dependence at two and three years of age with five-year-old obtaining nearly full score for independence. This indicated the ceiling of independence was close to being achieved by the participant of 5 years 2 months.

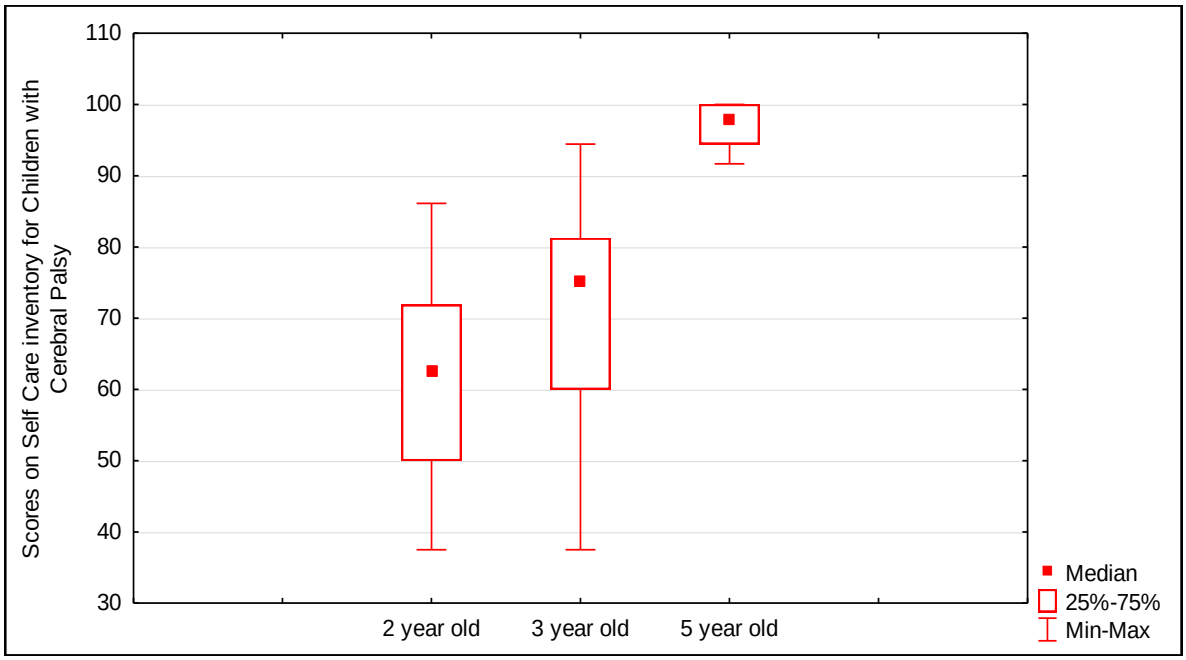

Figure 4.2: Comparison of scores for typical participants on the Self Care inventory for Children with Cerebral Palsy (2-year-old n=3; 3-year-old n=1, 5-year-old n=1

4.4.3 Item discrimination for child participants with cerebral palsy aged 2 to 7 years

Item discrimination determined whether the SCICP distinguishes between the performance of children with and without CP in terms of their independence in self-care[5]. The ability of the SCICP to discriminate dysfunction in the self-care of children with CP was evaluated according to both the age of the participants with CP as well as the severity of their CP using their GMFCS levels.

4.4.3.1 Participants' demographics

The SCICP was pilot tested on five child participants living in an under resourced area of KZN diagnosed with CP classified on levels I-V on the GMFCS. The code, chronological age, gender, GMFCS and MACS levels for each participant who took part in the field-testing were shown in Table 4.9. MACS levels were included as appropriate hand function is necessary for independence in self-care. Associated impairments were also included as these may influence the level of independence achieved by each child with CP.

Table 4.9: Demographics of participants living in an under resourced area of KZN diagnosed with CP

Code	Chronological age	Gender	GMFCS Level	MACS Level	Associated Impairments
CP 1	5 years 5 months	Male	I	III	Cognitive Impairment behavioural difficulties
CP 2	3 years 5 months	Male	II	II	None
CP 3	7 years 0 months	Female	III	III	None
CP 4	2 years 4 months	Male	IV	II	None
CP 5	6 years 7 months	Male	V	IV	Non Verbal

4.4.3.2 Percentage Independence of participants with cerebral palsy compared to that of typically developing participants according to age

The percentage of the five participants with CP was analysed using the re-ordered version of the SCICP set up for the correct item difficulty. Figure 4.2 indicated the percentage independence of these participants based on their age when compared to typically developing participants. Figures 4.2, 4.3 and 4.4 presented a comparison of the percentage independence scores for the participants with CP to those for 2-year-old, 3-year-old and 5-year-old typically developing participants.

Figure 4.3 showed the percentage of independence of the 2-year-old typically developing participants and that of a 2-year-old participant with more severe cerebral palsy (GMFCS IV, MACS II). The results demonstrated that in this case the SCICP is able to differentiate in the self-care and mobility related to self-care of between a 2-year-old typically developing child and a 2-year-old child with more severe CP.

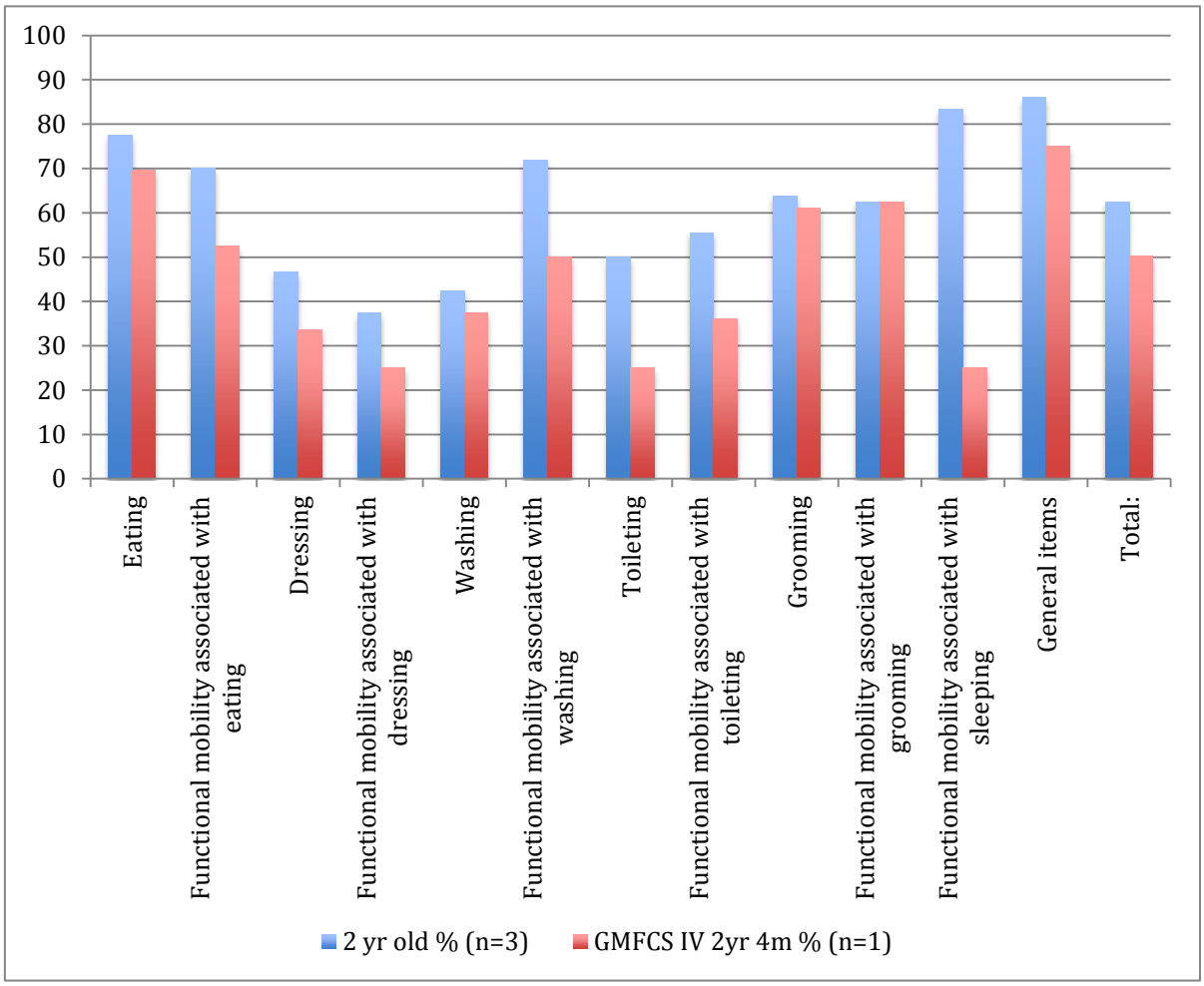

Figure 4.3: Percentages independence for 2-year-old - comparing typically developing participants and a child with cerebral palsy on the Self Care inventory for Children with Cerebral Palsy

Within each domain, the typically developing child achieved a higher percentage of independence, with the exception of functional mobility associated with grooming which was equal. These results indicated that the SCICP could identify dysfunction in a younger child with more severe forms of CP.

There was a significant difference between the participants with and without CP who were 2 years old (X^2= 7.36 (df-1) p=0.006). The 2-year-old child with CP did not reach as high a level of independence as the typically developing participants although they were all of a similar age between 2 years 1 month and 2 years 4 months (Figure 4.4).

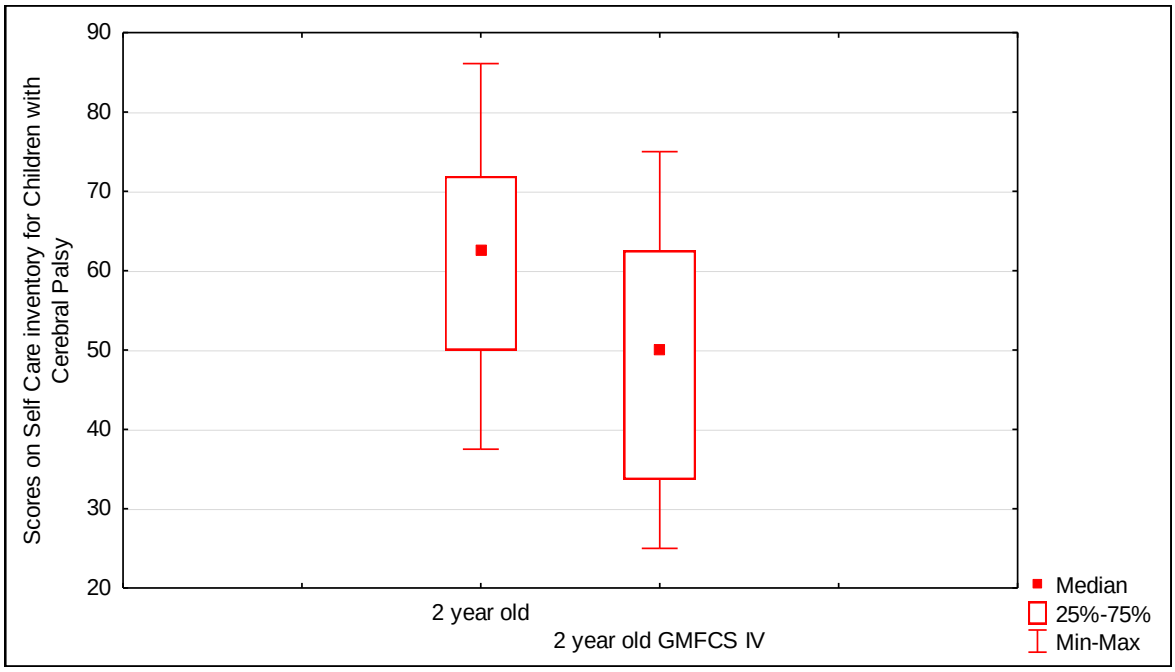

Figure 4.4: Scores for 2-year-old typically developing participants and a 2-year-old child with cerebral palsy on the Self Care inventory for Children with Cerebral Palsy (2-year-old n=3; 2-year-old GMFCS IV n=1)

Figure 4.5 showed the results of the 3-year-old typically developing participants and that of a participant with milder cerebral palsy, also three years old (GMFCS II). The typically developing participants only scored higher in domains of dressing and general functional mobility. Both participants scored the same for grooming and in other domains show higher independence of the participant with CP indicating the SCICP identified no dysfunction in self-care for this child with a less severe form of CP who is a similar age to the typically developing child. The difference between the scores for these children indicated that the participant with mild CP is significantly more independent than the typically developing child (X^2= 5.33 (df-1) p=0.020; figure 4.6).

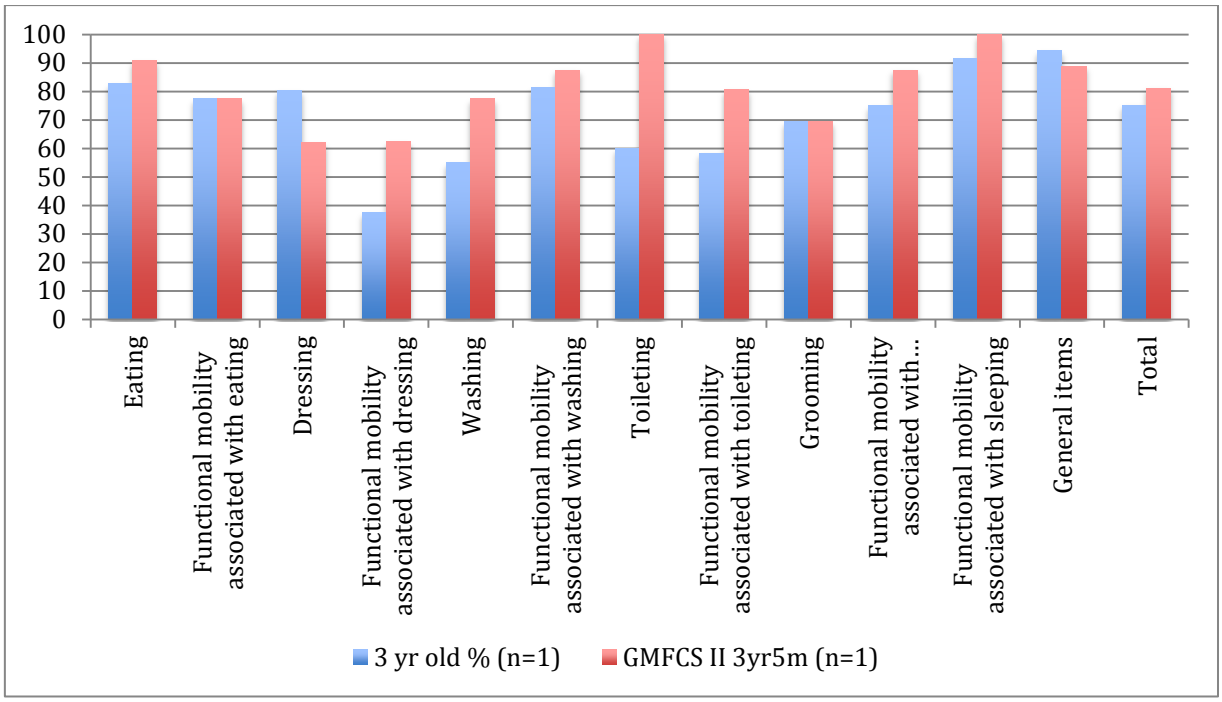

Figure 4.5: Percentages of independence for 3 year olds – comparing a typically developing child and a child with cerebral palsy on the Self Care Inventory for Children with Cerebral Palsy

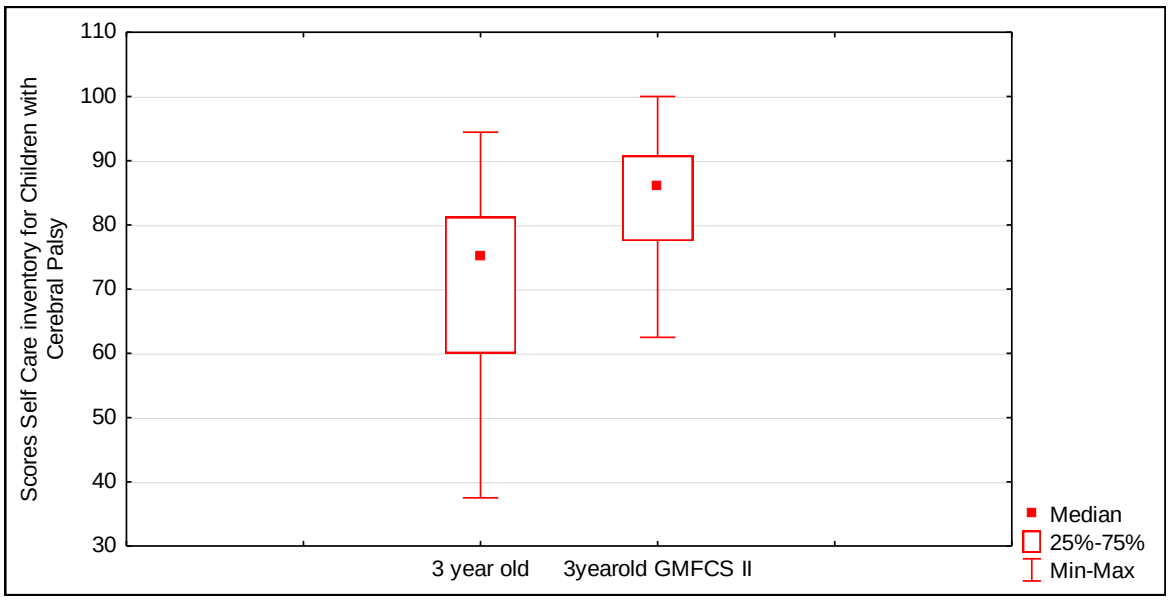

Figure 4.6: Scores for a 3-year-old typically developing participant and a 3-year-old participant with cerebral palsy on the Self Care inventory for Children with Cerebral Palsy (3-year-old n=1; 3-year-old GMFCS II n=1)

Figure 4.7 showed the percentage independence of a 5-year-old typically developing participant and that of three participants with cerebral palsy, aged five years and above. The figure showed that the typically developing 5-year-old achieved a higher percentage of independence within each domain of the SCICP

and overall. The results are ordered according to the level of function of the children within the sample.

The seven-year-old participant with moderate CP (GMFCS II, MACS II) achieved a higher percentage of independence than the five and six-year-old participants with mild and severe CP respectively, within all domains except eating. The 5-year-old participant with mild CP only achieved a higher score for general functional mobility.

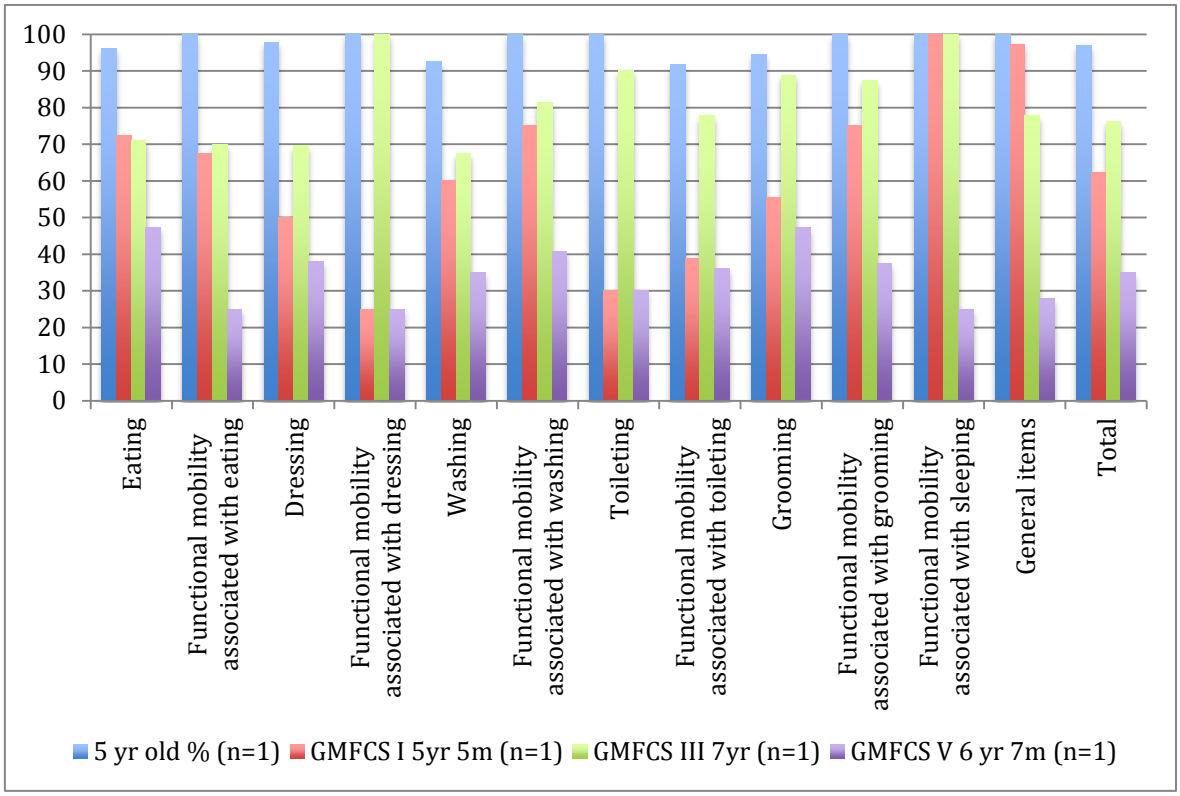

Figure 4.7: Percentages of independence for typically developing five-year-old participants and participants with cerebral palsy, aged 5 to 7 years on the Self Care inventory for Children with Cerebral Palsy.

The results indicated a significant difference in terms of age in Figure 4.8 (X^2= 32.60 (df-3) p=0.000) in participants with mild and severe CP. The 5-year-old with mild CP showed a range of abilities from complete dependence to complete independence.

The seven-year-old with milder CP (GMFCS III, MACS III) had independence that ranged from 65% to 100% scores while the six-year-old with severe CP did not achieve even 50% performance in any item. Therefore, age and level of CP affect the scores.

The results suggest the ability of the SCICP to differentiate the dysfunction in older participants with CP for all domains according to age even in participants over 5 years of age.

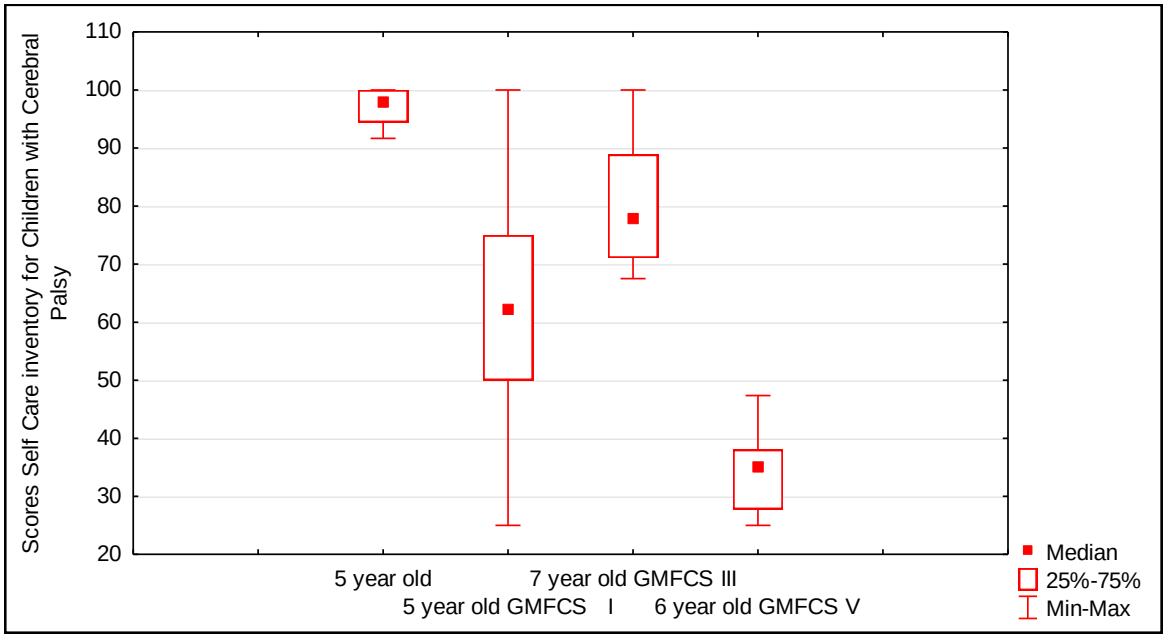

Figure 8: Scores for a 5-year-old typically developing participant and 5, 6 and 7-year-old participants with cerebral palsy on the Self Care inventory for Children with Cerebral Palsy (5-year-old n=1; 5-year-old GMFCS I n=1; 7-year-old GMFCS III n=1; 6-year-old GMFCS V n=1)

4.4.3.3 Percentage Independence of participants with cerebral palsy according to severity of cerebral palsy based on GMFCS levels

Figure 4.9 showed the results of the child participants with CP classified with GMFCS, with one child on each level. The figure showed that except for dressing, functional mobility associated with dressing, grooming, and functional mobility associated with grooming, functional mobility associated with sleeping and general functional mobility items, the child classified as GMFCS II (MACS II) was the most independent.

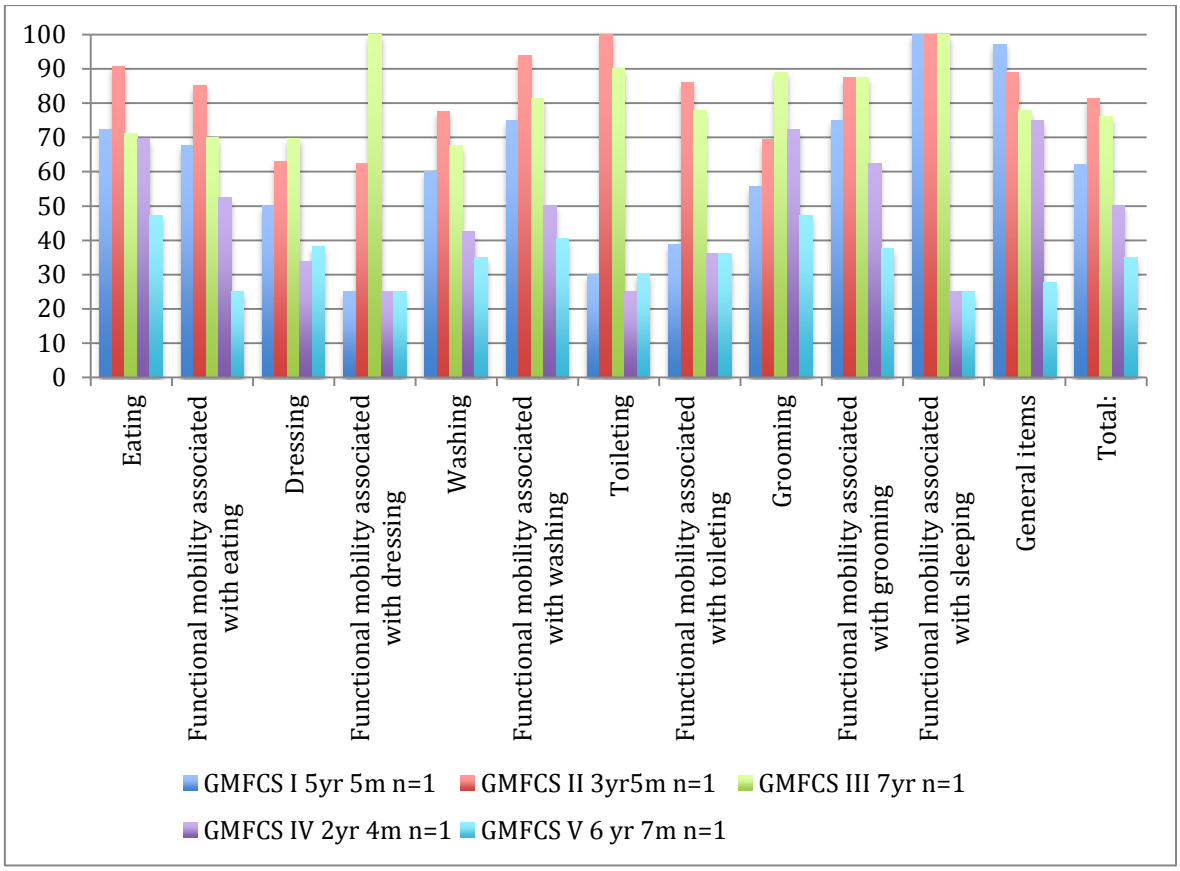

Figure 4.9: Percentage of independence of participants with cerebral palsy percentages of independence within each domain and overall

The participant with GMFCS V, MACS IV, scored the lowest percentage of independence for all domains with the exception of dressing and toileting.

The participant with GMFCS II, MACS II, scored higher independence than the participant with GMFCS III, for the domains of eating, washing, toileting, and general functional mobility. However, the participant with GMFCS III, MACS III scored at a more independent level than the participant with GMFCS II, MACS II for domains of dressing and grooming. Functional mobility associated with grooming was equal for these participants. This could be attributed to the participant with GMFCS II having higher GMFCS and MACS classification level that supported his posture, gross motor abilities and hand function. The age of the participant with GMFCS III, MACS III, allowed for increased independence in dressing and grooming.

Despite being younger and having a lower GMFCS classification level when compared to the participant with GMFCS I the participant with GMFCS II had a

higher MACS classification and better hand function, which is essentially unaffected. This results in the participant with GMFCS II having improved performance of self-care tasks, which rely on efficient hand function. The reported cognitive impairment and behavioural difficulties for the participant with GMFCS I, resulted in his caregiver completing many more activities for him, than the participant with GMFCS II, who did not have a cognitive impairment or behavioural difficulties.

Figure 4.10 showed the difference in the overall performance scores between the participants with different GMFCS levels and the scores obtained by the typically developing participants as indicated by 0 on the graph. This difference accommodated for age as it indicates the difference in the scores obtained by the typical 2-year-old and those obtained by the 2-year-old with CP. The results indicated that the performance does decrease as the level of CP measured by the GMFCS increases but that other factors played a role. Participants with GMFSC III and IV both had a similar difference from their typically developing peers of the same age and about a 15% decrease in their self-care ability.

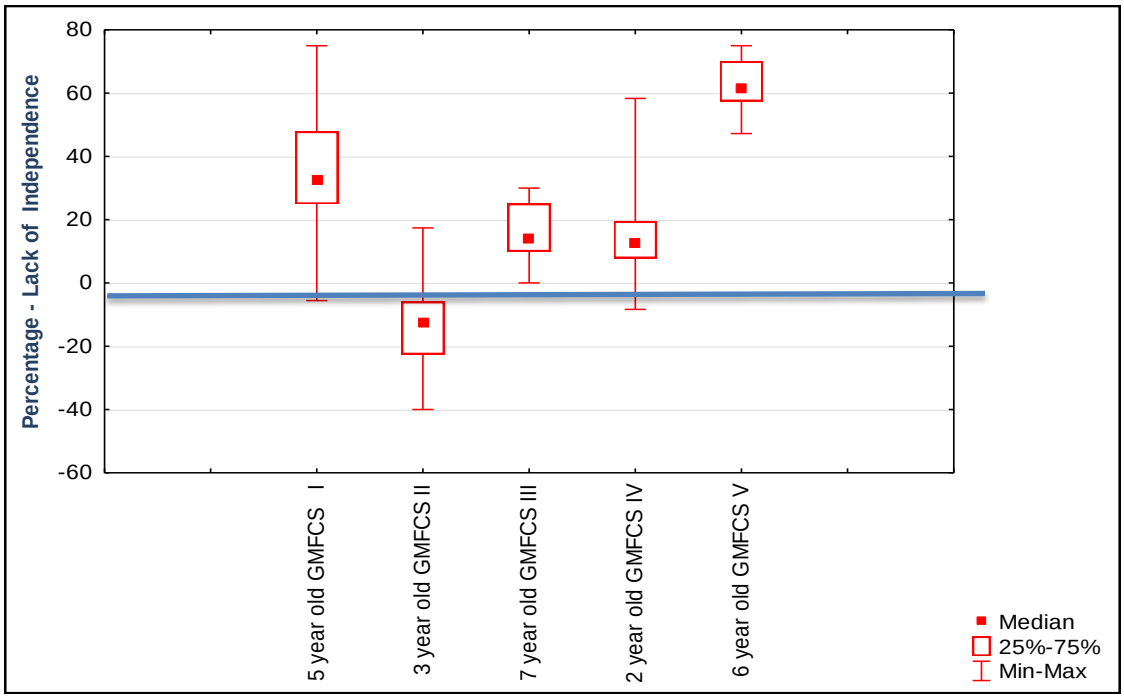

Figure 4.10: Differences from the expected scores as obtained by typically developing child participants, and child participants with cerebral palsy on the Self Care inventory for Children with Cerebral Palsy (5-year-old GMFCS I n=1; 3-year-old GMFCS II n=1; 7-year-old GMFCS III n=1; 2-year-old, GMFCS IV n=1; 6-year-old GMFCS V n=1)

The individual factors affecting the different domains were considered and analysed from the scoring and photographs of the participants. Observations were analysed with caution due to the small size of the sample. These analyses have highlighted that the children with CP, classified differently using the GMFCS and MACS, scored differently on the SCICP in terms of their self-care skills. These differing scores also demonstrated that different associated impairments had an effect on the scores and also self-care skills of children with CP. These are explained in detail for eating and mobility associated with eating. Individual factors for the other domains of the SCICP are found in Appendix P.

4.4.3.4 Individual factors affecting Eating and Functional Mobility Associated with Eating

The percentages of independence demonstrated by participants with CP within the eating and eating functional mobility section demonstrated decreased independence from levels GMFCS II to V, as can be expected.

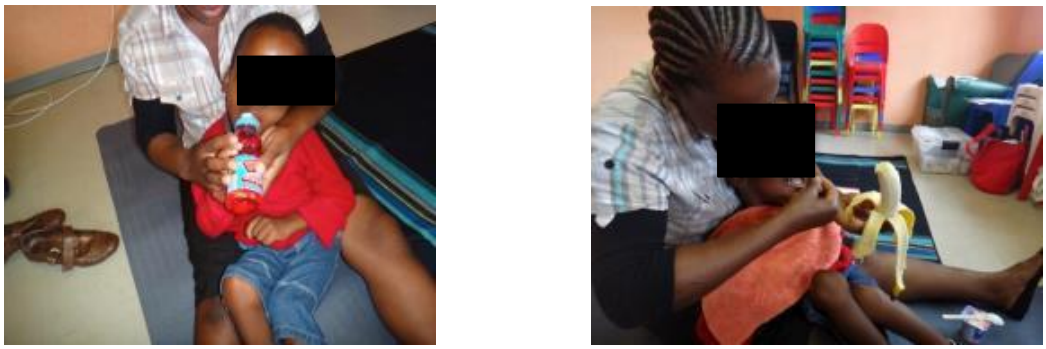

Figure 4.11: Dependent participant with GMFCS V, MACS V drinking with the assistance of his caregiver and eating a banana with the assistance of his caregiver

Child participant CP5 with GMFCS V, MACS IV needed hand over hand facilitation from his caregiver in order to hold the bottle of juice to his mouth in order to drink which scored a 2 (needs a lot of help). When eating the banana, he was unable to bite off pieces by himself. As a result, this caregiver broke off pieces for him and placed them into his mouth (Figure 4.11), which scores a 1 (dependent).

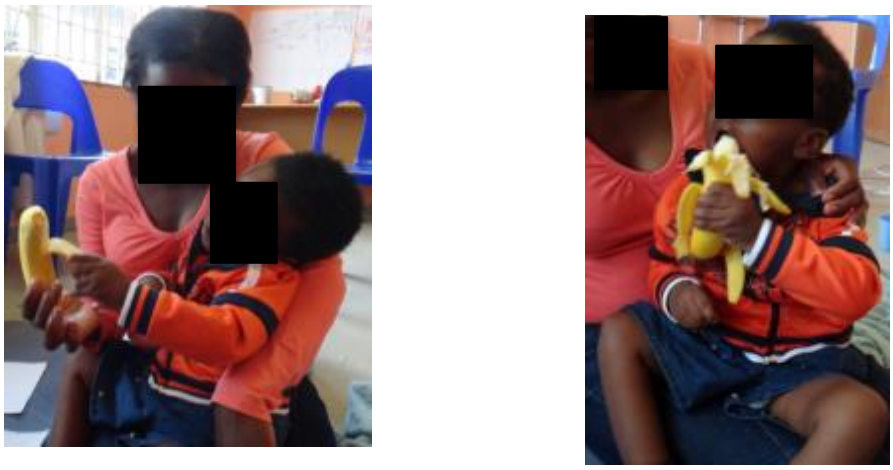

Figure 4.13: Participant with GMFCS IV, MACS II peeling a banana with the assistance of his caregiver and biting off a piece of food

Child participant CP4 with GMFCS IV, MACS II demonstrated peeling of banana, with his caregiver helping him by stabilising the banana and initiating the peeling for him that scored 2 (needs a lot of help). He was able to bite off a piece of food without the help of his caregiver (Figure 4.12) with a score of 4 (independent). CP4 with GMFCS IV had better use of his hands and a higher MACS classification (level II), and as a result was able to grasp items more independently than CP5 (GMFCS V, MACS IV). He was less dependent on his caregiver for self-care than CP5 despite being approximately four years younger.

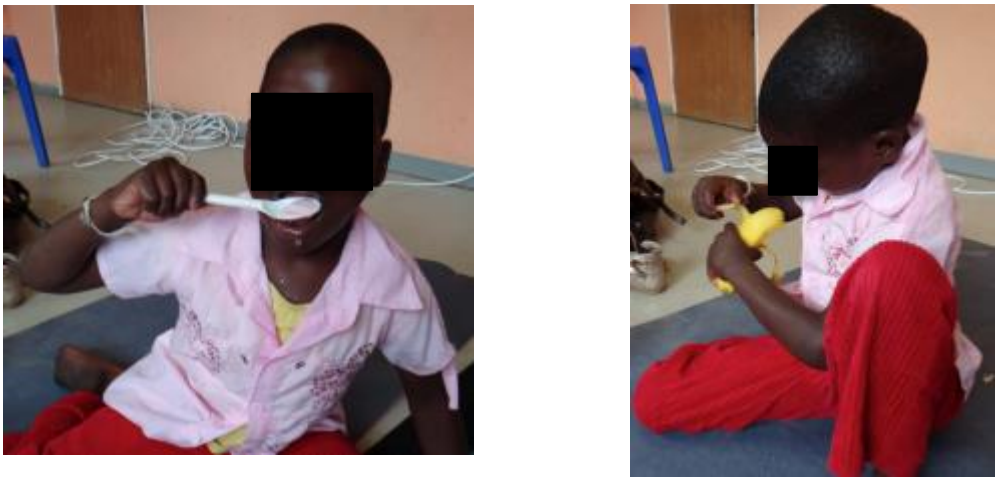

Figure 4.12: Participant with GMFCS III, MACS III feeding herself with a spoon filled with food and peeling a banana

Child participant, CP3, with GMFCS III, MACS III was able to feed herself yoghurt with a spoon, and peel a banana independently (Figure 4.13)

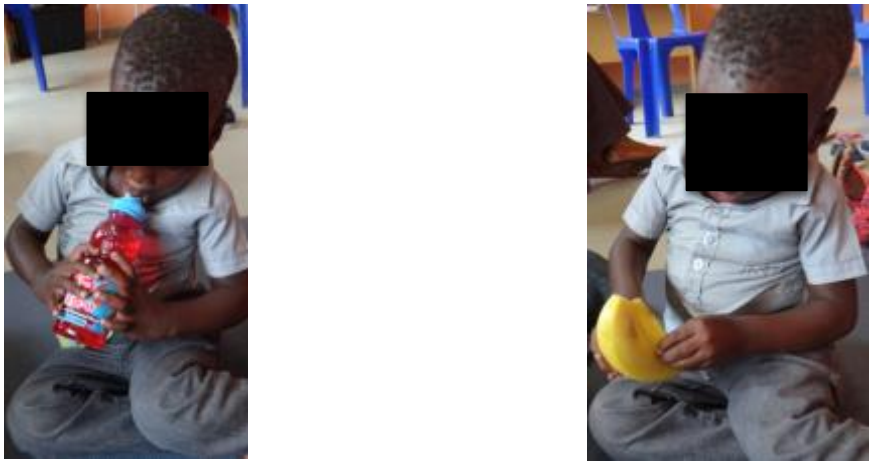

Figure 4.14: Participant with GMFCS II, MACS II picking up a bottle and drinking independently and peeling a banana to eat

Child participant, CP3 was only able to use a spoon independently for foods like yoghurt that were less likely to run off of the spoon and scored a 3 for eating using a spoon (needs a little bit of help) and a 4 for peeling a banana (independent). CP3 was more independent in this aspect of self-care than the CP4, even though their MACS score was similar because she was older.

Child participant, CP2 with GMFCS II, MACS II was able to drink from a bottle and peel a banana independently (Figure 4.14). Both of these items score a 4 (independent). Although CP2 and CP4 had the same MACS classification, CP2 is more independent in self-care due to better trunk and limb mobility and balance.

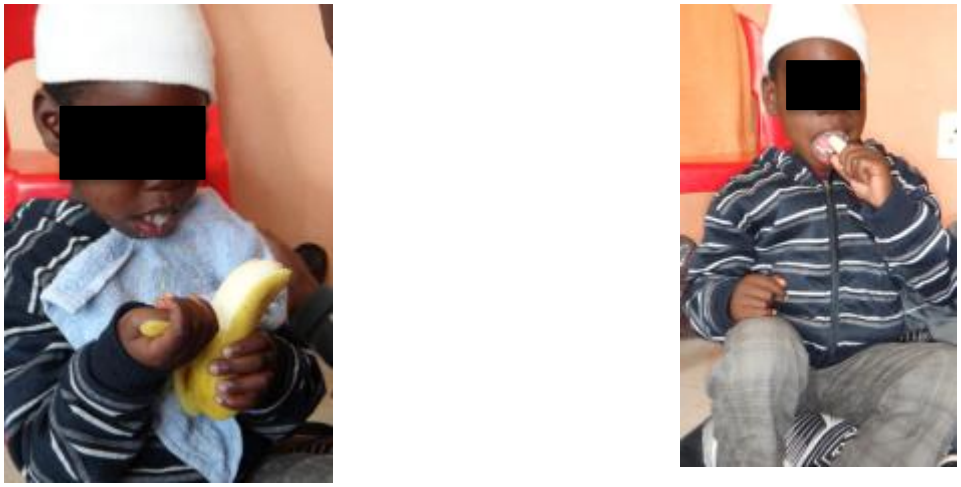

Figure 4.15: Participant with GMFCS I, MACS III peeling a banana and biting off a piece of food

When eating was assessed CP1, GMFCS I, MACS III was able to peel a banana and bite off a piece of food independently and score a 4 (independent). He needed verbal instruction to hold the banana and help from his caregiver to initiate the

peeling of a banana (Figure 4.15) and he took an increased amount of time to completely peel the banana. Therefore, he scored a 2 (needs a lot of help). He used his whole hand and not his fingertips like CP2 (Figure 4.14) as his MACS classification is higher and his hand function more affected.

Individual children with CP classified on differing levels of GMFCS and MACS with different ages and associated impairments demonstrated different scoring on the SCICP. This demonstrated the ability of the SCICP to differentiate between children with more and less severe CP.

4.4.4 Review of administration and scoring

The final scoring and administration criteria were reviewed for the domains after analysis of the field test pilot. At the same time, the total score of the SCICP was finalised. Total score was calculated by adding the maximum score for each item. As a result, 25 items were further adjusted - 2 items were edited and the scoring of 23 items adjusted. In addition, further editing in both English and isiZulu was necessary. Appendix N and O contain all items adjusted following the field test. Appendix Q contains the final version of the SCICP.

Table 4.9 shows which items were changed within the eating domain. Items were adjusted in order to ensure that the 5-year-old group was more independent in self-care than the 3-year-old and 2-year-old groups. “Uses fingers for eating” and “Lifts cup to drink” were edited in terms of wording. The scoring was adjusted for all ages, as all child participants were observed to complete the task, but caregivers reported incorrectly due to ambiguity in the item.

Table 4.10: Items for eating adjusted during data analysis

Domain	Total Items Changed	Scoring adjusted	Item	Itemed edited	
Eating	7	5-year-old score: 4 - able to finger feed	Feeds himself or herself crackers, carrot sticks or other finger foods (Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe)	2	Uses fingers for eating (Usebenzisa iminwe uma edla) Lifts cup to drink (Uphakamisa inkomishi khona ezophuza); All ages received 4s
		5-year-old score 4 - able to use spoon	Takes spoon filled with food to mouth (Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni)		
		2-year-old score: 2; 3-year-old score 3	Pours himself or herself a glass or cup of juice (Uzithelela yena uqobo ingilazi noma inkomishi yejusi)		
		2-year-old score: 2	Feeds self an entire meal using spoon (Uzidlela konke ukudla esebenzisa isipuni kanye)		
Functional mobility associated with eating	1	5-year-old score: 4	Returns spoon to bowl (Ubuyisela isipuni endishini)	0	

Items in the other domains were adjusted in terms of scoring (Table 4.11). Items were adjusted to reflect an increasing range of independence from two years old to five years old.

Table 4.11: Items for all domains adjusted during data analysis

Domain	Total Items Changed	Scoring adjusted	Itemed edited
Eating	7	5	2
Functional mobility associated with eating	1	1	0
Dressing	5	5	0
Functional mobility associated with dressing	0	0	0
Washing	2	2	0
Functional mobility associated with washing	0	0	0
Toileting	0	0	0
Functional mobility associated with toileting	2	2	0
Grooming	3	3	0
Functional mobility associated with grooming	1	1	0
Sleeping	0	0	0
Functional mobility associated with sleeping	0	0	0
General functional mobility	4	4	0
TOTAL:	25	23	2

Item administration was not changed. The pilot study highlighted the importance of the assessor to observe the participants performing each item because of inaccuracies seen in caregiver reporting. This may have been that the caregiver underestimated the participant's ability and as a result the assessment reflects lower levels of independence or that the caregiver overestimates the child's ability and this results in incorrectly high levels of independence. Another reason may have been that the children observed perform self-care activities more independently in their familiar home environment.

4.4.4.1 Analysis of Scoring

Child participants' performance was scored using the scoring system described in the methodology (appendix Q). This was not changed.

Differences between caregiver report and actual performance

During the administration of the SCICP, any differences in the child participant's actual performance and what the caregiver reported the participant to be able to do was recorded on the assessment form. Table 4.12 showed the number and percentages of the items that were affected for the whole test. An average of 4.8 items for the assessments of the 10 participants (4.4%) differed between what the caregiver reported and what was observed. It can be seen that the caregivers of the participants with CP report more accurately on their child's performance in self-care tasks. Appendices Q and R contain comparison of ages of independence.

Table 4.12: Number of items showing a difference between actual performance and caregiver report

	Number of items which differed	**Percentage**	**Average per Typically developing child participants and child participants with CP (%)**
T1	3	2.8	7.16%
T2	3	2.8	
T3	14	12.8	
T4	8	7.3	
T5	11	10.1	
CP1	4	3.7	1.66%
CP2	4	3.7	
CP3	0	0	
CP4	1	0.9	
CP5	0	0	
Average difference	4.8	4.4	

4.4.4.2 Time to administer

It took approximately 45 minutes to interview the caregiver and observe all items within the SCICP. When observing a participant with more severe CP, who could not perform many items, the time taken was shorter.

4.4.5 Review of age of independence

The comparison of age of independence was used in order to determine whether caregivers in this sample were able to accurately report on the performance of their children.

4.4.5.1 Comparison of age of independence of discussion group of caregiver participants and that reported by caregivers of child participants during the field-testing

When the age of independence of discussion group of caregiver participants and that reported by caregivers of child participants during the field-testing were compared, of the 109 items, the child participants achieved 40 items at an older age, 46 items were achieved at a younger age, and eight items were achieved at the age expected by the discussion groups' target population expert caregivers.

There were 15 items where the child participants were too young to have achieved them yet. Appendix R included the differences for all items within the SCICP for this section.

4.4.5.2 Comparison of age of independence of discussion group caregiver participants and the actual performance of child participants

The comparison of age of independence of discussion group caregiver participants and the actual performance of child participants showed that of the 109 items, 59 items were achieved within the same age ranges whilst 50 items were not. Twenty-five items were achieved later than the discussion group expert caregivers' opinion and 25 were achieved earlier. Since the field test was completed on five children this aspect needs further research to confirm an age band in which independence in activities is achieved as it may differ from child to child.

Appendix S included the differences for all items within the SCICP for this section. This demonstrated a higher number of items achieved at the age that the discussion group participants predicted than the child participant's caregivers' opinion of independence.

Table 4.13: Comparison of age of independence

Items (109)	Discussion opinion vs. Pilot field test caregivers	Discussion opinion vs. Actual performance
At the same age	8 (7%)	59 (54%)
Older than Discussion group opinion	40 (37%)	25 (23%)
Younger than Discussion group opinion	46 (42%)	25 (23%)
Too young to achieve yet	15 (14%)	0 (0%)

Table 4.13 showed that the actual performance of the typically developing child participants correlates more closely to the discussion group expert caregivers' opinion than to the reports of their caregivers. The caregiver's report showed seven per cent of items achieved at the same time as the discussion group. The actual performance of the child participants reflects 54% of items achieved at the same time. This highlights that the information from the discussion groups and the actual performance of children was a better indicator of age of independence than relying on caregiver reports.

Following this analysis, the SCICP was reformatted to reflect the ages of independence as per the actual field test performance (Appendix T).

4.5 Summary

In order to establish the SCICP, the construct and domains were established and the items were generated, and formatted. The next steps included SME survey, discussion groups and field-testing in order to determine final item selection and content validity. Prior to the survey, the SCICP contained 222 items.

Following the SME survey, 94 items were adjusted - 75 items were deleted and 21 were edited. The SCICP was left with 147 items included. Following the discussion groups with caregivers, 61 items were adjusted; 30 items were deleted and 31 items were edited and there were 117 items left in the assessment tool.

During the field test, 25 items being deleted. No items were edited. The child participants' occupational performance was analysed. It was found that for eating, the difficulty of the items decreased as the participants became older and therefore the difficulty of items for this domain was appropriate for the age groups assessed in this pilot study.

Results of the typical child participants' performance demonstrated increasing independence in activities of daily living in the participants' ages 2 years to 5 years old, which was as expected. Individual trends highlighted that the SCICP was able to differentiate between children with differing severities of CP. These results also indicated the various factors that continue to play a role in the development in self-care skills. These are age, hand function, associated impairments, GMFCS and MAC levels.

Once the field test was complete, the scores of the typically developing child participants were adjusted to ensure that the range of independence reflect the most independent being the five-year-old and the least independent the two year olds. Adjustments were also made to the wording of items, in order to increase their clarity.

When comparing the field test caregiver reports and actual performance of the child participants, on average 4.8 (4.4%) items were different.

Through two content validity reviews and a preliminary field test, the SCICP has shown potential in being a tool that has content validity and the potential to discriminate between typically developing children and children with various severities of CP. Further studied with larger sample sizes are needed in order to be able to draw stronger conclusions.

CHAPTER 5
DISCUSSION

5.1 Introduction

This chapter interprets the results gathered during Stages 1, 2, 3 and 4 of the study. The interpretation of the item checking and evaluation step of the assessment tool Self Care Questionnaire for Children with Cerebral Palsy (SCICP) development are discussed. The content validity is also interpreted based on the performance results of the field-testing with children living in Nquthu, KZN. In this manner appropriateness of items are interpreted and reasons for inclusion or exclusion are explained. The various confounding factors that affect a child's performance in self-care skills through the use of SCICP are explored as an indication of how the factors influence scoring of the assessment tool. This is important in order to assess how confounding factors play a role in self-care independence as well as how it will affect the usefulness of the SCICP. Implications for use of the SCICP are detailed as well as limitations of the current study and recommendations for future studies.

5.2 Item and Domain Generation

According to Patel (2000) the need for evidence based health care in developing countries[83], has resulted in the need for appropriate tools for functional clinical assessment and outcome evaluation. This should be based on an internationally recognised framework, for which the ICF and ICF-CY are recommended as providing a standard of reference for defining domains to be measured. These classifications are accepted global standards which are used to define and document disability and can be applied when identifying dysfunction in children on the basis of their function rather than their diagnoses. By basing the conceptualisation and analysis of the domains for self care[81] on that provided by the ICF and ICF-CY[84, 85], the research was able to expand on the content validity for the SCICP.

As Simeonsson, Leonardi, Lollar, Bjorck-Akesson et al. (2003) point out the ICF forms a sound basis for the development of an assessment for children in:

> "Differentiating components of childhood disability, identifying the purpose of measurement, and accounting for the mediating roles of developmental and environmental factors on childhood disability" p 604[86]

The researcher took these aspects into account as well as other aspects suggested by Simeonsson et al. (2003), that assessments for children should be based on their developmental level but still be able to identify the unique profile of each child's functional ability, allowing for intervention in terms of their functional abilities over time[86]. This accommodates the second important framework of development, when considering constructs for assessment in children. Thus the SCICP included the "moving target" or changes in function that occur at least initially on a one to six month and later a 12 month basis. The assessment was also specifically designed to accommodate the children's specific environment.

The manner in which the SCICP was to be used was to include both observation of actual performance and parent report. Haynes, Richard, Kubany (1995) highlighted the importance of high content validity for an assessment tool regardless of whether the tool encompassed self-report or observation of behaviours[87]. The researcher decided this due to the inaccuracies seen following the field test when comparing the results of the caregivers' reported independence and that of the child participants' actual performance. Abubakar et al. (2010) found that use of parent or caregiver report for a method of gathering assessment information is a valid and effective method, particularly in a resource-constrained setting. However, lack of knowledge of early child development amongst the caregivers would be something which would create inaccuracies within the reports[77]. In the study by Abubakar et al. (2010), the Developmental Milestones Checklist (DMC) was validated for use with the caregiver report rather than actual performance. It was found that the DMC had high internal consistency, test retest reliability and concurrent validity. Correlations between caregiver reports and the Kilifi Developmental Inventory (KDI) was highest for motor skills[77]. None of the other psychometric analyses completed on the DMC have yet been completed for the SCICP. Until this has been done, and the caregiver-report is shown to be effective and valid, the SCICP should use both caregiver-report and observed performance of self-care skills in order to determine a child's functional level.

5.3 Content validity and item appropriateness

5.3.1 Content validity and item appropriateness from Subject Matter Experts (SMEs)

The second step after the generation of items within the domain is to evaluate the content of each item and the assessment by exposing it to content SME review[81]. The content validity for the SCICP was assessed for items and not the scale per se.

According to the guide by Davis et al. (2004), subject matter experts (SME) should complete item reviews. Those who are experienced with the construct can be considered SMEs[5]. Polit and Beck (2006) and Davis et al. (2004) recommend at least two SMEs, preferably three SMEs are needed to review items in order to allow for satisfactory evaluation[2, 5]. Three SMEs, who were considered experienced in the construct of cerebral palsy, self-care and constraints in under resourced areas in South Africa, were accepted for the SME survey of the SCICP. Subject matter experts' input into the survey of the items allowed for the first round of modifications from the baseline of items developed from the commercially available assessment tools. The SCICP was reduced from 222 items to 147 items as a result of the SME survey. Forty-one items were deemed ambiguous, four items inappropriate to the age range, 30 items inappropriate to the isiZulu culture. The comments and opinions of the SMEs were supported by changes suggested in assessment adaptation and development in the studies by Bornman et al. (2010) and Matafwali et al. (2014)[11, 12]. In this study many of the items deleted also demonstrated inappropriate wording for use within an isiZulu culture and resource-constrained settings[12]. Words such as 'scoots' and 'tub' are examples of words inappropriate to the South African context.

Since all items from other tests and assessments were included, 28 items were also discarded as they were repetitive or assessed the same aspects of an activity. This occurred as the description of certain activities like eating with a spoon was assessed in slightly different ways in the assessments reviewed in constructing the items.

The SME occupational therapists were also asked to comment on appropriateness of the ages at which they thought the children would be independent in the various

activities assessed on the SCICP. The SME occupational therapists aided in the establishing of the content validity of the SCICP's items due to their contribution in terms of knowledge of theory of child development and self-care. Items that were deemed inappropriate due to age included: "Pour liquids (tea or coffee) from a pot" and "Styling hair". These items were expected of children older than seven years old, which was why they were excluded. The SME occupational therapists were not asked to analyze ages of independence for each item as this component was done with the caregivers of children living in the resource constrained area. The caregivers were thought to be able to provide valid input in terms of their experience of their children's achievement of self-care independence within their cultural context. A study by Elad, Barak, Eisenstein, Bar et al. (2012) supported this idea as the outcome of the comparison of the PEDI results and reliability when administered by health care professionals and mothers showed good reliability ratings when administered by both the mothers (ICC = 0.845-0.938 and Cronbach's α = 0.889–0.960) and the health care professionals (ICC = 0.940–0.976, Cronbach's α = 0.962–0.980)[94].

5.3.2 Content validity and item appropriateness from expert caregivers

The second method of ensuring content validity for the SCICP involved consulting with those caring for children in the target population. Mothers and grandmothers with experience, in this case being the caregivers of children from the context in which the assessment would be used. This supported the suggestion by Haynes et al. (1995) that different types of experts, including those from within the target population useful in establishing strong content validity. The consultation of the caregivers of children, although not common, has been described to enhance item development[91]. Therefore, the use of caregiver's opinion within the SCICP research greatly strengthens the content validity of the SCICP's items by contributing to their cultural relevance. Vogt, King and King (2004) report that about one in four researchers consult the target population, as in this study, to assist with item analysis. They advocate the use of groups rather that individual interviews[88] and this is what was held in order to determine relevance, appropriateness, cultural relevance, correct translation and age of independence for each item on the SCICP. This follows a methodology used by Abubakar et al.

(2010) in a low resourced area of Kenya and the development of the milestone monitoring assessment[77]. Use of two content validity reviews strengthened and supported the content validity of the SCICP as both groups contributed differing yet meaningful information regarding the items. Challenges include recruiting a sufficient number of both SMEs and caregivers for participation within each review. This challenge weakens the resultant content validity slightly.

The caregiver discussion yielded valuable information that contributed to the item selection and content validity of the SCICP. As experts in the field of raising children in a resource-constrained setting, they commented on the cultural relevance and the approximate age at which their children achieved independence within each item. Understanding this aided understanding of whether the items would be valid within the resource-constrained South African context.

Many items were deemed ambiguous within the discussion groups. The ambiguity came from the caregiver's understanding of whether her child could complete these items and at what age they began to do the action independently. Numerous items tended to be given a relatively late age for expected independence. This brings into question as to how reliable caregivers' memories are when asked to recall events from the past relating to small details of their children's development. For example: opens mouth for breast, bottle or spoon should be expected to be independent from birth in a typically developing child. Some caregivers did not report that it should be present from birth. The ambiguity for this item can either be through translation or through incorrect recall by caregivers. This finding is in contrast with the study by Abubakar et al. (2010), where caregiver report was found to be reliable and valid for use with the DMC, despite concerns regarding insufficient information regarding typical development in children[77].

Participation in the groups also varied and this may have affected the discussion and results. The caregivers within the first group felt more comfortable expressing their opinions to the translator and researcher initially. Two members of the group dominated this expression of opinion, while others remained quiet. By their second session, however, the caregivers felt more comfortable in discussing their opinions amongst themselves before coming to a conclusion. This is in contrast to the second group of caregivers. The second group was more cohesive and was able

to discuss their opinions and come to a conclusion from the beginning of the sessions. Although there were concerns about the first group in the first session, the cohesion attained in the second session and in the second group of caregivers made the process valid with discussion and decision making shared in providing the information required.

Another concern in the groups is that ambiguity may have arisen through the translation of the SCICP into isiZulu, and at times by the action described in the item itself. Words used by the translator were not always the words used within Nquthu and the dialect of isiZulu used. The caregivers explained this. Changes in language included: “kokukhohlela” changed to “khwehlela”. Both of these words mean cough or coughing, but “khwehlela” is the word used within the community. This again showed the importance of obtaining comment from those in the context in which the assessment will be used.

From the survey and discussion groups the main themes that were brought up multiple times were that items were ambiguous, inappropriate to age or culture and therefore were discarded. The main reasons for these comments were due to use of items from assessment tools developed in USA, different word usages within English used in USA and English used in South Africa and difficulties when translating from English into isiZulu.

The only item considered inappropriate to age was “Eats with a knife and fork, requires no help”. Caregivers explained that within their culture, they use their hands and spoons to eat a meal. They felt that it is appropriate to expect their children to learn to eat with a knife and fork, however it was not expected until the child turns 18 years old. This was because the caregivers wanted their children to have the table manners used in more western culture in case it was needed in the future. Items that were not done on a daily basis by the population were excluded. This was because false negatives may occur due to poor scoring of a particular item, which may then be incorrectly reflected as an inability.

Items inappropriate to culture included: “Sucks liquid from a glass or cup using a straw”, “Uses a fork without difficulty”, “Helps set table”, “Takes a bath or shower without help” and “Steps into and out of adult-sized tub”. The reason behind this was that within the isiZulu culture and the resource constraints in the area, these

items are not done. The items described actions that they did not use or complete, such as use a straw, fork, bathtub or shower or set a table for a meal.

Many factors influence a child's performance of self-care and how and when it develops, resulting in variance seen in age of independence. These factors can include the child's physical environment, specific demands of the activity, parent's expectations and caregiver responsiveness, cultural values and social routines[6, 61]. This is because the achievement of developmental milestones and acquisition of new skills as a child develops is dependent on many factors, both physical and environmental. Factors include development of postural and motor control, musculoskeletal system, sensory systems and motor learning for new skill acquisition. Motor development can be effected by and can effect development of cognitive, social and emotional development. All of these factors contribute to the rate and variability at which a child achieves developmental milestones and new skills[61, 89]. Even within a specific culture and similar physical environment, variation in achievement of independence of self-care skills is varied. A study by Guidetti, Soderback (2001) reported agreement with many factors influencing the achievement of self-care skills and that achievement of these skills is gradual and moves toward independence. Development of independence in a self-care skill is achieved through many hours of practice[61]. This finding correlates with the scores of the typically developing children on the SCICP. Even within the small sample, variance in self-care independence is seen. The variance underlines the ability of the SCICP to discriminate between children who are more independent in self-care skills from those who are more dependent in self-care skills.

While analysing the ages of the typically developing children, intervals of one year was used due to the small sample size and lack of variety in the ages of the child participants who took park in the field-testing. Ages of independence within other assessments such as the Peabody Developmental Motor Scales (PDMS-2) are reflected within intervals of one month for the first one or two years and then in bigger intervals of six or twelve months[90]. This is more accurate, as particularly during the first 2 years of life huge changes take place but were not included in this study for the SCICP because no children below 2 years were assessed. Items where independence is achieved by 2 years are indicated in this study. Although the sample size was small, the observations contribute to the starting point for

future studies and the overall development of the SCICP as a valid and reliable assessment tool to be used in resource-constrained settings of South Africa.

5.4 Item difficulty and ability to distinguish dysfunction

Davis et al. (2004) highlight that a proper sample representative of the overall population, should be chosen for the pilot testing stage of assessment tool development. A pilot sample should be small, but not too small that it may affect results[5]. Johansen, Brooks (2010) found that pilot studies with a sample size of between 10 and 30 allow for simplicity and ease of calculation when testing a hypothesis, without the sample being too small, making the results meaningless[91]. Although the target population for the SCICP is children with CP living in resource-constrained areas of South Africa, information was needed on typical development of children without CP before conclusions could be drawn about self-care skills of children with CP. Based on this information, a pilot study sample of 10 was chosen, including five typically developing children and five children with CP.

5.4.1 Typically developing children aged 2 to 5 years

The item difficulty for the occupational performance of the typically developing children (Figure 4.1) was analysed and reorganised so the items occurred in the order of least to most difficulty of the child participants. A limitation of the study was difficulty of items for typical children were based on observations the researcher and research assistant, who has a lot of experience with children with CP. These were not verified by another source. After the analysis the SCICP demonstrated increasing independence achieved with the lowest percentage independence in the youngest child participant at 2 years old and the greatest percentage independence in the child participant of 5 years of age. This is what is expected for typically developing children. As such, this result strengthens the content validity of the SCICP.

Knife use was one task that caregivers, across the sample, completed for the children. Even for typically developing children, the oldest child at five years old, was still considered too young to be using a knife. Although certain of the children were able to perform this item, their caregivers do not let them complete this task on a daily basis. This shows that at 5 years of age, the ceiling has not been reached in terms of complete independence of self-care skills.

The 2-year-old typical child participants demonstrated independence in a large number of items. This correlates with high achievement of motor skills development between birth and 2 years of age. This rapid development includes development of hand function and fine motor skills. This aids the development of independence in self-care, as many self-care tasks involve hand function and bimanual hand use[61]. By 12 months of age, a child is able to attempt to open a closed container, take off a sock, pick up small food items such as dry cereal, attempt to spoon feed and drink from a cup. At this age, children imitate caregiver's actions and are able to put a brush to their hair or hold a toothbrush and put it in their mouths. Many of these actions are the beginning of bimanual hand use. By 24 months, children are able to lick food from their lips[89]. Thus, this demonstrated high achievement of independence of two year olds within the field-testing sample, which correlates with what is expected within typical child development and therefore enhances the content validity of the SCICP. These observations form a starting point for future studies in order to determine overall ages of independence for items of the SCICP.

Although the same size was small, the differences noted through chi-squared testing (Figure 4.2) indicated that the SCICP was able to differentiate different ages and skill levels. It also showed that it was able to identify the correct order of independence, i.e. 3 year olds more independent than 2 year olds, and 5 year olds more independent than 3 year olds. The chi-squared test showed the 5-year-old with nearly full independence. This shows that the SCICP was able to distinguish differing levels of independence of self-care skills.

5.3.2 Child participants with cerebral palsy aged 2 to 7 years

Piloting the items following the item reviews allowed for understanding of how each item would work within the target population in terms of how they are administered, time taken, item difficulty and appropriateness to the sample. Piloting is one method to determine whether the item is problematic or valid to the new assessment tool. Pilot samples give an understanding of how the overall population may respond to the test items, and in doing so, this allows usefulness to be determined[5].

The SCICP has the potential to determine what a child's actual self-care performance is. Piloting the SCICP on a limited sample of typically developing children and children with CP demonstrated the SCICP's ability to distinguish differences in functional ability. Because of this, use of this tool can determine the child's independence in self-care, and where that child needs help with self-care. When used during an initial assessment, the SCICP can be used to determine foundational skills that are needed in order complete self-care tasks independently. Results indicate suggest content validity that supports the use of the SCICP in order to determine initial self-care independence. Due to the limited number of experts and small sample sizes, content validity will be further determined in a bigger sample in the future.

Specific ages of the children included were not a consideration. The focus for the field test was to include a child with CP who was scored within each different GMFCS level. This was to enable comparison of their scores to the typically developing children's scores in order to demonstrate whether the SCICP was able to discriminate between a typically developing child's level of independence in self-care and that for a child with CP. The results demonstrated a difference, which means that through initial field-testing, the SCICP might have the ability to distinguish between a typically developing child and a child with CP.

Testing the SCICP with children with CP and typically developing children of broader ages, up to seven-year-old will need to be completed within future studies in order to thoroughly assess the validity and reliability of the SCICP for use with children with CP.

The more severe the child with CP's disability, the more items the caregiver needed to complete for the child. However, the reasons behind completing the task for the child were not only time constraint and parent expectation. They also included safety to complete the task, intellectual disability as well as physical disability, where the child's cognition, hand function, postural strength and muscle tone interfered with the child's ability to perform the task.

5.4.2.1 Differentiation between children with cerebral palsy and typically developing children

When comparing the 2-year-old group of typically developing children and the 2-

year-old child with CP (CP4), who was 2 years 4 months old (figure 4.3, chapter 4), the typically developing children demonstrated a higher level of independence in self-care than the child with CP. The scores for CP4 were higher than expected. This may be although CP4 was classified as GMFCS IV, he was diagnosed with spastic diplegia and had relatively better function within his upper limbs than lower limbs. Child participant CP4 was classified as MACS II, supporting relatively better function in upper limbs than lower limbs. The results of comparing typically developing children with a child with CP of two years old, demonstrate that the SCICP is able to differentiate levels of self-care ability at that age.

In comparison of the 3-year-old typically developing child and the 3-year-old child with CP (CP2) (figure 4.5 and 4.6, chapter 4), the child with CP scored higher than was expected in comparison with a typically developing child. The child with CP was classified as GMFCS level II MACS level II, diagnosed with ataxia and was one of twins. He was able to walk independently with poor gait. This result highlights that the SCICP is able to differentiate when there is no difference between typically developing children and children with milder forms of CP and that this child does not have a problem with self-care. He actually needs other types of intervention since for his age he is independent in self-care and will only need to be monitored to determine that he retains this independence. This observation is made with caution due to the small sample size. Further studies, with a larger sample size need to be conducted in order to support or refute this claim.

When comparing the 5-year-old typically developing child and the children with CP, classified at GMFCS I, (5 years 5 months, MACS III, CP1), III (7 years 0 months, MACS III, CP3) and V (6 years 7 months, MACS IV, CP5) (figure 4.7, chapter 4), the typically developing 5-year-old, demonstrated higher independence in self-care skills than the children with CP. For this comparison, children with CP older than 5 years old were accepted for comparison. The assumption was that this comparison was applicable, as children with CP will be delayed in achieving independence in self-care and the more severe the CP, the greater the delay in development is. This statement correlates with findings by Smits, Ketelaar, Gorter, van Schie and Dallmeijer et al. (2011), where within the self-care domain, GMFCS and MACS levels are associated with level of self-care independence. Thus the

higher the level of functioning (lower GMFCS and MACS classification), the better the performance in self-care activities[92].

This was seen in the comparison of the 5-year-old typically developing child, with the child classified as GMFCS V (CP5). All scores show that the typically developing child is significantly more independent than the children with CP, despite him being more than 18 months older. Overall, the 5-year-old child scored 62% higher independence than the child with CP classified as GMFCS V (most severe). The difference ranged from 47% difference for grooming, to 75% difference for functional mobility associated with eating and functional mobility associated with sleeping. This also correlates with CP5 having a MACS IV classification and dyskinetic CP diagnosis resulting in severe physical disability. These scores demonstrate that the SCICP is able to determine severe delay in independence in self-care.

The child with CP (GMFCS I) achieved less independence than that of the typically developing 5-year-old child. This child was classified as having spastic hemiplegia of his left side with a cognitive impairment. During the field test, his caregiver stated that he would refuse to complete many of the items, even though he was physically capable in many instances. As a result, his caregiver completed many items for him. This is one of the reasons why his level of independence is observed to be lower than it should be.

The occupational performance of the children, both typically developing and with CP, shows that the SCICP is an assessment tool which can discriminate between children with CP and typically developing children and thus identify the need for intervention focused on self-care. Future studies should encompass a broader range of ages, associated impairments and physical abilities as are seen within many children with CP. This will allow the ability of the SCICP to differentiate between typically developing skills and delayed skills and for this to be generalizable to the target population.

5.4.2.2 Distinguishing factors that affect self-care in children with cerebral palsy

The field testing provided information about additional factors, which influence the independence in self-care scores. Both the GMFCS and the MACS appear to play

a role in self-care independence as did the various ages of the child participants with CP.

This study was in accordance with research by Ohrvall et al. (2010) who investigated self-care and mobility skills in children with CP and the relationships that exist to the GMFCS. They reported however, that GMFCS only accounts for 1% of the variance in self-care skills in his study on CP children[8.] Results indicate that the GMFCS contributed little to dysfunction in self-care of the child participants with CP when compared to the ability of the typical child participants in self-care. When comparing each child with CP across the GMFCS levels (Figure 4.9), the child classified as GMFCS II (CP2), achieved the overall highest level of independence, followed by the oldest child, classified as GMFCS III, who had independence similar to the child with GMFCS IV. The child classified as GMFCS V had the lowest independence in self-care but the child with GMFCS I was less independent in self-care than those with GMFCS II, III and IV. This demonstrates the GMFCS levels play a small role only in the acquisition of self-care skills independence (Figure 4.9 and 4.10). This also supports that MACS levels or hand function plays a greater role in the acquisition of self-care skills.

There were two reasons why the child classified as GMFCS I (CP1) scored lower than expected in self-care. One was due to a factor identified as intellectual and cognitive disability. Another reason was due to his MACS classification being MACS III. Therefore, CP1, presented with better gross motor ability than hand function.

These correlations reinforce the finding that the SCICP requires further investigation with respect to MACS classification, cognitive impairment and age as influencing factors.

This correlates with the study by Kadlec et al. (2005), which found that children with and without white matter brain damage experiences caregiver interactions which were different, in terms of the amount of assistance needed as well as positive engagement, to those between caregivers and term, typically developing children. In this instance, the caregiver of the child with GMFCS level I, completed more activities for him, and helped him to complete more activities than caregivers of the children classified as GMFCS II and III. Oskoui et al. (2012) also found that

children with cognitive impairment demonstrated more severe gross and fine motor skill impairments than those without cognitive impairment. This was highlighted through the use of MACS classification which classifies according to typical performance, rather than best performance, so that the influence of cognition can be seen in the child's performance[48].

The second reason the child classified as GMFCS I (CP1) scored lower was related to his MACS level and hand function also played a role in his dependence on his caregiver. This can be attributed to the child with GMFCS I, MACS III (CP1) having less bilateral hand function than the other children with lower GMFCS scores. The majority of the domains on the SCICP, showed the children with MACS levels of II, (GMFCS II CP2) and (GMFCS IV (CP4) demonstrated the highest levels of independence. Since many self-care items involved bimanual hand use, those with MACS levels III were less independent in self-care and the child with MACS IV was the most dependent (Figure 4.10).

Both participants CP4 and CP3 had diplegia, which meant they had better hand function and performance in self-care items, than CP5 who had quadriplegia. This is supported in a study by Oskoui et al. (2012), who found that GMFCS and MACS correlate in children with spastic quadriplegia and dyskinetic CP but not those with diplegia[48]. They found a lower correlation between the GMFCS and MACS in children with diplegia, due to involvement in the lower extremities, and better functioning within the upper limbs. Hidecker et al. (2012) confirmed the higher correlation between the MACS and GMFCS with children with quadriplegia, where all four limbs and trunk are involved, negatively impacting on participation within all activities of daily life. [54]. Within this study, the performance of child participant CP5 correlated with this finding. This child participant was 6 years 7 months, GMFCS V, MACS IV, and scored the lowest overall total score on the SCICP in comparison with children on higher GMFCS levels. According to Ohrvall et al. (2010) a child with CP levelled at MACS III, IV, V and GMFCS IV and V will have more pronounced limitations in performance of daily activities, demonstrated limited development of functional skills in the child CP5[8].

These findings indicate MACS can be predictive of function in self-care and are similar to those of Ohrvall et al. (2010) who also established the relationship

between self-care and mobility skills in children with CP through MACS. Using the PEDI, they found that MACS levels could explain 66 percent of variance seen in independence in self-care in children with CP[8]. This was supported by De Brito Brandao et al. (2012) who also found a significant correlation between manual ability and self-care skills[44]. This further indicates that hand function, or improved use of upper limbs plays an important role in the independence in self-care and highlights the need for the SCICP to be considered in terms of MACS classification.

Age also appeared to influence independence as despite differing functional abilities, an older child has had more time to practice and develop his skills. Variance in hand function resulted in differing levels of independence seen as well. The participant CP3 (GMFCS III) although she had MACS III level achieved close to the independence to the typically developing 5-year-old. This level of independence was achieved as she is two years older and has had more time to practice and has adapted and developed compensatory strategies to allow independence in self-care. For example, 'w-sitting' is a compensatory manner to ensure improved stability in sitting when teeth brushing (Figure 4.19). This increase in stability allows her to use her hands for fine motor activities, rather than concentrating on maintaining her upright posture. In this participant's case age affects the development of self-care skills (Figure 4.10).

Ohrvall et al. (2010) found that age only accounted for 13 percent of the variance, in self-care skills. Age tended to more strongly influence the self-care skills of children with CP who were classified on level I or II, whereas it had very little influence on when the child was classified on levels III, IV or V[8]. In this study it was found age still played a role in self-care in children on level III of MACS and GMFCS.

The SCICP was therefore able to show differentiation amongst children with CP based on their MACS classifications, as well as other factors that also influence their independence in self-care and participation within self-care tasks. Age, GMFCS and cognition were found to play a role in the performance of many self-care skills, and many items of the SCICP. For future studies, other influencing factors surrounding the development of self-care needed to be considered when

interpreting the scores. Use of the EDACS and CFCS in further comparative studies may be useful in ensuring the SCICP's discriminative capacity.

Future studies need to determine whether the SCICP is able to differentiate between self-care skills of children with CP regardless of age, associated impairments and classification levels.

5.5 Parent report vs. observation of child participants on the Self Care Inventory for Cerebral Palsy Children

Performance and independence in self-care skills in typically developing children is often achieved around seven years of age, however this is not the case for children with CP. Little is known regarding the ages of independence in self-care skills regarding children with CP[8]. This may be because CP is a heterogeneous group that encompasses many different levels of ability. Also different associated impairments may influence the development of skills differently across the spectrum of CP. This is why identification of age of independence is important and provides useful information for the future use of the SCICP. During the field test, many of the typically developing children only needed verbal instruction from their caregivers in order to complete the task. In comparison, children with CP needed more specific verbal instruction, and where the child's disability was more severe, more facilitation and guidance to complete the task.

Reporting on age of independence by caregivers was an important observation. Caregiver report may play a role in the way the SCICP is administered as it has implications for the resources needed to administer the assessment tool. The study by Abubakar, et al. (2010) correlated with this. There were differences in the ages reported by the expert caregivers and those observed and reported by caregivers during the field-testing of the SCICP. This may have occurred because as in a study by Velikos, Soubasi, Michalettou, Sarafidis et al. (2015), which used the Bayley-III Scales to assess developmental performance in children of 12 months, corrected age, it was found that parents tended to over-estimate their children's abilities. Their findings show that parent scores were significantly higher than that of the examiners[93]. This finding was supported in this study, and the caregiver reports were inaccurate when compared with actual performance of participants in terms of age, which may have affected the content validity of the

information obtained from the caregivers in the discussion group.

However, comparing the resultant ages of independence given by the expert caregivers from the discussion group to that given by the caregivers from the field-testing and the actual performance of the typically developing children, there was a 53% agreement in the match of age of independence. The comparisons involved different time intervals. The expert caregiver and field-test caregiver opinions were based on monthly intervals, whereas actual performance used was based on the ages of the children, and therefore “by 2 years of age”, “by 3 years of age” and “by 5 years of age” was used. This created significantly more overlap between the expert caregivers’ opinions and the actual performance of the typically developing children. This may well have affected the accuracy of the reporting by the expert caregivers and it is clear that except for the first year, the SCICP can be divided into six month levels for 12-14 months and after that one year levels so monthly detail is not necessary.

The expert caregivers’ ages of independence agreed 54% of the time with what was observed in the field test with typical children (Table 4.15). These differences can be accounted for as the participants were for the most part being asked to recall when their child or grandchild achieved independence. Since this might cover a few years’ accuracy could not be expected. The pilot field-testing was also only completed on five children so ability may not fully represent the typical population of children in the area. The problem with the accuracy of reporting the age of independence is that some of the caregivers, of both groups reported that although their child was able to complete the task, but at home, it was done for them. These tasks included being fed a meal with a spoon, dressing, washing. The reason behind this was time constraints, and expectations of their child. The caregivers felt it was easier for them to complete the task quickly, so that they could move on to another daily task and did not expect their children to be able to complete the task independently at their current ages. Thus determining if the child was actually independent was difficult and assumed by the caregivers for some activities.

According to Table 4.12 caregivers of the children with CP tended to demonstrate more accuracy in knowing what activities their children could perform, than the

caregivers of the typically developing children. This observation could be due to additional time spent by the caregiver with the child with CP in completing or assisting with tasks that the child cannot do independently thereby making the caregiver more aware of the child's actual self-care performance. This observation further confirms the need for a larger sample of typically developing children in order to determine accurate age of independence.

The expert caregivers and field-test caregivers only agreed 8% of the time as to the age of independence but the pilot field test caregivers were reporting on their child's ability at the present time, rather than the age of independence so this difference is not unexpected (Table 4.15). This comparison involved 20 discussion group participants and five caregivers of typically developing children. These numbers are not large enough to make the information generalizable to the entire population however. This is why further studies need to investigate the age of independence of typical developing children within resource-constrained areas. In doing so, the ability of the caregivers to report on their children's performance related to self-care skills can be observed on a larger scale. This will allow better conclusions to be drawn relating to the entire population.

The comparisons highlight possible small inaccuracies in caregiver reporting from the caregivers in the field test as the actual performance of the typically developing child participants, were closer to what was decided upon during the discussion groups. The caregivers in the field test were asked only about the present independence of their own child and in this study what they reported was not as accurate. Differences occurred for between 3-14 items on the SCICP (Table 4.12) which is a 7% discrepancy which is probably acceptable. These findings correlate with findings of Abubakar et al. (2010), McDougall, Bedell, Wright (2013) and Chien et al. (2012). All of these studies demonstrated consistency and validity in the use of parent reports[77, 94, 95]. Abubakar et al. (2010) found a significant correlation between use of caregiver reports and the scores of the KDI (Kilifi Developmental Inventory). The strongest relationship demonstrated was within the motor subscale of locomotion and eye-hand coordination[77]. McDougall et al. (2013) found strong internal consistency and internal structure validity when parent and child reports were used to assess participation within various environmental contexts[95]. Chien, Brown (2012) found that parent report was moderately

correlated through the use of the Children's Hand-Skill Ability Questionnaire (CHSQ) compared to the Assessment of Children's Hand Skills (ACHS) and the VBAS Personal Living Skills subscale[94]. These three studies demonstrate valid use of parent report for the identification of performance of skills of their children.

It is clear however that further studies with larger sample sizes are needed to further determine consistency and accuracy of the SCICP's target population's caregivers and their ability to report on the performance of self-care skills in their children.

5.6 Review of administration and scoring

The field test data were analyzed and items reviewed by the researcher in terms of the ages of the participants, the severity of their CP on the GMFCS scale, the administration and scoring as well as each item's properties in terms of the participants' cultural context. Items were adapted accordingly. This assessment development did not continue to the stage of detailed item analysis and determining reliability and construct validity of the SCICP.

Ambiguous items: "Uses fingers for eating, but does not chew" and "Lifts cup to drink, but cup may tip" were changed to "Uses fingers for eating" and "Lifts cup to drink" respectively. Through observation, the researcher was able to determine independence within these tasks. However, they were changed as each caregiver said that her child was still dependent in performing the item. By editing the wording of these items, in both English and isiZulu, the ambiguity was eliminated. The administration directions are included in Appendix S. The administration directions were drawn up following the field-testing as they were based on how the field-test was completed.

Scoring was adjusted for 20 items, within the typically developing children, in order to create a continuum for achievement of independence. Therefore, younger children (i.e. 2 year olds) were less independent than their older counterparts (i.e. 5 year olds). The reasons why the scoring needed to be edited was to do with limited sample size due to mothers who completed many self-care activities for their children, even though they could complete the task independently, or mothers who encouraged independence in her child. In our sample of typically developing

children, first born children and the only child of the particular mother were the children seen to be younger and more independent.

Examples of items edited for scoring: “Feeds himself or herself crackers, carrot sticks or other finger foods”, “Takes spoon filled with food to mouth”, “Removes pants including unfastening”, “Washes hands with soap”, “Stands on tip toes to reach objects”. Scoring in these items was adjusted to give the 5-year-old group independence. In this instance, the 5-year-old was observed to perform the tasks, but independence was not reported or wrongly reported by caregivers. This was due to the caregiver doing the task for the child at home.

The researcher considered 22 items difficult to observe at the time while using the SCICP. Some of these included: “Eats all textures of food”, “Obtains clothing from closet or drawer”, “Indicates when nappy needs to be changed”, “Consistently stays dry day and night”, “Bladder control during the day, but has to go quite often”, “Distinguishes between the need for urination and bowel movements”, “Bowel movements generally regular”, “Sleeps through most of the night, waking no more than one or two times”, “Gets in and out of car with no assistance or instruction”. Reasons why these items were difficult to observe were due to the length of time needed to observe the item, or use of a piece of equipment which was not accessible within the resource-poor setting at the time of the assessment.

Although observing the actual performance of each item might make the administration time of the SCICP longer, it may be more accurate in identifying independence in self-care than through parent reports. The comparison of actual performance and parent report should be analysed on a larger sample, in order to determine whether the inaccuracies seen during the field-testing are generalizable to the entire population or not.

5.7 Limitations of the study

This study was limited by the lack of initial SME occupational therapists within the survey. There were only three SMEs who responded to the survey, out of a possible 10. Unfortunately, due to the poor response rate of the SMEs the determination of content validity was limited. In this study changes to the content of the SCICP was made according to the SMEs who did respond and content

validity was assumed based on these responses for this study. The consequence of this was that the content validity through the expert review was not as strong as anticipated. The initial lack of cohesiveness within one of the discussion groups created dominance amongst a few members, and passivity amongst the rest. Although this influenced the participation within the group and the responses gained, the dominant members of the group began to encourage all the members to participate, allowing all opinions to be viewed.

The lack of agreement in age of independence amongst the discussion group expert caregivers, caregivers of typically developing children in the field-test and the actual performance of the children suggest that the small sample size influenced the ability to accurately identify appropriate developmental ages.

This study was limited in terms of sample size of the field-testing. A larger sample of both typically developing children and children with CP will allow better understanding of the predictability of the SCICP. Including children on each MACS classification level will also allow understanding of the SCICP to identify children with more or less involvement of hand function.

Even though the field test was able to distinguish between typically developing children and children with CP within the sample, it is very limited and does not give the research generalizability toward the entire resource-constrained South African population. This study was focused only on item selection and content validity testing. In order for the SCICP to become a standardised, usable assessment tool for use within resource-constrained areas of South Africa, further testing of other forms of validity and reliability is necessary.

5.8 Summary

Following development of items, content validity reviews and a preliminary field test demonstrated that the SCICP has the potential to become a useful resource for use amongst occupational therapists working with children with CP in resource-constrained areas of South Africa. The results of this study highlight how important it is to have culturally relevant and theoretically correct assessment tools in order to be able to correctly identify children with CP who have challenges in independence of self-care.

Despite having small sample sizes, the SCICP has been able to reflect differences in the independence in self-care of specific typically developing children and children with CP. The SCICP was also able to reflect differences of independence of self-care within specific children with different severities of CP as classified using the GMFCS. In order for the SCICP to become a useful tool for occupational therapists working with children with CP, further testing is needed. Further testing should begin with content validity reviews using a larger pool of SME occupational therapists and field tests with a larger sample size of both typically developing children and children with CP.

CHAPTER 6
CONCLUSION

6.1 Introduction to Conclusion

This chapter presents the conclusions drawn from the study regarding the content validity and usefulness of the Self Care Inventory for children with Cerebral Palsy (SCICP) as well as recommendations for future studies.

6.2 The item selection, content validity and field test of the Self Care Inventory for Children with Cerebral Palsy

The SCICP is an assessment tool for assessing self-care performance within a resource-constrained environment taking the cultural context into account. Use of item reviews through SMEs and discussion groups allowed the content validity of the items to be established whilst field-testing allowed observation of the SCICP to differentiate between children who are typically developing and children with CP. The SCICP is also able to identify those children with CP who have severe disabilities and are limited in their self-care abilities.

This study has thus provided the first stage of development of a tool to measure self-care performance in children with CP living in resource-constrained settings in South Africa. This is the first measure of its kind and offers the potential for a useful assessment tool with the ability to draw meaningful inferences regarding self-care independence in children with CP once complete. However, the development of a new tool is a mammoth task and several further studies are required before the tool can be used. This study presented limited content validity for the items of the SCICP. The content validity of the tool as a whole should be investigated in future studies.

The results of this study indicated that the SCICP can determine what the actual self-care performance is and thus the child's level of independence in self-care and where help is needed to improve self-care skills.

This study highlighted several factors that need to be taken into account when establishing independence in self-care in children with CP. These factors include

age, hand function, cognition, classification levels and other associated impairments.

An interesting but perhaps surprising observation was that the opinions and comparisons regarding developmental ages demonstrated inaccuracies between caregiver report and observation of performance. This is an area where further studies are necessary in order to determine the exact age range of expected independence in self-care skills, taking into account variation seen in the mastery of skills within typical child development. Further studies in this area will also highlight the accuracy of caregiver reports within a larger sample. Until this has been investigated, the SCICP's scores should be based on the caregiver report as well as observation of actual performance of each child.

Although the sample sizes were small, they give an indication of the usefulness of the SCICP, and with further studies including larger sample sizes, this usefulness will be able to be extrapolated to the entire target population. This will allow the results of the SCICP to be interpreted with confidence and accuracy.

Throughout the study, the researcher gained insight regarding the many useful assessment tools for assessing self-care. This study reinforces the studies of Matafwali et al. (2014), Bornman et al. (2010) and Abubakar et al. (2010) in that assessment tools in one setting does not necessarily mean that they will be valid in another setting. Adapting an assessment tool for use in a resource-constrained area involves a large amount of work in order for the tool to become useful and meaningful. Insight was also gained regarding the myriad of factors that affect the acquisition of self-care skills and self-care performance and how culture and society also play an important role in self-care performance.

6.3 Recommendations

The SCICP should be reviewed by using at least 10 SME occupational therapists in order to establish good quality content validity. As without the content validity, the SCICP cannot be used to correctly interpret self-care independence in children with CP in resource-constrained areas of South Africa. Developmental ages should be reviewed by SME occupational therapists and a new group of caregivers living in Nquthu based on their experiences raising children. The results

of both of these reviews should be compared in order to understand the how culture plays a role in the developmental ages at which children in resource-constrained areas achieve independence in various self-care activities. This will aid the establishment of reliability of the SCICP in terms of coefficient of equivalence, test-retest reliability, internal consistency reliability.

Discriminant validity should be established using field tests with larger sample size of both typically developing children and children with CP. This will aid identification of variance in typical developmental ages for self-care skills. Sample sizes should include between five and 10 children per domain of the SCICP. Therefore, as one domain includes the self-care activity and the functional mobility associated with the activity, ideally a larger sample size should consist of between 35 and 70 typically developing children and between 35 and 70 children with CP. The sample should include matching for age between typically developing children and children with CP. The sample should also include children with CP classified on each classification level of the GMFCS, MACS and EDACS. Including all classification levels will allow for comparison of SCICP scores of these children and determine whether the SCICP is able to discriminate not only between typically developing children and children with CP, but also between children of various severities of CP.

Responsiveness of the SCICP should be established by analysing the results of the SCICP used with children with CP over time in order to determine whether the SCICP can be used as an outcomes measure so that improvement in self-care independence during occupational therapy intervention can be measured.

Although there is still a large amount of input that is required before the SCICP can be used with children with CP within resource-constrained settings, this study provides a starting point. It has demonstrated that the SCICP has the potential to identify children with CP with delays in self-care skills. The structure of the SCICP and its items have been developed and refined. This study has demonstrated that the SCICP has limited content validity for the items included. As a result, content validity studies will need to be completed with a larger amount of SMEs. The SCICP has been shown to be able to differentiate between children who are typically developing and children with CP within a small sample as well as

differentiate between children with more severe forms of CP, again within a small sample. With further research, the SCICP has the potential to be an assessment tool that can measure self-care independence in children with CP and identify whether occupational therapy intervention is needed. The SCICP has the potential to be a free resource that can be used accurately within resource-constrained areas of South Africa

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APPENDICES

Appendix A: Scoring

The scoring for the SCICP is ordinal, and ranges between a score of one and four:

1 The child is completely dependent on his caregiver

2 The child is able to perform parts of the activity but needs help from his caregiver as well as additional environmental support and adaptations such as equipment.

3 The child is able to complete parts of the task but needs some help in the form of extra time, adapted utensils (e.g. built-up spoon), modified fastenings or a universal cuff.

4 The child is completely independent in the activity.

Appendix B: SME Content Validity Survey on Survey Monkey

Development of a Self Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

There are 15 questions to this survey, please answer each question by choosing whether the items in each question are relevant to typically developing children, are simple and clear in the way they are written or perhaps ambiguous in the way they are written. Please indicate whether you feel the item should be re-worded or discarded. After each question, there is space for you to write any suggestions or comments you may have. Please do so, any constructive feedback is useful!

*** 1. Eating**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Does not Turn head toward nipple when cheek is touched	☐	☐	☐	☐	☐	☐
Opens mouth for breast, bottle or spoon	☐	☐	☐	☐	☐	☐
Shows recognition of food	☐	☐	☐	☐	☐	☐
Swallows liquids without coughing	☐	☐	☐	☐	☐	☐
Eats smooth soft foods	☐	☐	☐	☐	☐	☐
Eats ground/lumpy foods	☐	☐	☐	☐	☐	☐
Eats cut up/chunky/diced foods	☐	☐	☐	☐	☐	☐
Eats all textures of table food	☐	☐	☐	☐	☐	☐
Scoops with a spoon and brings to the mouth	☐	☐	☐	☐	☐	☐
Takes spoon filled	☐	☐	☐	☐	☐	☐

with food to mouth						
Licks food from around mouth	☐	☐	☐	☐	☐	☐
Uses fingers for eating, but does not chew	☐	☐	☐	☐	☐	☐
Bites off piece of food	☐	☐	☐	☐	☐	☐
Chews solid foods	☐	☐	☐	☐	☐	☐
Feeds himself or herself crackers, biscuits, carrot sticks or other finger foods	☐	☐	☐	☐	☐	☐
Picks up bottle and drinks independently	☐	☐	☐	☐	☐	☐
Lifts cup to drink, but cup may tip	☐	☐	☐	☐	☐	☐
Holds and drinks from a sipping cup	☐	☐	☐	☐	☐	☐
Drinks from a cup with some help	☐	☐	☐	☐	☐	☐
Drinks from a cup without help	☐	☐	☐	☐	☐	☐
Sucks liquid from a glass or cup using a straw	☐	☐	☐	☐	☐	☐
Uses spoon when eating without requiring help	☐	☐	☐	☐	☐	☐
Pierces food with fork and brings to mouth	☐	☐	☐	☐	☐	☐
Uses a fork without difficulty (food can be cut and prepared)	☐	☐	☐	☐	☐	☐

Uses a knife for "spreading" butter, jam etc	☐	☐	☐	☐	☐	☐
Cuts soft foods with knife (banana, baked potato)	☐	☐	☐	☐	☐	☐
Cuts meat or other food into bite-size pieces	☐	☐	☐	☐	☐	☐
Uses table knife for "cutting" without much difficulty	☐	☐	☐	☐	☐	☐
Eats with a knife and fork, requires no help	☐	☐	☐	☐	☐	☐
Feeds self entire meal using spoon and fork	☐	☐	☐	☐	☐	☐
Pours himself or herself a cup of juice or water	☐	☐	☐	☐	☐	☐
Peels 3 foods (banana, naartjie, egg)	☐	☐	☐	☐	☐	☐
Eats independently	☐	☐	☐	☐	☐	☐

Comments or Suggestions

*** 2. Functional Mobility Associated with Eating**

*** Functional Mobility is defined as the mobility needed to complete everyday activities**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Carried a cup of juice or plate of food to the table	☐	☐	☐	☐	☐	☐
Stretched to reach a high shelf	☐	☐	☐	☐	☐	☐
Reaches for bottle	☐	☐	☐	☐	☐	☐
Returns spoon to bowl	☐	☐	☐	☐	☐	☐
Picks up and replaces cup upright on table	☐	☐	☐	☐	☐	☐
Locates and picks up own utensils at table	☐	☐	☐	☐	☐	☐
Stirs liquid with a spoon	☐	☐	☐	☐	☐	☐
Cleans up spills,	☐	☐	☐	☐	☐	☐

getting own cloth

Carries container cup with water or juice without spilling	☐	☐	☐	☐	☐	☐
Serves self at table	☐	☐	☐	☐	☐	☐
Helps set table	☐	☐	☐	☐	☐	☐
Opens milk box	☐	☐	☐	☐	☐	☐
Prepares sandwich or other snack	☐	☐	☐	☐	☐	☐

Comments or Suggestions

Next

Development of a Self Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

*** 3. Dressing**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Removes T-shirt, dress or sweater (pullover garment without fasteners)	☐	☐	☐	☐	☐	☐
Puts on T-shirt, dress or sweater	☐	☐	☐	☐	☐	☐
Puts on and removes front opening shirt, not including fasteners	☐	☐	☐	☐	☐	☐
Puts on and removes front opening shirt, including fasteners	☐	☐	☐	☐	☐	☐
Unbuckles belt or shoes	☐	☐	☐	☐	☐	☐
Zips and unzips with help	☐	☐	☐	☐	☐	☐
Zips and unzips without help	☐	☐	☐	☐	☐	☐
Buttons and unbuttons	☐	☐	☐	☐	☐	☐
Assists, such as pushing legs through pants	☐	☐	☐	☐	☐	☐
Removes pants with elastic waist	☐	☐	☐	☐	☐	☐
Puts on pants with elastic waist	☐	☐	☐	☐	☐	☐
Removes pants,	☐	☐	☐	☐	☐	☐

including unfastening						
Puts on pants, including fastening	☐	☐	☐	☐	☐	☐
Removes socks and unfastened shoes	☐	☐	☐	☐	☐	☐
Unties shoes	☐	☐	☐	☐	☐	☐
Puts on unfastened shoes	☐	☐	☐	☐	☐	☐
Puts on shoes or boots with help	☐	☐	☐	☐	☐	☐
Puts on socks	☐	☐	☐	☐	☐	☐
Puts on shoes on the correct feet; manages velcro fasteners	☐	☐	☐	☐	☐	☐
Ties shoelaces	☐	☐	☐	☐	☐	☐
Takes off coat when unfastened	☐	☐	☐	☐	☐	☐
Puts on gloves	☐	☐	☐	☐	☐	☐
Puts on a hat	☐	☐	☐	☐	☐	☐
Buckles belt	☐	☐	☐	☐	☐	☐
Puts belt through belt loops	☐	☐	☐	☐	☐	☐

Comments or Suggestions

*** 4. Functional Mobility associated with Dressing**

*** Functional Mobility is defined as the mobility needed to complete everyday activities**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Holds out arms and legs while being dressed	☐	☐	☐	☐	☐	☐
Finds back of clothing	☐	☐	☐	☐	☐	☐
Obtains clothing from closet or drawer	☐	☐	☐	☐	☐	☐
Folds simple clothing (Tshirts, shirts)	☐	☐	☐	☐	☐	☐

Comments or Suggestions

Prev Next

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*** 5. Washing**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Holds hands out to be washed	☐	☐	☐	☐	☐	☐
Rubs hands together to clean	☐	☐	☐	☐	☐	☐
Washes hands with soap and water with assistance	☐	☐	☐	☐	☐	☐
Washes hands with soap	☐	☐	☐	☐	☐	☐
Washes hands thoroughly	☐	☐	☐	☐	☐	☐
Dries hands with towel	☐	☐	☐	☐	☐	☐
Dries hands thoroughly	☐	☐	☐	☐	☐	☐
Wipes own face when given a cloth by an adult	☐	☐	☐	☐	☐	☐
Washes face more or less adequately (not necessarily behind ears)	☐	☐	☐	☐	☐	☐
Dries face with a towel	☐	☐	☐	☐	☐	☐
Washes body thoroughly, not including face	☐	☐	☐	☐	☐	☐
Dries body thoroughly	☐	☐	☐	☐	☐	☐

Bathes himself adequately without much supervision	☐	☐	☐	☐	☐	☐
Takes a bath or shower without help	☐	☐	☐	☐	☐	☐

Comments or Suggestions

*** 6. Functional Mobility associated with Washing**

*** Functional Mobility is defined as the mobility needed to complete everyday activities**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Sits if supported by equipment or caregiver in a tub or sink	☐	☐	☐	☐	☐	☐
sits unsupported and moves in tub	☐	☐	☐	☐	☐	☐
Climbs or scoots in and out of tub	☐	☐	☐	☐	☐	☐
Sits down and stands up from	☐	☐	☐	☐	☐	☐

inside tub						
Steps/transfers into and out of adult-sized tub	☐	☐	☐	☐	☐	☐
Obtains soap (and soaps washcloth, if used)	☐	☐	☐	☐	☐	☐

Comments or Suggestions

Prev Next

Development of a Self Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

*** 7. Toileting**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Indicates when wet in diapers or training pants	☐	☐	☐	☐	☐	☐
Occasionally indicates need to urinate (daytime)	☐	☐	☐	☐	☐	☐
Consistently indicates need to use the urinate with time to get to the toilet (daytime)	☐	☐	☐	☐	☐	☐
Takes self to the bathroom to urinate (daytime)	☐	☐	☐	☐	☐	☐
Bladder control during the day, but has to go quite often	☐	☐	☐	☐	☐	☐
"Toilet trained" with infrequent accidents	☐	☐	☐	☐	☐	☐
Consistently stays dry day and night	☐	☐	☐	☐	☐	☐
Indicates need to be changed	☐	☐	☐	☐	☐	☐
Bowel movements generally regular	☐	☐	☐	☐	☐	☐
Has established some regularity during day time and waits a	☐	☐	☐	☐	☐	☐

reasonable time before attended to						
Occasionally indicates need to use the toilet (daytime)	☐	☐	☐	☐	☐	☐
Consistently indicates the need to use the toilet with time to get to the toilet (daytime)	☐	☐	☐	☐	☐	☐
Distinguishes between the need for urination and bowel movements	☐	☐	☐	☐	☐	☐
Uses pot when placed on it	☐	☐	☐	☐	☐	☐
Tells parent or other adult when he or she needs to use the bathroom	☐	☐	☐	☐	☐	☐
Asks to go to the toilet or goes regularly without asking	☐	☐	☐	☐	☐	☐
Takes self to the bathroom for bowel movements, has no bowel accidents	☐	☐	☐	☐	☐	☐
Attends to toilet needs without help except wiping	☐	☐	☐	☐	☐	☐
Used the toilet paper and flushed the toilet	☐	☐	☐	☐	☐	☐
Cares for himself at the toilet, cleans himself and washes hands	☐	☐	☐	☐	☐	☐
Uses bathroom	☐	☐	☐	☐	☐	☐

without help						

Comments or Suggestions

*** 8. Functional Mobility associated with Toileting**

*** Functional Mobility is defined as the mobility needed to complete everyday activities**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Sits if supported by equipment or caregiver						
Sits unsupported on toilet or potty chair						
Gets on and off low toilet or potty						
Gets on and off adult-sized toilet						
Gets on and off toilet, not needing own arms						
Assists with clothing						

management

Tries to wipe self after toileting	☐	☐	☐	☐	☐	☐
Manages toilet seat, gets toilet paper and flushes toilet	☐	☐	☐	☐	☐	☐
Manages clothes before and after toileting	☐	☐	☐	☐	☐	☐
Wipes self thoroughly after bowel movements	☐	☐	☐	☐	☐	☐

Comments or Suggestions

Prev Next

*** 9. Grooming**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Holds head in position while hair is combed	☐	☐	☐	☐	☐	☐
Brings brush or comb to hair	☐	☐	☐	☐	☐	☐
Brushes or combs hair	☐	☐	☐	☐	☐	☐
Washes his or her own hair	☐	☐	☐	☐	☐	☐
Allows nose to be wiped	☐	☐	☐	☐	☐	☐
Blows nose into held tissue	☐	☐	☐	☐	☐	☐
Wipes nose using tissue on request	☐	☐	☐	☐	☐	☐
Wipes nose using tissue without request	☐	☐	☐	☐	☐	☐
Blows and wipes nose without request	☐	☐	☐	☐	☐	☐
Opens mouth for teeth to be brushed	☐	☐	☐	☐	☐	☐
Brushes own teeth with little fussing when told by an adult	☐	☐	☐	☐	☐	☐
Brushes teeth; but not a thorough job	☐	☐	☐	☐	☐	☐

Thoroughly brushes teeth	☐	☐	☐	☐	☐	☐
Brushes teeth regularly	☐	☐	☐	☐	☐	☐

Comments or Suggestions

*** 10. Functional Mobility Associated with Grooming**

*** Functional Mobility is defined as the mobility needed to complete everyday activities**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Puts toothpaste on toothbrush	☐	☐	☐	☐	☐	☐
Holds toothbrush	☐	☐	☐	☐	☐	☐

Comments or Suggestions

Prev Next

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*** 11. Sleeping**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Sleeps through most of the night, waking no more than one or two times	☐	☐	☐	☐	☐	☐
Sleeps through the entire night without waking	☐	☐	☐	☐	☐	☐
Goes to bed with few or no complaints	☐	☐	☐	☐	☐	☐

Comments or Suggestionsp

*** 12. Functional Mobility Associated with Sleeping**

*** Functional Mobility is defined as the mobility needed to complete everyday activities**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Raises to a sitting position in bed or crib	☐	☐	☐	☐	☐	☐
Comes to sit at edge of bed; lies down from sitting at edge of bed	☐	☐	☐	☐	☐	☐
Got in and out of bed	☐	☐	☐	☐	☐	☐

Comments or Suggestions

Prev Next

*** 13. General Functional Mobility**

*** Functional Mobility is defined as the mobility needed to complete everyday activities**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Changes physical location purposefully	☐	☐	☐	☐	☐	☐
Moves objects along the floor	☐	☐	☐	☐	☐	☐
Carries objects small enough to be held in one hand	☐	☐	☐	☐	☐	☐
Carries objects large enough to require two hands	☐	☐	☐	☐	☐	☐
Reaches out and grasps an object placed nearby	☐	☐	☐	☐	☐	☐
Moves an object back and forth from one hand to another	☐	☐	☐	☐	☐	☐
Reaches for objects by leaning forward	☐	☐	☐	☐	☐	☐
Stands on Tip toes to reach objects	☐	☐	☐	☐	☐	☐
Stretched to reach a high shelf	☐	☐	☐	☐	☐	☐
Picked up things from the floor	☐	☐	☐	☐	☐	☐
Looks for fallen	☐	☐	☐	☐	☐	☐

objects by bending over						
Carried my backpack	☐	☐	☐	☐	☐	☐

Prev Next

Development of a Self Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

*** 14. Scoring**

	Relevant	Ambiguous	Simple	Clear	Edit wording	Discard
Not applicable - 0 (For items past developmental level)	☐	☐	☐	☐	☐	☐
Child is unable to do the task at all: 1	☐	☐	☐	☐	☐	☐
Child is able to do the task, but needs a lot of help: 2 (From caregiver, environmental support, adaptations to environment such as standing frame, chair, walker)	☐	☐	☐	☐	☐	☐
Child is almost able to the task but needs a little bit of help: 3 (Such as built up spoon, modified Velcro fastenings, universal cuff)	☐	☐	☐	☐	☐	☐
Child is able to do the task without any help: 4	☐	☐	☐	☐	☐	☐

Comments or Suggestions

Prev Next

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15. Are there any items that you feel should be added? Please explain.

Prev Done

Appendix C: Tools used for Field Testing

Tools needed	Domain used for	Items used for
Cup	Eating	- Lifts cup to drink - Drinks from a cup without help - Pours a cup of juice - Reaches for a cup - Picks up and replaces cup upright on the table - Carries a cup of juice without spilling
Spoon	Eating	- Feeds entire meal with spoon - Takes spoon filled with food to mouth - Stirs with a spoon - Returns spoon to bowl
Knife	Eating	- Uses a knife for "spreading" butter, jam etc. - Cuts soft foods with knife (banana, baked potato) - Cuts meat or other food into bite-sized pieces - Prepares sandwich or other snack
Juice	Eating	- Swallows liquids without coughing - Picks up bottle and drinks independently - Pours himself or herself a glass or cup of juice - Carries cup filled with juice without spilling - Opens milk or juice box
Naartjie	Eating	- Peels 3 foods (banana, naartjie, boiled egg)
Banana	Eating	- Peels 3 foods (banana, naartjie, boiled egg) - Cuts soft foods with knife (banana, baked potato) - Chews solid food - Bites off piece of food
Yoghurt	Eating	- Eats smooth soft foods - Takes spoon filled with food to mouth - Licks food from around mouth
Boiled eggs	Eating	- Peels 3 foods (banana, naartjie, boiled egg) - Prepares sandwich or other snack
Bread	Eating	- Prepares sandwich or other snack - Uses a knife for "spreading" butter, jam etc. - Cuts meat or other food into bite-sized pieces
Margarine	Eating	- Prepares sandwich or other snack - Uses a knife for "spreading" butter, jam etc.

Serviettes	Eating	- Cleans up spills, getting own cloth
Shoes (laces and Velcro fastening)	Dressing	- Removes socks and unfastened shoes - Puts on unfastened shoes - Unties shoes - Puts shoes on the correct feet - Manages Velcro fasteners - Ties shoelaces
T-shirt	Dressing	- Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners) - Puts on loose T-shirt, dress or jersey - Finds back of clothing - Folds simple clothing (T-Shirts, shirts)
Button up shirt	Dressing	- Puts on and removes a front opening shirt, not including fasteners - Puts on and removes front opening shirt, including fasteners - Buttons and unbuttons
Pants (with elastic waist and zip and button)	Dressing	- Removes pants with elastic waist - Puts on pants with elastic waist - Removes pants including unfastening - Puts on pants, including fastening - Zips and unzips without help
Jacket	Dressing	- Takes off Jacket when unfastened
Hat	Dressing	- Puts on a hat
Gloves	Dressing	- Puts on gloves
Belt	Dressing	- Unbuckles belt - Buckles belt - Puts belt through belt loops
Socks	Dressing	- Removed socks and unfastened shoes - Puts on socks
Tissues	Grooming	- Allows nose to be wiped - Blows nose into held tissue - Wipes nose using tissue on request - Blows and wipes nose without request
Face cloth	Washing, Grooming	- Wipes own face when given a cloth by an adult - Washes face more or less adequately (not necessarily behind ears) - Washes body thoroughly, not including face
Wash basin	Washing	- Washes using the basin without help - Sits if supported by equipment or caregiver in a tub or basin - Sits unsupported and moves in the

		basin - Climbs or slides on his or her bottom in and out of the basin - Sits down and stands up from inside the basin - Fills up a basin with water for washing - Empties basin after washing, cleans the basin
Hand towel	Washing	- Dries body thoroughly - Dries face with a towel - Dries hands with towel
Soap	Washing	- Obtains soap (and soaps washcloth, if used) - Washes hands with soap
Comb	Grooming	- Brushes or combs hair - Holds head in place while hair is combed
Brush	Grooming	- Brushes or combs hair - Holds head in place while hair is combed
Tooth brush	Grooming	- Opens mouth for teeth to be brushed - Thoroughly brushes teeth - Holds toothbrush - Puts toothpaste on toothbrush
Tooth paste	Grooming	- Puts toothpaste on toothbrush
Adult sized toilet	Toileting	- Sits if supported by equipment or caregiver - Gets on and off adult sized toilet - Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet - Uses toilet without help
Potty or Chamber pot	Toileting	- Uses potty/chamber pot when placed on it - Sits if supported by equipment or caregiver - Sits unsupported on potty chair - Gets on and off potty
Toilet Paper	Toileting	- Uses the toilet paper and throws it into the toilet - Gets toilet paper - Wipes self thoroughly after bowel movements
Toy car	Functional mobility	- Reaches out and grasps an object placed nearby - Reaches for objects by leaning forward - Moves an object back and forth from one hand to another - Moves objects along the floor - Carries objects small enough to be held in one hand

		- Picks up things from the floor
Ball	Functional mobility	- Carries objects large enough to require two hands

Appendix D: Items observed

	Eating Items	**Observed**	**Not Observed**	**Reason for not observing**
2	**Ugwinya uketshezi ngaphandle khwehlela;** Swallows liquids without coughing	✓		
3	**Udla ukudla okubushelelezi okuthambile;** Eats smooth soft foods	✓		
4	**Udla ukudla okugayiwe/izigaxa;** Eats ground/lumpy foods	✓		
5	**Usebenzisa iminwe uma edla, kodwa akahlafuni;** Uses fingers for eating, but does not chew	✓		
6	**Uyaliluma iqhuzwana lokudla;** Bites off piece of food	✓		
7	**Uphakamisa ibhodlela bese eziphuzela engasizwa muntu;** Picks up bottle and drinks independently	✓		
8	**Uphakamisa inkomishi khona ezophuza, kodwa kungenzeka inkomishi iwe;** Lifts cup to drink, but cup may tip	✓		
9	**Uyakuhlafuna ukudla okuqinileyo;** Chews solid food	✓		
10	**Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe;** Feeds crackers, carrot sticks or other finger foods	✓		
11	**Udla ukudla okusikiwe kwaba yizicucwana/izigaxana/amadayisana;** Eats cut up/chunky/diced foods	✓		
13	**Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni;** Takes spoon filled with food to mouth	✓		
14	**Uphuza ngenkomishi ngaphandle kosizo;** Drinks from a cup without help	✓		

16	**Uyakukhotha ukudla okuzungeze umlomo;** Licks food from around mouth	✓		
17	**Uzithelela yena uqobo ingilazi noma inkomishi yejusi;** Pours himself or herself a glass or cup of juice	✓		
18	**Uhluba ukudla oku-3 (ubhanana, inantshi, neqanda elibilisiweyo);** Peels 3 foods (banana, naartjie, boiled egg)	✓		Observed one food
19	**Usebenzia ummese khona "ezogcoba" ibhotela, ujamu njll;** Uses a knife for "spreading" butter, jam etc.	✓		
20	**Usika ukudla okuthambile ngommese (ubhanana, izambane elibhakiweyo);** Cuts soft foods with knife (banana, baked potato)	✓		
21	**Usika inyama noma okunye ukudla kube izingcucwana ezizolumeka;** Cuts meat or other food into bite-sized pieces	✓		
22	**Uzidlela konke ukudla esebenzisa isipuni kanye;** Feeds self entire meal using spoon	✓		
	Functional mobility associated with Eating			
1	**Ufinyelela ebhodleleni noma enkomishini;** Reaches for bottle or cup	✓		
2	**Uyalugoqoza uketshezi ngesipuni;** Stirs liquid with a spoon	✓		
3	**Uyasula lapho kuchitheke khona, azithathele indwangu yakhe;** Cleans up spills, getting own cloth	✓		
4	**Uphathe ipuleti elinokudla ngaphandle kokuchitha, waliyise etafuleni;** Carries a plate with food on it without spilling, to the table	✓		
5	**Uyazelula ukuze afinyelele eshalofini eliphezulu;** Stretches to reach a high shelf	✓		
6	**Ubuyisela isipuni endishini;** Returns spoon to bowl	✓		

7	**Uyayiphakamisa futhi ayibuyisele inkomishi ihlale iqonde etafuleni;** Picks up and replaces cup upright on the table	✓		
8	**Uphatha inkomishi egcwaliswe ujusi ngaphandle kokuchitheka;** Carries cup filled with juice without spilling	✓		
9	**Uyalivula ibhokisi lobisi okanye lejusi;** Opens milk or juice box	✓		
10	**Ulungisa isemeshi noma esinye isinekhi;** Prepares sandwich or other snack	✓		

	Dressing			
1	**Uyazikhumula amasokisi kanye nezicathulo ezingafaswa;** Removes socks and unfastened shoes	✓		
2	**Uyazifaka izicathulo ezingafaswa;** Puts on unfastened shoes	✓		
3	**Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa);** Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners)	✓		
4	**Uyazigqokisa isikibha,ingubo noma ijezi okuxegayo;** Puts on loose T-shirt, dress or jersey	✓		
5	**Uyazikhumula ibhulukwe elinelastiki okhalo;** Removes pants with elastic waist	✓		
6	**Uyaziqaqa izintambo zezicathulo;** Unties shoes	✓		
7	**Uyazikhumula ibhantshi uma lingafasiwe;** Takes off Jacket when unfastened	✓		
8	**Uyazigqokisa isigqoko;** Puts on a hat	✓		
9	**Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa;** Puts on and removes a front opening shirt, not including fasteners	✓		

10	**Uyazigqokisa noma azikhumule ihembe elivuleka ngaphambili, okuhlanganisa okokufasa;** Puts on and removes front opening shirt, including fasteners	✓		
11	**Uyazigqokisa ibhulukwe elinelastiki okhalo;** Puts on pants with elastic waist	✓		
12	**Uyazikhumula ibhulukwe, elinga fasiwe;** Removes pants including unfastening	✓		
13	**Uyalikhumula ibhande;** Unbuckles belt	✓		
14	**Uyazigqokisa ibhulukwe , okuhlanganisa ukulifasa;** Puts on pants, including fastening	✓		
15	**Uyazigqokisa amasokisi;** Puts on socks	✓		
16	**Uyazigqokisa izicathulo onyaweni okuyilo;** Puts shoes on the correct feet	✓		
17	**Asebenzise kahle okokokufasa ukungamavelikho;** Manages Velcro fasteners	✓		
18	**Uyazibopha ibhande;** Buckles belt	✓		
19	**Uyazifasa izinkinobho abuye aziqaqe izinkinobho;** Buttons and unbuttons	✓		
20	**Uyazibopha izintambo zezicathulo;** Ties shoelaces	✓		
21	**Uyazigqokisa ibhande alifake emalupheni;** Puts belt through belt loops	✓		
22	**Uyazifasa abuye aqaqe uziphu, engasizwa;** Zips and unzips without help	✓		
23	**Uyazigqokisa amagilavu;** Puts on gloves	✓		

	Functional Mobility Associated with Dressing			
4	**Uyalibona ingemuva lezingubo;** Finds back of clothing	✓		
5	**Uyazigoqa izingubo ezilula (izikipha, amahembe);** Folds simple clothing (T-Shirts, shirts)	✓		

	Washing Items			
1	**Uyazihlikihla izandla zombili khona ezozihlanza;** Rubs hands together to clean	✓		
2	**Uyazesula ubuso bakhe uma enikezwe indwangu ngumuntu omdala;** Wipes own face when given a cloth by an adult	✓		
3	**Uyazigeza izandla ngensipho;** Washes hands with soap	✓		
4	**Uyazigezisisa kahle izandla;** Washes hands thoroughly	✓		
5	**Uyazesula izandla ngethawula;** Dries hands with towel	✓		
6	**Uyazigeza ubuso cishe ngokwanele (kodwa hhayi ngemuva kwezindebe);** Washes face more or less adequately (not necessarily behind ears)	✓		
7	**Uyabomisa ubuso ngethawula;** Dries face with a towel	✓		
8	**Uyawugezisisa kahle umzimba, ungabuhlanganisi ubuso;** Washes body thoroughly, not including face		✓	**Time**
9	**Uyawomisisa kahle umzimba;** Dries body thoroughly		✓	**Time**
10	**Uyazigeza umzimba wonke kahle engasizwa;** Washes using the basin without help		✓	**Time**

	Functional Mobiliy Associated with Washing			
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli ebhavini noma endishini;** Sits if supported by equipment or caregiver in a tub or basin	✓		
2	**Uyazihlalela engasekeliwe futhi anyakaze kubhavu;** Sits unsupported and moves in the basin	✓		
3	**Uyazilula izandla khona zizogezwa;** Holds hands out to be washed	✓		
4	**Uyazigibelela noma azishushuluzela ngezinqe engena noma ephuma kubhavu;** Climbs or slides on his or her bottom in and out of the basin	✓		
5	**Uyazihlalela phansi abuye azisukumele ephakathi endishini;** Sits down and stands up from inside the basin	✓		
6	**Uyazitholela insipho (kanye nendwangu yensipho, uma isetshenziswa);** Obtains soap (and soaps washcloth, if used)	✓		
7	**Uyazithathela amanzi endishini ukuze ageze;** Fill up a basin with water for washing		✓	**Time; Waste of resources**
8	**Uyazichithela amanzi endishini emuva kokugeza, ayihlanze endishi;** Empties basin after washing, cleans the basin		✓	**Time**

	Toileting Items			
2	**Uyalisebenzisa ipowa uma ebekwe kulo;** Uses potty/chamber pot when placed on it	✓		
14	**Uyakwenza adinga ukukwenza ethoyilethi engasizwa ngaphandle uma esedinga ukusulwa izinqe;** Attends to toilet needs without help, except wiping	✓		
15	**Ulisebenzisile iphepha eliwulwelwesi lasethoyilethi futhi waliphonsa ethoyilethi walishaya lahamba;** Uses the toilet paper and throws it into the toilet	✓		
16	**Uyazinakekela uma esethoyilethi, azisule kahle futhi ageze nezandla;** Cares for self at the toilet, cleans self and washes hands	✓		

17	**Uyalisebenzisa ithoyilethi ngaphandle kosizo;** Uses toilet without help	✓		
	Functional mobility associated with Toileting			
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli;** Sits if supported by equipment or caregiver	✓		
2	**Uyazihlalela engasekeliwe noma esihlalweni esinepowa;** Sits unsupported on potty chair	✓		
3	**Uyakwazi ukuzihlalela abuye azisukumele elifushane noma epoweni;** Gets on and off potty	✓		
4	**Uyakwazi ukuzihlalela abuye azisukumele labantu abadala;** Gets on and off adult sized toilet	✓		
5	**Uya kwazi ukuzi thathela iphepha lasethwayelethi;** Gets toilet paper	✓		
6	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to undo clothing fastenings, pulling down pants and underpants	✓		
7	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to pull pants and underpants back up and redo fastenings	✓		
8	**Uyazisulisisa kahle emuva kokukaka;** Wipes self thoroughly after bowel movements	✓		
9	**Uyakwazi ukuzihlalela abuye azisukele ethoyilethi, angadingi ukusebenzisa izingalo zakhe ukuze zimesekele uma ethwayiletile;** Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet	✓		

	Grooming Items			
1	**Uyawuvula umlomo khona uzomxubha amazinyo;** Opens mouth for teeth to be brushed	✓		

2	**Uyavuma ukusulwa amafinyila;** Allows nose to be wiped	✓		
3	**Uyafinya ebanjelwe ulwelwesana lwephepha;** Blows nose into held tissue	✓		
4	**Uyazisula amafinyila esebenzisa ulwelwesana lwephepha uma eceliwe;** Wipes nose using tissue on request	✓		
5	**Uyazibhulasha noma azikame izinwele;** Brushes or combs hair	✓		
7	**Uyaliqinisa ikhanda lime kahle ngesikhathi umkama izinwele;** Holds head in place while hair is combed	✓		
8	**Uyazigeza izinwele zakhe;** Washes his or her own hair		✓	**Time**
9	**Uyazifinyisa futhi azisule amafinyila ngaphandle kokucelwa;** Blows and wipes nose without request	✓		
10	**Uyazixubhisisa kahle amazinyo;** Thoroughly brushes teeth	✓		
	Functional Mobility Associated with Grooming			
1	**Uyasibamba isixubho;** Holds toothbrush	✓		
2	**Uyawufaka umuthi wokuxubha esixubheni;** Puts toothpaste on toothbrush	✓		

	Sleeping Items			
	Functional Mobility Associated with Sleeping			
1	**Uyaphakama ahlale embhedeni noma;** Raises to a sitting position in bed	✓		
2	**Alale phansi emuva kokuhlala osebeni lombhede;** Lies down from sitting at the edge of bed	✓		

3	**Uyazingenela futhi aziphumele embhedeni;** Gets in and out of bed	✓		

	General Functional mobility Items			
1	**Uyeluleka abambe into ebekwe eduzane;** Reaches out and grasps an object placed nearby	✓		
2	**Uyeluleka athathe izinto ngokugoba aye phambili;** Reaches for objects by leaning forward	✓		
3	**Uyayinyakazisa into ayiyise emuva naphambili esebenzisa isandla esisodwa ayiyise kwesinye;** Moves an object back and forth from one hand to another	✓		
4	**Uyazihudula izinto phansi;** Moves objects along the floor	✓		
5	**Ukuphatha izinto ezinkulu ngokwanele ezidinga ukuphathwa ngezandla ezimbili;** Carries objects large enough to require two hands	✓		
6	**Ukuphatha izinto ezincane ngokwanele eziphatheka ngesandla esisodwa;** Carries objects small enough to be held in one hand	✓		
7	**Uyacokama ukuze afinyelele ezintweni;** Stands on tip toes to reach objects	✓		
8	**Uyazicosha izinto phansi;** Picks up things from the floor	✓		
9	**Uyakuhlafuna ukudla okuqinileyo;** Chews solid food	✓		
10	**Uyaziphatha izinto ezichobokayo noma ezichithekayo;** Carries fragile or spillable objects	✓		

Appendix E: Ethical Clearance Certificate and Amendments

Amendments to ethics committee submission

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Miss Julia Burg

CLEARANCE CERTIFICATE	**M120361**
PROJECT	Validation of a Revised Version of the Paediatric Evaluation of Disability Inventory (PEDI) for Children with Cerbral Palsy Living in Poorly Resourced Contexts in south Africa
INVESTIGATORS	Miss Julia Burg.
DEPARTMENT	Department of Occupational Therapy
DATE CONSIDERED	30/03/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

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

DATE 29/06/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Denise Franszen

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementi 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...

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Academic & Research)

MEMORANDUM

TO: **Ms Julia Burg**
Department of Occupational Therapy
EMAIL: js.burg@yahoo.com

FROM: Ms Anisa Keshav
Secretary: Human Research Ethics Committee (Medical)
Tel 717-1234 fax 011 717 1265
e-mail: anisa.keshav@wits.ac.za

DATE: 13 June 2012

REF: ***R14/49***

The protocol below was considered at a meeting of the Human Research Ethics Committee (Medical**) on Friday30 March 2012. Below please see the Committee's decision:**

M120361
Validation of a Revised Version of the Paediatric Evaluation of Disability Inventory (PEDI) for Children with Cerebral Palsy Living in Poorly Resourced Contexts in South Africa

Approved subject to:

- In the information sheet:
  - rather say "should you have any queries or concerns regarding you or your child's rights as research participants you may contact …"

  -Indicate that the photographs will only be used by the researcher and are not for public viewing

Please submit the above so I may issue your clearance certificate.

Please highlight any changes made and send two hard copies to this office.

Changes for ethics

In the information sheet:
- rather say "should you have any queries or concerns regarding you or your child's rights as research participants you may contact …"
  - This has been changed

-Indicate that the photographs will only be used by the researcher and are not for public viewing
  - This has been added

Please note that one change has had to be made to the study.

As permission to translate the PEDI was declined, the researcher will develop a new assessment tool. This will be done using existing assessment tools as well as expert opinion but the overall study will not change.

2. Changes made to information sheet of consent forms

1. **CONSENT FOR DISCUSSION GROUPS**
   RESEARCH

Validation of a Test of Disability in Paediatrics for children with cerebral palsy living in poorly resourced contexts in South Africa

CAREGIVER INFORMATION SHEET FOR DISCUSSION GROUPS

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

Good day parent / caregiver

Thank you for taking the time to read and listen to this information. My name is Julia Burg and I am an Occupational Therapist. I am 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.

By taking part, we mean that we are asking you to agree to be interviewed together with a group of other mothers and caregivers. We are interested in learning about how an assessment tool called the Test of Disability in Paediatrics, can be used in South Africa. This test was looks at different activities that a child can do at different ages within his life and helps to give the therapist an indication of whether the child is participating in daily activities at an age appropriate level or not. Before we can use it in South Africa, we need to see which parts of it are appropriate to use within our setting. We need to see if all of these activities are ones that South African children also partake in.

Each discussion will take about 90 minutes. All information shared within this group will be kept private. No names will be recorded on forms. It will only be shared with researchers of this study. The tapes will be destroyed two years after we have written about the results of the study.

If you do not want to be part of this discussion group, you do not have to. If you do decide to join the discussion group, and then you change your mind, you can do so at any time without any consequences for you or your child.

Should you have any queries or concerns regarding you or your child's rights as research participants you may contact me at 082-874 9443or the chairperson of the Human Research Ethics Committee- Prof P Cleaton –Jones at 0117171234 or anisa.keshav@wits.ac.za

Thank you for your help.
Julia Burg
Occupational Therapist
082-874 9443

RESEARCH

Validation of a Test of Disability in Paediatrics for children with cerebral palsy living in poorly resourced contexts in South Africa

WRITTEN CAREGIVER INFORMED CONSENT FORM

Date: _____

I, _____,
confirm that I have been told about the research in a language that I understand. 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 take myself out of the study. I understand that if I decide not to take part, or I change my mind, nothing will happen to me. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.

I agree that I will volunteer to take part in this study.

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

Parent's / Caregiver's signature: _____

Interviewer's name: _____ (please print)

Interviewer's signature: _____

2. CONSENT TO PARTICIPATE WITHIN COMPARATIVE STUDY (PART2): RESEARCH

Validation of a Test of Disability in Paediatrics for children with cerebral palsy living in poorly resourced contexts in South Africa

CAREGIVER INFORMATION SHEET FOR COMPARATIVE STUDY

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

Good day parent / caregiver

Thank you for taking the time to read and listen to this information. My name is Julia Burg and I am an Occupational Therapist. I am doing some research and I would like to invite you to volunteer yourself and your child 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.

By taking part, we mean that we are asking you to agree to be interviewed by me. During the interview, I will be asking you questions that form part of an assessment tool called the Test of Disability in Paediatrics. These questions relate to your child and what he/she can do for himself or herself in terms of self-care, mobility and social interaction. We will also look at how must assistance your child requires from you and what types of equipment or assistive devices he/she is using on a day-to-day basis.

The Test of Disability in Paediatrics looks at different activities that a child can do at different ages within his life. The Test of Disability in Paediatrics helps to give the therapist an indication of whether the child is participating in daily activities at an age appropriate level or not. The Test of Disability in Paediatrics will be translated into isiZulu and culturally adapted.

The interview will take about 2 hours. Photographs may be taken during the interview. All information shared will be kept private. No names will be recorded on forms. It will only be shared with researchers of this study. All photographs will be used by the researcher only, and will not be for public use.

If you do not want to be part of this study, you do not have to. If you do decide to participate in the study, and then you change your mind, you can do so at any time without any consequences for you or your child.

Should you have any queries or concerns regarding you or your child's rights as research participants you may contact me at 082-874 9443or the chairperson of the Human Research Ethics Committee- Prof P Cleaton –Jones at 0117171234 or anisa.keshav@wits.ac.za.

Thank you for your help.
Julia Burg
Occupational Therapist
082-874 9443

RESEARCH

Validation of a Test of Disability in Paediatrics for children with cerebral palsy living in poorly resourced contexts in South Africa

COMPARATIVE STUDY

WRITTEN CAREGIVER INFORMED CONSENT FORM

Date: _____

I, _____,
Caregiver/Mother/Father of_____
confirm that I have been told about the research in a language that I understand. 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 take myself and my child out of the study. I understand that if I decide not to take part, or I change my mind, nothing will happen to me or 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.

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

Parent's / Caregiver's signature: _____

Interviewer's name: _____ (please print)

Interviewer's signature: _____

RESEARCH

Validation of a Test of Disability in Paediatrics for children with cerebral palsy living in poorly resourced contexts in South Africa

COMPARATIVE STUDY

WRITTEN CAREGIVER INFORMED CONSENT FORM FOR PHOTOGRAPHS/VIDEO

Date: _____

I, _____,
Caregiver/Mother/Father of_____
give consent/do not give consent (circle appropriate response) for Julia Burg to take photographs and/or videos for the purposes of her study.

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

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

Parent's / Caregiver's signature: _____

Interviewer's name: _____
(please print)

Interviewer's signature: _____

Appendix F: Expert Occupational Therapist consent for participation in survey

RESEARCH

Development of a Self-Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

INFORMATION SHEET FOR SURVEY

Good day

My name is Julia Burg and I am an occupational therapist completing a postgraduate degree at the University of the Witwatersrand. I am researching what activities children do to help care for themselves and how they do these. This includes aspects like dressing, washing and eating. I am interested in learning about how children in South Africa do these activities so we can develop a new assessment tool to be used with South African children with cerebral palsy.

I am inviting you to take part in this study, because you have experience with working with children. 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 am asking that you complete this survey, which should take you approximately 30 minutes to complete. Informed consent will be assumed if you complete the survey and submit it.

By using the Survey Monkey server (www.surveymonkey.com) the information can be gathered anonymously. The information gathered will be stored in a safe place and will be destroyed after six years or publication of the study according to HPCSA regulations, after we have written about the results of the study.

Participation is voluntary if you do decide to answer the survey. There will be no consequences if you do decide to withdraw at any stage.

The survey consists of items relating to self-care tasks of eating, dressing, washing, toileting, grooming and sleeping. Please analyze each item in terms of their relevance to typically developing children in any society. You can also analyze the item in terms on clarity, simplicity and ambiguity. Please indicate if you feel that the item's wording needs to be reviewed or if the item should be discarded. There is space following each question for you to add any comments, suggestions or explanations as you feel are necessary.

Please click on the following link to be directed to the survey. Please ensure that you have a good internet connection for the duration of the survey.
https://www.surveymonkey.com/s/selfcareitems

Feedback on the study will be available on request.

If you have any questions, please feel free to contact me at 082-874 9443 or js.burg@yahoo.com. Any queries or concerns about ethics can be discussed with the Chairman of the Ethics Committee at the University of the Witwatersrand, Prof P Cleaton-Jones who can be contacted at 011 7171234.

Julia Burg
Occupational Therapist

Appendix G: Discussion Group Consent to Participate

CONSENT FOR DISCUSSION GROUPS
RESEARCH

Development of a Self-Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

CAREGIVER INFORMATION SHEET FOR DISCUSSION GROUPS

(To be read to the caregiver of the child in his or her own home language)

Good day

My name is Julia Burg and I am an occupational therapist completing a postgraduate degree at the University of the Witwatersrand. I am researching what activities children do to help care for themselves and how they do these. This includes aspects like dressing, washing and eating. I am interested in learning about how children in South Africa do these activities so we can develop an assessment tool to be used with children with cerebral palsy for use in this country.

I would like to invite you 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.

If you agree to participate you will be included in a discussion group together with other mothers and caregivers to discuss all of the activities your children do and how they do it. Each discussion will take about 90 minutes. I am also asking that you give permission for the discussion groups to be taped.

All information shared within this group cannot be kept confidential or private but your name will not be used in any written documents. The tapes and information will be stored in a safe place and will be destroyed after six years or publication of the study according to HPCSA regulations, after we have written about the results of the study.

Participation is voluntary and if you do decide to join the discussion group, and you change your mind you can leave at any time without any consequences for yourself.

Feedback on the study will be available on request.

If you have any questions, please feel free to contact me at 082-874 9443. Any queries or concerns about ethics can be discussed with the Chairman of the Ethics Committee at the University of the Witwatersrand, Prof P Cleaton-Jones who can be contacted at 011 7171234.

If you agree to take part in this study, please sign the forms attached.
Julia Burg
Occupational Therapist

RESEARCH

Development of a Self-Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

CAREGIVER
WRITTEN INFORMED CONSENT FORM

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

I am aware that any information I give to the researcher cannot be kept private because it is collected in a group situation and all the results will be anonymously processed.

I understand that at any stage, I may take myself out of the study. I understand that if I decide not to take part, or I change my mind, there will be no consequences for me. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.

I agree that I will volunteer to take part in this study.

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

Parent's / Caregiver's signature: _____

Interviewer's name: _____
(please print)

Interviewer's signature: _____

Date: _____

Recording consent form

RESEARCH

Validation of a revised version of the Pediatric Evaluation of Disability Inventory (PEDI) for children with cerebral palsy living in poorly resourced contexts in South Africa

CAREGIVER
PERMISSION TO AUDIO TAPE DISCUSSION GROUPS

I, _____, give permission for the taping of the discussion group which I have agreed to participate in

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

Parent's / Caregiver's signature: _____

Date: _____

Appendix H: Consent Form for Field Test

RESEARCH

Development of a Self-Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

CAREGIVER INFORMATION SHEET FOR PILOT STUDY

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

Good day parent / caregiver

Thank you for taking the time to read and listen to this information. My name is Julia Burg and I am an Occupational Therapist. I am doing some research and I would like to invite you to volunteer yourself and your child 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.

By taking part, we mean that we are asking you to agree to be interviewed by me. During the interview, I will be asking you questions that form part of an assessment tool which I am developing. These questions relate to your child and what he/she can do for himself or herself in terms of washing, dressing, eating and grooming. We will also look at how must assistance your child requires from you and what types of equipment or assistive devices he/she is using on a day-to-day basis.

The interview will take about 2 hours. Photographs may be taken during the interview. All information shared will be kept private. No names will be recorded on forms. It will only be shared with researchers of this study. All photographs will be used by the researcher only, and will not be for public use.

If you do not want to be part of this study, you do not have to. If you do decide to participate in the study, and then you change your mind, you can do so at any time without any consequences for you or your child.

Should you have any queries or concerns regarding you or your child's rights as research participants you may contact me.

Thank you for your help.
Julia Burg
Occupational Therapist
082-874 9443

RESEARCH

Development of a Self-Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

PILOT STUDY

WRITTEN CAREGIVER INFORMED CONSENT FORM

Date: _____

I, _____,
Caregiver/Mother/Father of _____
confirm that I have been told about the research in a language that I understand. 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 take myself and my child out of the study. I understand that if I decide not to take part, or I change my mind, nothing will happen to me or 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.

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

Parent's / Caregiver's signature: _____

Interviewer's name: _____
(please print)

Interviewer's signature: _____

RESEARCH

Development of a Self-Care Questionnaire for children with cerebral palsy living in poorly resourced contexts in South Africa

PILOT STUDY

WRITTEN CAREGIVER INFORMED CONSENT FORM FOR PHOTOGRAPHS/VIDEO

Date: _____

I, _____, Caregiver/Mother/Father of_____ give consent/do not give consent (circle appropriate response) for Julia Burg to take photographs and/or videos for the purposes of her study.

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

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

Parent's / Caregiver's signature: _____

Interviewer's name: _____ (please print)

Interviewer's signature: _____

Appendix I: Items prior to ICF Mapping

Key:

- Pediatric Evaluation of Disability Inventory (PEDI)
- Functional Independence Measure for Children (WeeFIM)
- Bayley Scales of Infant and Toddler Development (Adaptive behaviour)
- Life skills inventory
- Activities for Kids (ASK)
- Primary Progress Assessment Chart of Social Development
- Oregon Project for Visually Impaired and Blind Preschool Children

Eating

- Eats pureed/blended/strained foods
- Eats ground/lumpy foods
- Eats cut up/chunky/diced foods
- Eats all textures of table food
- Finger feeds
- Scoops with a spoon and brings to the mouth
- Uses a spoon well
- Uses a fork well
- Uses a knife to butter bread, cuts soft foods
- Holds bottle or spout cup
- Lifts cup to drink, but cup may tip
- Lifts open cup securely with two hands
- Lifts open cup securely with one hand
- Pours liquid from carton or pitcher
- Holds a cup by himself/herself and sips from it. (Note: any cup is acceptable)
- Scoops food with a spoon and tastes it
- Eating includes the use of suitable utensils to bring food and liquid to mouth, chewing and swallowing, once meal has been presented in the customary manner on a table or tray
- Swallows liquids with no difficulty
- Nurses, drinks or eats willingly with no encouragement
- Swallows soft, strained or mashed food (e.g. Baby food or applesauce)
- Opens mouth when offered food on a spoon
- Feeds himself or herself crackers, cookies, dry cereal or other finger foods
- Drinks from a cup or glass, even if another person must hold it
- Holds and drinks from a sipping cup
- Cuts meat or other food into bite size pieces
- Ate my meals (used a knife & fork)
- Used my finger to eat small foods
- Sucks food well
- Shows recognition of food
- Puckers mouth for food
- Takes semi-solids from spoon
- Uses fingers for eating, but does not chew
- Rubs spoon across plate - puts it to mouth for licking

- Chews biscuits, rusks etc.
- Uses spoon (may spill some food)
- Drinks from cup unaided without spilling and holds it
- Eats unaided
- Uses a fork without difficulty (food can be cut and prepared)
- Capable of taking a drink by himself without help
- Uses spoon when eating without requiring help
- Drinks without spilling, holding glass in one hand
- Uses a fork without difficulty (food can be cut and prepared)
- Capable of taking a drink by himself without help
- Serves himself and eats without requiring much help
- Uses a knife for "spreading" butter, jam etc.
- Uses table knife for "cutting" without much difficulty
- Eats with a knife and fork, requires no help
- Pours liquids (tea or coffee) from a pot
- Uses a knife for peeling fruit
- Sucks and swallows liquid
- Opens mouth for breast, bottle or spoon
- Turns head toward nipple when cheek is touched
- Swallows liquefied foods fed with a spoon
- Mouths blended or strained foods fed with a spoon
- Picks up bottle and drinks independently
- Chews mashed table foods fed with a spoon
- Drinks from a cup (child's hands on cup) with help
- Bites off piece of food
- Feeds self with fingers
- Chews solid foods
- Holds and drinks from cup using two hands
- Takes spoon filled with food to mouth
- Eats 3 new foods of different textures
- Licks food from around mouth
- Terminates bottle feeding
- Holds and drinks from cup with one hand
- Scoops food with a spoon
- Sucks liquid from a glass or cup using a straw
- Uses napkins when reminded
- Pierces food with fork and brings to mouth
- Feeds self entire meal using spoon and fork
- Pours from small pitcher (6-8oz) into glass
- Peels 3 foods (banana, tangerine, egg)
- Cuts soft foods with knife (banana, baked potato)
- Uses knife for spreading
- Uses salt and pepper shakers

Functional Mobility related to Eating

- Makes a snack

- Pours himself/herself a drink
- Carries a drink or food to the table
- Stretched to reach a high shelf
- Reaches for bottle
- Holds bottle without help while drinking from prone position
- Returns spoon to bowl
- Picks up and replaces cup upright on table
- Locates and picks up own utensils at table
- Stirs liquid with a spoon
- Cleans up spills, getting own cloth
- Clears place at table
- Carries container filled with liquid without spilling
- Serves self at table
- Helps set table
- Opens milk carton
- Prepares cold cereal
- Picks up, carries, sets down filled tray
- Prepares sandwich
- Prepares sack lunch
- Puts hands at bottle when drinking

Dressing

- Assists, such as pushing arms through shirt
- Removes T-shirt, dress or sweater (pullover garment without fasteners)
- Puts on T-shirt, dress or sweater
- Puts on and removes front opening shirt, not including fasteners
- Puts on and removes front opening shirt, including fasteners
- Tries to assist with fasteners
- Zips and unzips, doesn't separate or hook zipper
- Snaps and unsnaps
- Buttons and unbuttons
- Zips and unzips, separates and hooks zipper
- Assists, such as pushing legs through pants
- Removes pants with elastic waist
- Puts on pants with elastic waist
- Removes pants, including unfastening
- Puts on pants, including fastening
- Removes socks and unfastened shoes
- Puts on unfastened shoes
- Puts on socks
- Puts on shoes on the correct feet; manages velcro fasteners
- Ties shoelaces
- Dressing - Upper body

- Dressing - Upper body includes dressing and undressing above the waist (including pullover garments or front opening garments). This item also includes obtaining clothes from customary places (such as drawers and closets); managing buttons, zippers and snaps as needed; and applying and removing prostheses and orthoses when applicable
- Dressing - Lower body
- Dressing - Lower body includes dressing and undressing from the waist down (including underpants, slacks, skirts, socks and shoes). This item also includes obtaining clothes from customary places (such as drawers and closets); managing buttons, zippers and snaps as needed; and applying and removing prostheses and orthoses when applicable
- Lifts arms as needed when another person is dressing or undressing him or her
- Takes shoes off
- Dresses himself or herself
- Buttons his or her own clothing
- Can dress self (including underwear, socks and tied shoes) in a reasonably acceptable fashion
- Put my shirt on
- Put my pants on
- Fastened my clothes (buttons and zippers)
- Put socks on my feet
- Put my shoes on and did them up
- Cooperates passively when being dressed
- Holds out arms and feet when being dressed
- Assists in getting dressed (e.g. Hands on clothing etc.)
- Pulls off shoes, socks, gloves, mittens etc.
- Removes and puts on simple articles of clothing
- Unbuttons accessible buttons
- Pulls off socks
- Assists in getting dressed
- Removes and puts on simple articles of clothing
- Unbuttons accessible buttons
- Fastens and adjusts his/her clothing (button, buckles, zips)
- Dresses in the morning with little supervision
- Undresses at night with little supervision
- Puts on most ordinary articles of clothing
- Ties bows and/or shoelaces
- Ties a tie or a hair ribbon
- Takes off unfastened hat
- Puts hat on
- Pulls off socks
- Pushes head through neck opening, arms through sleeves, legs through pants legs
- Takes off shoes when laces are untied and loosened
- Unties shoes
- Takes off coat when unfastened
- Takes off pants when unfastened

- Unzips zipper
- Zips engaged zipper
- Unsnaps clothing
- Takes off pullover shirt
- Takes off all clothing that has been unfastened
- Puts on socks
- Unbuckles belt or shoes
- Unbuttons large buttons
- Puts on shoes or boots with help
- Puts on coat or shirt (front opening)
- Puts on pants
- Puts on pullover shirt
- Snaps own clothing
- Puts on mittens
- Buttons own clothing
- Initiates and completes dressing and undressing except fasteners
- Buckles belt or shoes
- Puts belt through belt loops
- Puts zipper foot in catch
- Laces shoes
- Ties shoes
- Ties hood strings
- Places left shoe on left foot and right shoe on right foot

Functional mobility related to Dressing

- Takes own clothes from drawers or closet when getting dressed
- Got my clothes out
- Holds out arms and legs while being dressed
- Places coat on hook
- Removes coat from hook
- Finds back of clothing
- Places own dirty clothing in hamper or box
- Puts coat on hanger and replaces hanger on a low bar
- Obtains clothing from closet or drawer
- Folds simple clothing (T-shirts, shirts)
- Puts folded clothing on shelf or in drawer

Washing

- Allows nose to be wiped
- Blows nose into held tissue
- Wipes nose using tissue on request
- Wipes nose using tissue without request
- Blows and wipes nose without request
- Holds hands out to be washed
- Rubs hands together to clean
- Washes hands thoroughly

- Dries hands thoroughly
- Tries to wash parts of body
- Washes body thoroughly, not including face
- Obtains soap (and soaps washcloth, if used)
- Dries body thoroughly
- Washes and dries face thoroughly
- Bathing
- Bathing includes washing, rinsing and drying the body below the neck (excluding the back) in a tub, shower or sponge/bed bath
- Washes hands with soap
- Wipes own face when given a cloth by an adult
- Takes a bath or shower without help
- Can bath self
- Dries hands adequately without much assistance
- Washes hands with soap in an acceptable way
- Washes face more or less adequately (not necessarily behind ears)
- Bathes himself adequately without much supervision
- Washes hands with soap and water with assistance
- Dries hands with towel
- Dries face with a towel
- Washes face
- Washes and dries hands and face at appropriate times
- Bathes self

Functional Mobility related to Washing

- Transfers: Tub, Shower
- Transfers: Tub, Shower includes getting into or out of a tub or shower stall
- Sits if supported by equipment or caregiver in a tub or sink
- Sits unsupported and moves in tub
- Climbs or scoots in and out of tub
- Sits down and stands up from inside tub
- Steps/transfers into and out of adult-sized tub
- Turns on the tap
- Prepares bath (runs bath and assembles what is needed)
- Turns water faucet on and off
- Places own dirty clothing in hamper or box
- Hangs up wash cloth and towel
- Adjusts water temperature in sink or tub
- Prepares bath
- Turns water on and off, obtains soap

Grooming

- Holds head in position while hair is combed
- Brings brush or comb to hair
- Brushes or combs hair
- Manages tangles and parts hair

- Grooming includes oral care (brushing teeth); hair grooming (combing or brushing hair); washing, rinsing and drying hands; and washing, rinsing and drying the face
- Combed his/her hair
- Ties a hair ribbon
- Combs or brushes hair
- Washes his or her own hair
- Styling hair
- Brushes and combs hair
- Combs or brushes hair
- Opens mouth for teeth to be brushed
- Prepares toothbrush with toothpaste
- Grooming includes oral care (brushing teeth); hair grooming (combing or brushing hair); washing, rinsing and drying hands; and washing, rinsing and drying the face
- Brushes own teeth with little fussing when told by an adult
- Brushes teeth regularly
- Prepares and brushes own teeth
- Brushes teeth

Functional Mobility related to grooming

- Puts toothpaste on toothbrush
- Holds toothbrush

Toileting

- N. Management of Bladder
- Indicates when wet in diapers or training pants
- Occasionally indicates need to urinate (daytime)
- Consistently indicates need to urinate with time to get to the toilet (daytime)
- Takes self to the bathroom to urinate (daytime)
- Consistently stays dry day and night
- O. Management of Bowel
- Indicates need to be changed
- Occasionally indicates need to use the toilet (daytime)
- Consistently indicates the need to use the toilet with time to get to the toilet (daytime)
- Distinguishes between the need for urination and bowel movements
- Takes self to the bathroom for bowel movements, has no bowel accidents
- Toileting includes maintaining perineal hygiene (i.e. Wiping self) and adjusting clothing before and after using a toilet or bedpan
- Bladder management includes the safe use of any equipment or agents necessary for bladder control
- Bladder Management - Frequency of Accidents
- Bowel Management - Level of Assistance

- Bowel management includes safe use of any equipment or agents for bowel control
- Bowel Management - Frequency of accidents
- Bowel management includes complete intentional control of bowel managements and, if necessary, use of any equipment or agents for bowel control
- Transfers: Toilet includes all aspects of transferring on and off a toilet
- Tells parent or other adult when he or she needs to use the bathroom
- Uses bathroom without help
- Used the toilet paper and flushed the toilet
- Uses pot when placed on it
- Bowel movements generally regular
- Has established some regularity during day time and waits a reasonable time before attended to
- Indicates when wet and/or dirty
- Bladder control during the day, but has to go quite often
- "Toilet trained" with infrequent accidents
- Asks to go to the toilet or goes regularly without asking
- Attends to toilet needs without help except wiping
- Cares for himself at the toilet, cleans himself and washes hands

I

Functional mobility related to Toileting

- Sits if supported by equipment or caregiver
- Sits unsupported on toilet or potty chair
- Gets on and off low toilet or potty
- Gets on and off adult-sized toilet
- Gets on and off toilet, not needing own arms
- Assists with clothing management
- Tries to wipe self after toileting
- Manages toilet seat, gets toilet paper and flushes toilet
- Manages clothes before and after toileting
- Wipes self thoroughly after bowel movements
- Sits on the toilet or potty seat without being held
- Gets on and off the toilet
- Climbs on lavatory seat

Sleeping

- Sleeps through most of the night, waking no more than one or two times
- Sleeps through the entire night without waking
- Goes to bed with few or no complaints

Functional mobility related to Sleeping

- D. Bed Mobility/Transfers
- Raises to a sitting position in bed or crib
- Comes to sit at edge of bed; lies down from sitting at edge of bed
- Gets in and out of own bed
- Gets in and out of own bed, not needing own arms
- Got in and out of bed

General functional Mobility

- H. Indoor Locomotion: Pulls/Carries Objects
- Changes physical location purposefully
- Moves objects along the floor
- Carries objects small enough to be held in one hand
- Carries objects large enough to require two hands
- Carries fragile or spillable objects
- B. Chair/Wheelchair Transfers
- Sits if supported by equipment or caregiver
- Sits unsupported on chair or bench
- Gets on and off low chair or furniture
- Gets in and out of adult-sized chair/wheelchair
- Gets in and out of chair, not needing own arms
- C. Car Transfers
- Moves in car; scoots on seat or gets in and out of car seat
- Gets in and out of car with little assistance or instruction
- Gets in and out of car with no assistance or instruction
- Manages seat belt or chair restraint
- Gets in and out of car and opens and closes car door
- Reaches out and grasps an object placed nearby
- Moves an object back and forth from one hand to another
- Transfers: Chair, Wheelchair includes all aspects of transferring to and from a chair or wheelchair. This includes coming to a standing position if walking is the typical mode of locomotion
- Stands on tips toes to reach objec66ts
- Understands and uses seat belts
- Got in and out of an automobile
- Got on and off a bus
- Carried things in two hands
- Carried my backpack
- Got in and out of a chair
- Stretched to reach a high shelf
- Picked up things from the floor
- Reaches for objects by leaning forward
- Seats himself at table
- Looks for fallen objects by bending over

Appendix J: ICF Mapping to the items

Code	Item
Eating	
d550: Eating	Eats pureed/blended/strained foods
	Eats ground/lumpy foods
	Eats cut up/chunky/diced foods
	Eats all textures of table food
	Finger feeds
	Scoops with a spoon and brings to the mouth
d4402: manipulating	Uses a spoon well
	Uses a fork well
	Uses a knife to butter bread, cuts soft foods
d4401: grasping	Holds bottle or spout cup
d4400: picking up	Lifts cup to drink, but cup may tip
	Lifts open cup securely with two hands
	Lifts open cup securely with one hand
d4402: manipulating	Pours liquid from carton or pitcher
d4401: grasping	Holds a cup by himself/herself and sips from it. (Note: any cup is acceptable)
d550: Eating and d4402: manipulating	Scoops food with a spoon and tastes it
	Eating includes the use of suitable utensils to bring food and liquid to mouth, chewing and swallowing, once meal has been presented in the customary manner on a table or tray
d560: drinking	Swallows liquids with no difficulty
	Nurses, drinks or eats willingly with no encouragement
d550: Eating	Swallows soft, strained or mashed food (eg. Baby food or applesauce)
	Opens mouth when offered food on a spoon
	Feeds himself or herself crackers, cookies, dry cereal or other finger foods
d560: drinking	Drinks from a cup or glass, even if another person must hold it
d4401: grasping and d560: drinking	Holds and drinks from a sipping cup
d4401: grasping	Cuts meat or other food into bite size pieces
	Ate my meals (used a knife & fork)
d4401: grasping and d4400 picking up and d550 eating	Used my finger to eat small foods
d550: eating	Sucks food well
	Shows recognition of food
	Puckers mouth for food
	Takes semi-solids from spoon
d4401: grasping	Uses fingers for eating, but does not chew

and d4400 picking up and d550 eating	Rubs spoon across plate - puts it to mouth for licking
d550: eating	Chews biscuits, rusks etc
d4402: manipulating	Uses spoon (may spill some food)
d560: drinking	Drinks from cup unaided without spilling and holds it
d550: eating	Eats unaided
d4402: manipulating	Uses a fork without difficulty (food can be cut and prepared)
d560: drinking	Capable of taking a drink by himself without help
d4402: manipulating	Uses spoon when eating without requiring help
d560: drinking	Drinks without spilling, holding glass in one hand
d4402: manipulating	Uses a fork without difficulty (food can be cut and prepared)
d560: drinking	Capable of taking a drink by himself without help
d4402: manipulating	Serves himself and eats without requiring much help
	Uses a knife for "spreading" butter, jam etc
	Uses table knife for "cutting" without much difficulty
d4402: manipulating and d550: eating	Eats with a knife and fork, requires no help
d4402: manipulating	Pours liquids (tea or coffee) from a pot
d4402: manipulating	Uses a knife for peeling fruit
d560: drinking	Sucks and swallows liquid
d560: drinking or d550 eating	Opens mouth for breast, bottle or spoon
	Turns head toward nipple when cheek is touched
	Swallows liquefied foods fed with a spoon
	Mouths blended or strained foods fed with a spoon
d4401: grasping and d4400 picking up and d550 eating	Picks up bottle and drinks independently
d550: eating	Chews mashed table foods fed with a spoon
d4401: grasping and d4400 picking up and d560 drinking	Drinks from a cup (child's hands on cup) with help
d550: eating	Bites off piece of food
d4401: grasping and d4400 picking up and d560 drinking	Feeds self with fingers
d550: eating	Chews solid foods

d4401: grasping and d4400 picking up and d560 drinking	Holds and drinks from cup using two hands
d4402: manipulating	Takes spoon filled with food to mouth
d550: eating	Eats 3 new foods of different textures
d550: eating	Licks food from around mouth
d560: drinking	Terminates bottle feeding
d4401: grasping and d4400 picking up and d560 drinking	Holds and drinks from cup with one hand
d4402: manipulating	Scoops food with a spoon
d560: drinking	Sucks liquid from a glass or cup using a straw
d4401: grasping and d4400 picking up	Uses napkins when reminded
d4402: manipulating and d550: eating	Pierces food with fork and brings to mouth
	Feeds self entire meal using spoon and fork
d4401: grasping and d4400 picking up and d560 drinking	Pours from small pitcher (6-8oz) into glass
d4402: manipulating and d550: eating	Peels 3 foods (banana, tangerine, egg)
d4402: manipulating	Cuts soft foods with knife (banana, baked potato)
	Uses knife for spreading
	Uses salt and pepper shakers
<u>Functional Mobility related to Eating</u>	
d4402: manipulating and d550: eating	Makes a snack
d4401: grasping and d4400 picking up and d560 drinking	Pours himself/herself a drink
d450 walking, d4401 grasping	Carries a drink or food to the table
d4452: reaching	Stretched to reach a high shelf
	Reaches for bottle
d4401: grasping and d560 drinking	Holds bottle without help while drinking from prone position

d4401: grasping and d4403: release	Returns spoon to bowl
	Picks up and replaces cup upright on table
	Locates and picks up own utensils at table
d4401: grasping, d4400: picking up, d4402: manipulating and d4403: release	Stirs liquid with a spoon
	Cleans up spills, getting own cloth
	Clears place at table
	Carries container filled with liquid without spilling
	Serves self at table
	Helps set table
d4402: manipulating	Opens milk carton
d4401: grasping, d4400: picking up, d4402: manipulating and d4403: release	Prepares cold cereal
	Picks up, carries, sets down filled tray
	Prepares sandwich
	Prepares sack lunch
d4401: grasping, d560: drinking	Puts hands at bottle when drinking
<u>Dressing</u>	
d5400: putting on clothes and d5401 taking off clothes	Assists, such as pushing arms through shirt
d5401: taking off clothes	Removes T-shirt, dress or sweater (pullover garment without fasteners)
d:5400: putting on clothes	Puts on T-shirt, dress or sweater
	Puts on and removes front opening shirt, not including fasteners
	Puts on and removes front opening shirt, including fasteners
d5400: putting on clothes, d5401 taking off clothes and d4402: manipulating	Tries to assist with fasteners
	Zips and unzips, doesn't separate or hook zipper
	Snaps and unsnaps
	Buttons and unbuttons
	Zips and unzips, separates and hooks zipper

d5400: putting on clothes and d5401 taking off clothes	Assists, such as pushing legs through pants
d5401: taking off clothes	Removes pants with elastic waist
d5400: putting on clothes	Puts on pants with elastic waist
d5401: taking off clothes	Removes pants, including unfastening
d5400: putting on clothes	Puts on pants, including fastening
d5401: taking off clothes and d5403 taking off footwear	Removes socks and unfastened shoes
d5402: putting on footwear	Puts on unfastened shoes
d5400: putting on clothes	Puts on socks
d5402 putting on footwear and d4402: manipulating	Puts on shoes on the correct feet; manages velcro fasteners
	Ties shoelaces
d5400: putting on clothes, d5401 taking off clothes, d5404 choosing appropriate clothing, d4400 picking up, d4401 grasping and d4402: manipulating	Dressing - Upper body
	Dressing - Upper body includes dressing and undressing above the waist (including pullover garments or front opening garments). This item also includes obtaining clothes from customary places (such as drawers and closets); managing buttons, zippers and snaps as needed; and applying and removing prostheses and orthoses when applicable
d5400: putting on clothes, d5401 taking off clothes, d5402: putting on footwear; d5403: taking off footwear, d5404 choosing appropriate clothing, d4400 picking up, d4401 grasping and d4402: manipulating	Dressing - Lower body
	Dressing - Lower body includes dressing and undressing from the waist down (including underpants, slacks, skirts, socks and shoes). This item also includes obtaining clothes from customary places (such as drawers and closets); managing buttons, zippers and snaps as needed; and applying and removing prostheses and orthoses when applicable

d4300: lifting	Lifts arms as needed when another person is dressing or undressing him or her
d5403: taking footwear off	Takes shoes off
d5400: putting on clothes	Dresses himself or herself
d5400: putting on clothes, d4402: manipulating	Buttons his or her own clothing
d5400: putting on clothes, d5402: putting on footwear and d4402: manipulating	Can dress self (including underwear, socks and tied shoes) in a reasonably acceptable fashion
d5400: putting on clothes	Put my shirt on
	Put my pants on
d5400: putting on clothes and d4402: manipulating	Fastened my clothes (buttons and zippers)
d5400: putting on clothes	Put socks on my feet
d5402 putting on footwear and d4402: manipulating	Put my shoes on and did them up
d5400: putting on clothes and d4100 lying down	Cooperates passively when being dressed
d4300: lifting	Holds out arms and feet when being dressed
d5400: putting on clothes	Assists in getting dressed (eg. Hands on clothing etc)
d5401: taking off clothes and d5403 taking off footwear	Pulls off shoes, socks, gloves, mittens etc
d5401: taking off clothes	Removes and puts on simple articles of clothing
d5401: taking off clothes and d4402: manipulating	Unbuttons accessible buttons
d5401: taking off clothes	Pulls off socks
d5400: putting on clothes	Assists in getting dressed

d5401: taking off clothes	Removes and puts on simple articles of clothing
d5401: taking off clothes and d4402: manipulating	Unbuttons accessible buttons
d5400: putting on clothes and d4402: manipulating	Fastens and adjusts his/her clothing (button, buckles, zips)
d5400: putting on clothes	Dresses in the morning with little supervision
d5401: taking off clothes	Undresses at night with little supervision
d5400: putting on clothes	Puts on most ordinary articles of clothing
d5400: putting on clothes and d4402: manipulating	Ties bows and/or shoelaces
	Ties a tie or a hair ribbon
d5401: taking off clothes	Takes off unfastened hat
d5400: putting on clothes	Puts hat on
d5401: taking off clothes	Pulls off socks
d5400: putting on clothes	Pushes head through neck opening, arms through sleeves, legs through pants legs
d5403: taking footwear off	Takes off shoes when laces are untied and loosened
d5403: taking off footwear and d4402: manipulating	Unties shoes
d5401: taking off clothes	Takes off coat when unfastened
	Takes off pants when unfastened
d5401: taking off clothes and d4402: manipulating	Unzips zipper
d5400: putting on clothes and d4402: manipulating	Zips engaged zipper
d5401: taking off clothes and d4402: manipulating	Unsnaps clothing

d5401: taking off clothes	Takes off pullover shirt
	Takes off all clothing that has been unfastened
d5400: putting on clothes	Puts on socks
d5401: taking off clothes, d5403 taking off footwear and d4402: manipulating	Unbuckles belt or shoes
	Unbuttons large buttons
d5402: putting on footwear	Puts on shoes or boots with help
d5400: putting on clothes	Puts on coat or shirt (front opening)
	Puts on pants
	Puts on pullover shirt
d5400: putting on clothes and d4402: manipulating	Snaps own clothing
d5400: putting on clothes	Puts on mittens
d5400: putting on clothes and d4402: manipulating	Buttons own clothing
d5400: putting on clothes, d5401 taking off clothes, d5402: putting on footwear and d5403: taking off footwear	Initiates and completes dressing and undressing except fasteners
d5400: putting on clothes, d5402: putting on footwear and d4402: manipulating	Buckles belt or shoes
d5400: putting on clothes and d4402: manipulating	Puts belt through belt loops
d5400: putting on clothes and d4402: manipulating	Puts zipper foot in catch

d5402: putting on footwear and d4402: manipulating	Laces shoes
	Ties shoes
d5400: putting on clothes and d4402: manipulating	Ties hood strings
d5402: putting on footwear and d4402: manipulating	Places left shoe on left foot and right shoe on right foot
<u>Functional mobility related to Dressing</u>	
d5404: chooses appropriate clothing, d4301 carrying in the hands, d4401 grasping	Takes own clothes from drawers or closet when getting dressed
	Got my clothes out
d5400: putting on clothes	Holds out arms and legs while being dressed
d5401: taking off clothes and d4403: releasing	Places coat on hook
d5400: putting on clothes and d4400 picking up	Removes coat from hook
d5400: putting on clothes	Finds back of clothing
d5401: taking off clothes and d4403: releasing	Places own dirty clothing in hamper or box
d5401: taking off clothes and d4403: releasing	Puts coat on hanger and replaces hanger on a low bar
d5400: putting on clothes and d4400 picking up	Obtains clothing from closet or drawer
d4401: grasping and d4402: manipulating	Folds simple clothing (T-shirts, shirts)
d4453: reaching	Puts folded clothing on shelf or in drawer

Washing	
d5200: caring for skin	Allows nose to be wiped
	Blows nose into held tissue
	Wipes nose using tissue on request
	Wipes nose using tissue without request
	Blows and wipes nose without request
d5100: washing body parts	Holds hands out to be washed
	Rubs hands together to clean
	Washes hands thoroughly
d5102: drying oneself	Dries hands thoroughly
d5100: washing body parts	Tries to wash parts of body
	Washes body thoroughly, not including face
d5101: washing whole body and d4401: grasping	Obtains soap (and soaps washcloth, if used)
d5102: drying oneself	Dries body thoroughly
d5100: washing body parts and d5102: drying oneself	Washes and dries face thoroughly
d5100: washing body parts and, d5101 washing whole body and d5102: drying oneself	Bathing
	Bathing includes washing, rinsing and drying the body below the neck (excluding the back) in a tub, shower or sponge/bed bath
d5100: washing body parts and d5101 washing whole body	Washes hands with soap
	Wipes own face when given a cloth by an adult
	Takes a bath or shower without help
	Can bath self
d5102: drying oneself	Dries hands adequately without much assistance
d5100: washing body parts and d5101 washing whole body	Washes hands with soap in an acceptable way
	Washes face more or less adequately (not necessarily behind ears)
	Bathes himself adequately without much supervision
	Washes hands with soap and water with assistance
d5102: drying oneself	Dries hands with towel
	Dries face with a towel

d5100: washing body parts	Washes face
d5100: washing body parts and, d5101 washing whole body and d5102: drying oneself	Washes and dries hands and face at appropriate times
	Bathes self
Functional Mobility related to Washing	
d5101: washing whole body, d4101 standing and d4103: sitting	Transfers: Tub, Shower
	Transfers: Tub, Shower includes getting into or out of a tub or shower stall
d5101: washing whole body and d4153: maintains a sitting position	Sits if supported by equipment or caregiver in a tub or sink
	Sits unsupported and moves in tub
d5101: washing whole body and d4200 transferring oneself while sitting	Climbs or scoots in and out of tub
d5101: washing whole body and d4200 transferring oneself while sitting	Sits down and stands up from inside tub
	Steps/transfers into and out of adult-sized tub
d4402: manipulating	Turns on the tap
d4452 reaching and d4402: manipulating	Prepares bath (runs bath and assembles what is needed)
	Turns water faucet on and off
d4452 reaching, d4402: manipulating, d4401 grasping and d4403 releasing	Places own dirty clothing in hamper or box
	Hangs up wash cloth and towel
	Adjusts water temperature in sink or tub
	Prepares bath
	Turns water on and off, obtains soap

Grooming	
d5202: caring for hair and d4153 maintaining a sitting position or d4150 maintaining a lying position	Holds head in position while hair is combed
d5202: caring for hair	Brings brush or comb to hair
	Brushes or combs hair
	Manages tangles and parts hair
d5202: caring for hair, d5201 caring for teeth, d5100 washing body parts and d5102 drying oneself	Grooming includes oral care (brushing teeth); hair grooming (combing or brushing hair); washing, rinsing and drying hands; and washing, rinsing and drying the face
d5202: caring for hair	Combed his/her hair
	Ties a hair ribbon
	Combs or brushes hair
	Washes his or her own hair
	Styling hair
	Brushes and combs hair
	Combs or brushes hair
d5201: caring for teeth	Opens mouth for teeth to be brushed
d5201: caring for teeth, d4401 grasping, d4453 twisting of hands	Prepares toothbrush with toothpaste
d5202: caring for hair, d5201 caring for teeth, d5100 washing body parts and d5102 drying oneself	Grooming includes oral care (brushing teeth); hair grooming (combing or brushing hair); washing, rinsing and drying hands; and washing, rinsing and drying the face
d5201: caring for teeth	Brushes own teeth with little fussing when told by an adult
	Brushes teeth regularly
	Prepares and brushes own teeth
	Brushes teeth

Functional Mobility related to grooming	
d5201: caring for teeth, d4401: grasping, d4402: manipulating	Puts toothpaste on toothbrush
	Holds toothbrush
Toileting	
d5300: regulating urination, d4500 walking short distances	Management of Bladder
	Indicates when wet in diapers or training pants
	Occasionally indicates need to urinate (daytime)
	Consistently indicates need to urinate with time to get to the toilet (daytime)
	Takes self to the bathroom to urinate (daytime)
	Consistently stays dry day and night
d5300: regulating defecation, d4500 walking short distances	Management of Bowel
	Indicates need to be changed
	Occasionally indicates need to use the toilet (daytime)
	Consistently indicates the need to use the toilet with time to get to the toilet (daytime)
	Distinguishes between the need for urination and bowel movements
	Takes self to the bathroom for bowel movements, has no bowel accidents
d5300: regulating defecation, d5300: regulating urination, d5400 putting on clothes, d5401 taking off clothes	Toileting includes maintaining perineal hygiene (ie. Wiping self) and adjusting clothing before and after using a toilet or bedpan
d5300: regulating urination	Bladder management includes the safe use of any equipment or agents necessary for bladder control
	Bladder Management - Frequency of Accidents
d5300: regulating defecation	Bowel Management - Level of Assistance
	Bowel management includes safe use of any equipment or agents for bowel control
	Bowel Management - Frequency of accidents
	Bowel management includes complete intentional control of bowel managements and, if necessary, use of any equipment or agents for bowel control

d5300: regulating defecation, d5300: regulating urination, d420 transferring oneself	Transfers: Toilet includes all aspects of transferring on and off a toilet
d5300: regulating defecation, d5300: regulating urination	Tells parent or other adult when he or she needs to use the bathroom
d5300: regulating defecation, d5300: regulating urination, d5400 putting on clothes, d5401 taking off clothes	Uses bathroom without help
d5300: regulating defecation, d5300: regulating urination, d4401: grasping, d4402: manipulting	Used the toilet paper and flushed the toilet
d5300: regulating defecation, d5300: regulating urination	Uses pot when placed on it
d5300: regulating defecation,	Bowel movements generally regular
d5300: regulating defecation, d5300: regulating urination	Has established some regularity during day time and waits a reasonable time before attended to
	Indicates when wet and/or dirty
	Bladder control during the day, but has to go quite often
	"Toilet trained" with infrequent accidents
	Asks to go to the toilet or goes regularly without asking
	Attends to toilet needs without help except wiping

d5300: regulating defecation, d5300: regulating urination, d5400 putting on clothes, d5401 taking off clothes, d5100: washing body parts	Cares for himself at the toilet, cleans himself and washes hands
<u>Functional mobility related to Toileting</u>	
d4153: maintaining a sitting position	Sits if supported by equipment or caregiver
	Sits unsupported on toilet or potty chair
d420: transfers, d5300: regulating defecation, d5300: regulating urination	Gets on and off low toilet or potty
	Gets on and off adult-sized toilet
	Gets on and off toilet, not needing own arms
d5400: putting on clothes, d5401: taking off clothes	Assists with clothing management
d5300: regulating defecation, d5300: regulating urination, d5400 putting on clothes, d5401 taking off clothes, d5100: washing body parts	Tries to wipe self after toileting
	Manages toilet seat, gets toilet paper and flushes toilet
	Manages clothes before and after toileting
	Wipes self thoroughly after bowel movements
d4153: maintaining a sitting position	Sits on the toilet or potty seat without being held
d420: transfers, d5300: regulating defecation, d5300: regulating urination	Gets on and off the toilet
	Climbs on lavatory seat

Sleeping	
d4100: lying down, d4150: maintaining a lying position	Sleeps through most of the night, waking no more than one or two times
	Sleeps through the entire night without waking
	Goes to bed with few or no complaints
Functional mobility related to Sleeping	
d4100: lying down, d4150: maintaining a lying position, d420 transfers	Bed Mobility/Transfers
	Raises to a sitting position in bed or crib
	Comes to sit at edge of bed; lies down from sitting at edge of bed
	Gets in and out of own bed
	Gets in and out of own bed, not needing own arms
	Got in and out of bed
General functional Mobility	
	Indoor Locomotion: Pulls/Carries Objects
d4500: walking short distances	Changes physical location purposefully
d4301: carrying in the hands, d4303: carrying in the arms, d4400 picking up, d4401: grasping	Moves objects along the floor
	Carries objects small enough to be held in one hand
	Carries objects large enough to require two hands
	Carries fragile or spillable objects
d4153: maintaining a sitting position, d420 transferring	Chair/Wheelchair Transfers
	Sits if supported by equipment or caregiver
	Sits unsupported on chair or bench
	Gets on and off low chair or furniture
	Gets in and out of adult-sized chair/wheelchair
	Gets in and out of chair, not needing own arms
	Car Transfers
	Moves in car; scoots on seat or gets in and out of car seat
	Gets in and out of car with little assistance or instruction
	Gets in and out of car with no assistance or instruction
d4402: manipulating	Manages seat belt or chair restraint
d4153: maintaining a sitting position, d420 transferring	Gets in and out of car and opens and closes car door

d4452: reaching, d4401 grasping	Reaches out and grasps an object placed nearby
	Moves an object back and forth from one hand to another
d4153: maintaining a sitting position, d420 transferring	Transfers: Chair, Wheelchair includes all aspects of transferring to and from a chair or wheelchair. This includes coming to a standing position if walking is the typical mode of locomotion
d4106: shifting body's centre of gravity	Stands on tips toes to reach objects
d4402: manipulating	Understands and uses seat belts
d4153: maintaining a sitting position, d420 transferring	Got in and out of an automobile
	Got on and off a bus
d4301: carrying in the hands, d4303: carrying in the arms, d4400 picking up, d4401: grasping	Carried things in two hands
	Carried my backpack
d4153: maintaining a sitting position, d420 transferring	Got in and out of a chair
d4106: shifting body's centre of gravity	Stretched to reach a high shelf
d4400: picking up	Picked up things from the floor
d4452: reaching, d4401 grasping, d4400 picking up	Reaches for objects by leaning forward
d4153: maintaining a sitting position, d420 transferring	Seats himself at table
d4106: shifting body's centre of gravity	Looks for fallen objects by bending over

Appendix K: Final items validated through survey

Key:

- 100 – ambiguous – discard/edit
- 75 – simple, clear and relevant - Keep
- Less than 75 – missing clarity, simplicity or relevance – Discard.
- If not marked as relevant, automatically scored 0 – Discard.

	Eating Items	percentage of agreement by SMEs (%)
1	**Does not** Turns head toward nipple when cheek is touched	75
2	Opens mouth for breast, bottle or spoon	75
3	Sucks food well	25
4	Shows recognition of food	50
5	Nurses, drinks or eats willingly with no encouragement	25
6	Swallows liquids with no difficulty	75
7	Eats pureed/blended/strained foods	75
8	Eats ground/lumpy foods	75
9	Eats cut up/chunky/diced foods	75
10	Eats all textures of table food	75
11	Rubs spoon across plate, puts it to mouth for licking	25
12	Scoops with a spoon and brings to the mouth by himself/herself	75
13	Uses a spoon	25
14	Takes spoon filled with food to mouth	75
15	Scoops with a spoon	50
16	Licks food from around mouth	75
17	Uses fingers for eating, but does not chew	75
18	Bites off piece of food	75
19	Chews solid foods	75
20	Feeds himself or herself crackers, cookies, dry cereal or other finger foods	75
21	Picks up bottle and drinks independently	75
22	Lifts cup to drink, but cup may tip	75
23	Drinks from a cup or glass (even if another person must hold it)	50
24	Holds and drinks from a sipping cup	75
25	Drinks from a cup (child's hands on cup) with help	75
26	Holds and drinks from cup with one hand	75
27	Holds and drinks from cup using two hands	25
28	Sucks liquid from a glass or cup using a straw	75
29	Capable of taking a drink by himself without help	50
30	Uses spoon when eating without requiring help	75
31	Pierces food with fork and brings to mouth	50
32	Uses a fork without difficulty	50
33	Uses a knife for "spreading" butter, jam etc.	75
34	Cuts soft foods with knife (banana, baked potato)	75
26	Cuts meat or other food into bite-size pieces	75
27	Uses table knife for "cutting" without much difficulty	75
28	Eats with a knife and fork, requires no help	50
29	Feeds self entire meal using spoon and fork	75

30	Pours from small pitcher (6-8oz) into glass	75
31	Pours liquids (tea or coffee) from a pot	25
32	Peels 3 foods (banana, tangerine, boiled egg)	75
33	Uses salt and pepper shakers	0
34	Uses napkins when reminded	25
35	Serves himself and eats without requiring much help	25
36	Eats unaided	75

Functional Mobility Associated with Eating

1	Carries a drink or food to the table	75
2	Stretches to reach a high shelf	75
3	Reaches for bottle or cup	75
4	Holds bottle without help while drinking from prone position	25
5	Returns spoon to bowl	75
6	Picks up and replaces cup upright on table	75
7	Locates and picks up own utensils at table	75
8	Stirs liquid with a spoon	75
9	Cleans up spills, getting own cloth	75
10	Clears place at table	25
11	Carries container filled with liquid without spilling	75
12	Serves self at table	75
13	Helps set table	75
14	Opens milk carton	75
15	Passes serving dish at table	25
16	Prepares cold cereal	25
17	Picks up, carries, sets down filled tray	25
18	Prepares sandwich	75
19	Prepares sack lunch	25
20	Made a snack	25

Dressing Items

1	Removes loose T-shirt skipper, dress or sweater (pullover garment without fasteners)	75
2	Puts on loose T-shirt, dress or sweater	75
3	Puts on and removes front opening shirt, not including fasteners	75
4	Puts on and removes front opening shirt, including fasteners	75
5	Tries to assist with fasteners	25
6	Unbuckles belt	75
7	Unbuttons large buttons	25
8	Zips and unzips, doesn't separate or hook zipper	75
9	Snaps and unsnaps	25
10	Buttons and unbuttons	75
11	Unzips zipper	75
12	Zips engaged zipper	25
13	Assists, such as pushing legs through pants	75
14	Removes pants with elastic waist	75
15	Puts on pants with elastic waist	75
16	Removes pants, including unfastening	75

17	Puts on pants, including fastening	75
18	Removes socks and unfastened shoes	75
19	Unties shoes	75
20	Puts on unfastened shoes	75
21	Puts on shoes or boots with help	75
22	Puts on socks	75
23	Puts on shoes on the correct feet; manages velcro fasteners	75
24	Ties shoelaces	75
25	Takes off coat when unfastened	75
26	Initiates and completes dressing and undressing except fasteners	25
27	Dresses in the morning with little supervision	25
28	Undresses at night with little supervision	25
29	Ties bows and/or shoelaces	25
30	Ties a tie or a hair ribbon	25
31	Puts on mittens	75
32	Puts on a hat	75
33	Buttons own clothing	25
34	Buckles belt	25
35	Puts belt through belt loops	25
36	Puts zipper foot in catch	25
37	Laces shoes	25
38	Ties shoes	0
39	Ties hood strings	25
40	Places left shoe on left foot and right shoe on right foot	25

Functional Mobility Associated with Dressing

1	Holds out arms and pushes them through sleeves	75
2	Places coat on hook	25
3	Removes coat from hook	25
4	Finds back of clothing	75
5	Places own dirty clothing in hamper or box	25
6	Puts coat on hanger and replaces hanger on a low bar	25
7	Obtains clothing from closet or drawer	75
8	Folds simple clothing (T-shirts, shirts)	75
9	Puts folded clothing on shelf or in drawer	25

Washing items

1	Holds hand out to be washed	75
2	Rubs hands together to clean	75
3	Washes hands with soap and water with assistance	75
4	Washes hands with soap	75
5	Washes hands thoroughly	75
6	Dries hands with towel	75
7	Dries hands thoroughly	75
8	Wipes own face when given a cloth by an adult	75
9	Washes face more or less adequately (not necessarily behind ears)	75
10	Dries face with a towel	75
11	Washes and dries hands and face at appropriate times	100

12	Tries to wash part of body	100
13	Washes body thoroughly, not including face	75
14	Dries body thoroughly	75
15	Bathes himself adequately without much supervision	75
16	Takes a bath or shower without help	75

Functional Mobility Associated with Washing

1	Transfers: Tub, shower includes getting into or out of a tub or shower stall	50
2	Sits if supported by equipment or caregiver in a tub or sink	75
3	Sits unsupported and moves in tub	75
4	Climbs or slides on his or her bottom in and out of tub	75
5	Sits down and stands up from inside tub	75
6	Steps/transfers into and out of adult-sized tub	75
7	Prepares bath (runs bath and assembles what is needed)	0
8	Turns water faucet on and off	0
9	Places dirty clothing in hamper or box	0
10	Hangs up wash cloth and towel	0
11	Adjusts water temperature in sink or tub	0
12	Obtains soap (and soaps washcloth, if used)	75

Toileting items

1	Indicates when nappy needs to be changed	75
2	Occasionally indicates need to urinate (daytime)	75
3	Consistently indicates need to urinate with time to get to the toilet (daytime)	75
4	Takes self to the bathroom to urinate (daytime)	75
5	Bladder control during the day, but has to go quite often	75
6	"Toilet trained" with infrequent accidents	75
7	Consistently stays dry day and night	75
8	Indicates need to be changed	50
9	Bowel movements generally regular	75
10	Has established some regularity during day time and waits a reasonable time before attended to	25
11	Occasionally indicates need to use the toilet for bowel movements (daytime)	75
12	Consistently indicates the need to use the toilet for bowel movements with time to get to the toilet (daytime)	75
13	Distinguishes between the need for urination and bowel movements	75
14	Uses potty when placed on it	75
15	Tells parent or other adult when he or she needs to use the bathroom	75
16	Asks to go to the toilet or goes regularly without asking	75
17	Takes self to the bathroom for bowel movements, has no bowel accidents	75
18	Attends to toilet needs without help except wiping	75
19	Used the toilet paper and flushed the toilet	75
20	Cares for himself at the toilet, cleans himself and washes hands	75
21	Uses bathroom without help	75

Functional Mobility Associated with Toileting

1	Sits if supported by equipment or caregiver	75
2	Sits unsupported on toilet or potty chair	75
3	Gets on and off low toilet or potty	75
4	Gets on and off adult-sized toilet	75
5	Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet	75
6	Assists with undoing fastenings, pulling down pants and underpants, and pulling them back up and redoing fastenings	75
7	Tries to wipe self after toileting	75
8	Manages toilet seat, gets toilet paper and flushes toilet	75
9	Manages clothes before and after toileting	75
10	Wipes self thoroughly after bowel movements	75

Grooming items

1	Holds head in position while hair is combed	75
2	Brings brush or comb to hair	75
3	Brushes or combs hair	75
4	Manages tangles and parts hair	0
5	Washes his or her own hair	75
6	Ties a hair ribbon	0
7	Styling hair	0
8	Allows nose to be wiped	75
9	Blows nose into held tissue	75
10	Wipes nose using tissue on request	75
11	Wipes nose using tissue without request	75
12	Blows and wipes nose without request	75
13	Opens mouth for teeth to be brushed	75
14	Brushes own teeth with little fussing when told by an adult	75
15	Prepares toothbrush with toothpaste	0
16	Brushes teeth; but not a thorough job	75
17	Thoroughly brushes teeth	75
18	Brushes teeth regularly	75

Functional Mobility Associated with Grooming

1	Puts toothpaste on toothbrush	75
2	Holds toothbrush	75

Sleeping items

1	Sleeps through most of the night, waking no more than one or two times	75
2	Sleeps through the entire night without waking	75
3	Goes to bed with few or no complaints	75

Functional Mobility Associated with Sleeping

1	Raises to a sitting position in bed or crib	75

2	Comes to sit at edge of bed; lies down from sitting at edge of bed	75
3	Gets in and out of bed	75
4	Gets in and out of own bed, not needing own arms	0

General functional mobility items

1	Changes physical location purposefully	75
2	Moves objects along the floor	75
3	Carries objects small enough to be held in one hand	75
4	Carries objects large enough to require two hands	75
5	Carries fragile or spillable objects	75
6	Sits if supported by equipment or caregiver	0
7	Sits unsupported on chair or bench	0
8	Gets on and off low chair or furniture	0
9	Gets in and out of adult-sized chair/wheelchair	0
10	Gets in and out of chair, not needing own arms	0
11	Seats himself at table	0
12	Moves in car; scoots on seat or gets in and out of car seat	0
13	Gets in and out of car with little assistance or instruction	75
14	Gets in and out of car with no assistance or instruction	75
15	Manages seat belt or chair restraint	75
16	Gets in and out of car and opens and closes car door	75
17	Reaches out and grasps an object placed nearby	75
18	Moves an object back and forth from one hand to another	75
19	Reaches for objects by leaning forward	75
20	Stands on tip toes to reach objects	75
21	Stretches to reach a high shelf	0
22	Picks up things from the floor	75
23	Looks for fallen objects by bending over	25
24	Carries own backpack	50

Appendix L: Items modified post expert survey

	Eating Items	Ambiguous	Repetition	Inappropriate for under 7 years	Culturally inappropriate	Difficult to observe	Edit wording	Discard	Changed to
1	Sucks food well	✓	✓	✓	✓	✓		✓	
2	Nurses, drinks or eats willingly with no encouragement	✓	✓	✓	✓	✓		✓	
3	Swallows liquids with no difficulty						✓		Swallows without coughing
4	Eats pureed/blended/strained foods						✓		Eats soft/mushy foods
5	Rubs spoon across plate, puts it to mouth for licking	✓	✓	✓	✓			✓	
6	Uses spoon (may spill some food)		✓	✓	✓			✓	
7	Scoops with a spoon		✓	✓	✓			✓	
8	Feeds himself or herself crackers, cookies, dry cereal or other finger foods						✓		Feeds himself or herself carrot sticks, biscuits or other finger foods
9	Drinks from a cup or glass (even if another person must hold it)		✓	✓	✓			✓	
10	Drinks from a cup (child's hands on cup) with help		✓	✓	✓		✓		Drinks from a cup with some help
11	Holds and drinks from cup with one hand		✓	✓	✓		✓		Drinks from cup without help
12	Holds and drinks from cup using two hands		✓	✓	✓			✓	
13	Capable of taking a drink by himself without help					✓		✓	
14	Pierces food with fork and brings to mouth				✓			✓	

15	Uses a fork without difficulty (food can be cut and prepared)				✓			✓	
16	Eats with a knife and fork, requires no help				✓			✓	
17	Pours from small pitcher (6-8oz) into glass	✓			✓		✓		Pours a glass of juice
18	Pours liquids (tea or coffee) from a pot			✓				✓	
19	Peels 3 foods (banana, tangerine, egg)				✓		✓		Peels 3 foods (banana, naartjie, egg)
20	Uses salt and pepper shakers			✓				✓	
21	Uses napkins when reminded				✓			✓	
22	Serves himself and eats without requiring much help	✓					✓		Serves himself food
23	Eats unaided	✓					✓		Eats independently
	Functional mobility associated with Eating								
1	Carried a drink or food to the table	✓					✓		Carries cup/plate
2	Holds bottle without help while drinking from prone position	✓						✓	
3	Clears place at table				✓			✓	
4	Carries container filled with liquid without spilling	✓					✓		Carries cup filled with juice without spilling
5	Opens milk carton	✓							Opens milk box
6	Passes serving dish at table				✓			✓	
7	Prepares cold cereal				✓			✓	
8	Picks up, carries, sets down filled tray	✓			✓			✓	
9	Prepares sandwich						✓		Prepares sandwich or other snack
10	Prepares sack lunch	✓			✓			✓	
11	Made a snack	✓						✓	
	Dressing								

1	Tries to assist with fasteners	✓				✓		✓	
2	Unbuttons large buttons	✓	✓					✓	
3	Zips and unzips, doesn't separate or hook zipper	✓					✓		Zips and unzips with help
4	Snaps and unsnaps	✓			✓			✓	
5	Unzips zipper		✓					✓	
6	Zips engaged zipper		✓					✓	
7	Initiates and completes dressing and undressing except fasteners	✓						✓	
8	Dresses in the morning with little supervision		✓			✓		✓	
9	Undresses at night with little supervision		✓			✓		✓	
10	Ties bows and/or shoelaces		✓					✓	
11	Ties a tie or a hair ribbon		✓					✓	
12	Puts on mittens	✓					✓		Puts on gloves
13	Buttons own clothing		✓					✓	
14	Buckles belt or shoes	✓					✓		Buckles belt
15	Puts zipper foot in catch	✓	✓					✓	
16	Laces shoes	✓	✓					✓	
17	Ties shoes		✓					✓	
18	Ties hood strings	✓						✓	
19	Places left shoe on left foot and right shoe on right foot		✓					✓	
	Functional Mobility Associated with Dressing								
1	Places coat on hook	✓			✓			✓	
2	Removes coat from hook	✓			✓			✓	
3	Places own dirty clothing in hamper or box	✓						✓	

4	Puts coat on hanger and replaces hanger on a low bar	✓			✓			✓	
5	Puts folded clothing on shelf or in drawer				✓			✓	
	Washing Items								
1	Washes and dries hands and face at appropriate times					✓		✓	
2	Tries to wash parts of body	✓						✓	
	Functional Mobiliy Associated with Washing								
1	Transfers: Tub, Shower includes getting into or out of a tub or shower stall	✓						✓	
2	Prepares bath (runs bath and assembles what is needed)	✓			✓		✓	✓	Changed to: Fills up basin with water for washing AND empties basin after washing, cleans the basin
3	Turns water faucet on and off				✓			✓	
4	Places own dirty clothing in hamper or box				✓			✓	
5	Hangs up wash cloth and towel				✓			✓	
6	Adjusts water temperature in sink or tub				✓			✓	
	Toileting Items								
1	Has established some regularity during day time and waits a reasonable time before attended to	✓						✓	
	Functional mobility associated with Toileting								
1	Assists with clothing management	✓	✓					✓	

2	Manages clothes before and after toileting		✓				✓	✓	Manages to undo clothing fastenings, pulling down pants and underpants, and pulling them back up and redoing fastenings
	Grooming Items								
1	Manages tangles and parts hair				✓			✓	
2	Ties a hair ribbon			✓	✓			✓	
3	Styling hair			✓	✓			✓	
4	Prepares toothbrush with toothpaste		✓					✓	
	Functional Mobility Associated with Grooming								
	Sleeping Items								
	Functional Mobility Associated with Sleeping								
1	Gets in and out of own bed, not needing own arms	✓						✓	
	General functional mobility Items								
1	Sits if supported by equipment or caregiver	✓	✓					✓	
2	Sits unsupported on chair or bench		✓					✓	
3	Gets on and off low chair or furniture		✓					✓	
4	Gets in and out of adult-sized chair/wheelchair		✓					✓	
5	Gets in and out of chair, not needing own arms		✓					✓	
6	Seats himself at table		✓					✓	
7	Moves in car; scoots on seat or gets in and out of car seat		✓					✓	
8	Looks for fallen objects by bending over	✓						✓	
9	Carries own backpack				✓			✓	

Appendix M: Items modified post discussion groups

	Eating Items	Ambiguous	Repetition	Inappropriate for under 7 years	Culturally inappropriate	Difficult to observe	Edit wording	Discard	Changed to
1	**Does not** Turns head toward nipple when cheek is touched	✓				✓		✓	
2	Swallows liquids without coughing (Ugwinya uketshezi ngaphandle kokukhohlela)						✓		IsiZulu spelling corrected: Ugwinya uketshezi ngaphandle khwehlela
3	Eats ground/lumpy foods (Udla ukudla okugayiwe/okunamaqhuzwana)								IsiZulu word corrected: Udla ukudla okugayiwe/izigaxa
4	Scoops with a spoon and brings to the mouth by himself or herself (Ukha ngesipuni bese eziyisela sona emlonyeni)		✓					✓	
5	Bites off piece of food (Uyaliluma iphuzwaca lokudla)						✓		IsiZulu word corrected: Uyaliluma iqhuzwana lokudla
6	Feeds himself or herself crackers, carrot sticks or other finger foods (Uyazidlela yena amakhrekhazi, izindukwana zizaqathi noma okunye ukudla okudleka ngeminwe)						✓		IsiZulu word corrected: Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe
7	Holds and drinks from a sipping cup		✓					✓	
8	Sucks liquid from a glass or cup using a straw				✓			✓	
9	Uses spoon when eating without requiring help		✓					✓	
10	Pierces food with fork and brings to mouth				✓			✓	
11	Uses a fork without difficulty				✓			✓	
12	Eats with a knife and fork, requires no help			✓				✓	

13	Feeds self entire meal using spoon and fork		✓					✓	
14	Pours himself or herself a glass or cup of juice		✓					✓	
15	Eats independently		✓					✓	
	Functional mobility associated with Eating								
1	Locates and picks up own utensils at table	✓			✓			✓	
2	Serves self at table				✓			✓	
3	Helps set table				✓			✓	
4	Opens milk box (Uyalivula ibhokisi lobisi)						✓		Edited item: Opens milk or juice box (Uyalivula ibhokisi lobisi okanye lejusi)
	Dressing								
1	Removes T-shirt, dress or sweater (pullover garment without fasteners) (Uyazikhumula, ingubo noma ijezi okuxegayo (isembatho esingenamkhono esingenakho okokufasa))						✓		Edit English: Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners); Edit isiZulu: Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa)
2	Puts on T-shirt, dress or sweater (Uyazigqokisa isikibha,ingubo noma ijezi okuxegayo)						✓		Edit English: Puts on loose T-shirt, dress or jersey
3	Puts on and removes front opening shirt, not including fasteners						✓		Edit isiZulu: Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa
4	Puts on and removes front opening shirt, including fasteners						✓		Edited isiZulu: Uyazigqokisa noma azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa

5	Zips and unzips, with help		✓					✓	
6	Zips and unzips without help						✓		Edited isiZulu: Uyazifasa abuye aqaqe uziphu, engasizwa
7	Puts on shoes or boots with help	✓						✓	
8	Puts on shoes on the correct feet; manages velcro fasteners (Uyazigqokisa izicathulo onyaweni okuyilo; asebenzise kahle okokokufasa ukungamavelikho)						✓		Split into 2 items
9	Takes off coat when unfastened						✓		Edited English: Takes off jacket when unfastened
	Functional Mobility Associated with Dressing								
2	Cooperates passively when being dressed	✓						✓	
	Washing Items								
1	Washes hands with soap and water with assistance		✓					✓	
2	Dries hands thoroughly		✓					✓	
3	Bathes himself adequately without much supervision		✓					✓	
4	Takes a bath or shower without help (Uyazigeza ebhavini noma eshaweni ngaphandle kokusizwa)				✓		✓		Edited English: Washes using the basin without help; Edited isiZulu: Uyazigeza umzimba wonke kahle engasizwa

	Functional Mobiliy Associated with Washing								
1	Sits if supported by equipment or caregiver in a tub or sink (Uyazihlalela uma usekelwe ngento ethile noma ngumnakekeli ebhavini noma kusinki)						✓		Edited English: Sits if supported by equipment or caregiver in a tub or basin; Edited isiZulu: Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli ebhavini noma endishini
2	Sits unsupported and moves in tub (Uyazihlalela engasekeliwe futhi anyakaze kubhavu)						✓		Edited English: Sits unsupported and moves in the basin
3	Climbs or slides on his or her bottom in and out of the tub (Uyazigibelela noma azishushuluzela ngezinqe engena noma ephuma kubhavu)						✓		Edited English: Climbs or slides on his or her bottom in and out of the basin
4	Steps into and out of adult-sized tub				✓			✓	
	Toileting Items							✓	
1	Occasionally indicates need to urinate (daytime)		✓					✓	
2	Consistently indicates need to urinate with time to get to the toilet (daytime)						✓		Edit English: Indicates need to urinate with time to get to the toilet (daytime)
3	Takes self to the bathroom to urinate (daytime)						✓		Edit English: Takes self to the toilet to urinate (daytime)
4	Consistently indicates the need to use the toilet for bowel movements with time to get to the toilet during the day						✓		Edit English: Indicates the need to use the toilet for bowel movements with time to get to the toilet during the day
5	Tells parent or other adult when he or she needs to use the bathroom						✓		Edited English: Tells parent or other adult when he or she needs to use the toilet

6	Takes self to the bathroom for bowel movements, has no bowel accidents						✓		Edited English: Takes self to the toilet for bowel movements, has no bowel accidents
7	Uses the toilet paper and flushes the toilet						✓		Edited English: Used toilet paper and threw it into the toilet
8	Uses bathroom without help						✓		Edited English: Uses toilet without help
	Ulisebenzisile iphepha eliwulwelwesi lasethoyilethi futhi waliphonsa ethoyilethi walishaya lahamba								Edited English: Used the toilet paper and threw it into the toilet
	Functional mobility associated with Toileting								
1	Sits unsupported on toilet or potty chair (Uyazihlalela engasekeliwe ethoyilethi noma esihlalweni esinepowa)						✓		Edited isiZulu: Uyazihlalela engasekeliwe noma esihlalweni esinepowa. Edited English: Sits unsupported on potty chair
2	Gets on and off low toilet or potty (Uyakwazi ukuzihlalela abuye azisukumele ethoyilethi elifushane noma epoweni)						✓		Edited isiZulu: Uyakwazi ukuzihlalela abuye azisukumele elifushane noma epoweni. Edited English: Gets on and off potty
3	Assists with undoing fastenings, pulling down pants and underpants, and pulling them back up and redoing fastenings							✓	
4	Tries to wipe self after toileting							✓	
5	Manages toilet seat, gets toilet paper and flushes toilet						✓		Edited isiZulu: Uya kwazi ukuzi thathela iphepha lasethwayelethi. Edited English: Gets toilet paper;
6	Manages to undo clothing fastenings, pulling down pants and underpants, and pulling them back up and redoing fastenings						✓		Split into 2 items
	Grooming Items								

1	Brings brush or comb to hair	✓	✓					✓	
2	Wipes nose using tissue without request		✓					✓	
3	Opens mouth for teeth to be brushed						✓		Edited isiZulu: Uyawuvula umlomo khona uzomxubha amazinyo
4	Brushes teeth; but not a thorough job		✓					✓	
	Functional Mobility Associated with Grooming								
	Sleeping Items								
	Functional Mobility Associated with Sleeping								
1	Comes to sit at edge of bed; lies down from sitting at edge of bed						✓		Edited isiZulu: Alale phansi emuva kokuhlala osebeni lombhed. Edited English: Lies down from sitting at edge of bed
	General functional mobility Items								
1	Changes physical location purposefully	✓						✓	
2	Carries objects small enough to be held in one hand						✓		Edited isiZulu: Ukuphatha izinto ezincane ngokwanele eziphatheka ngesandla esisodwa
3	Carries objects large enough to require two hands						✓		Edited isiZulu: Ukuphatha izinto ezinkulu ngokwanele ezidinga ukuphathwa ngezandla ezimbili
4	Carries fragile or spillable objects						✓		Edited isiZulu: Uyaziphatha izinto ezichobokayo noma ezichithekayo
5	Gets in and out of car with little assistance or instruction		✓					✓	
6	Manages seat belt or chair restraint						✓		

Appendix N: Items modified post field test

	Eating Items	Ambiguous	Repetition	Inappropriate for under 7 years	Culturally inappropriate	Difficult to observe	Edit wording	Discard	Changed to
1	Opens mouth for breast, bottle or spoon (Uyakhamisa khona ezoncela ibele, ibhodlela noma adle ngesipuni)	✓						✓	
2	Eats all textures of food (Udla zonke izimo zokudla)					✓		✓	
3	Uses spoon when eating without requiring help (Usebenzisa isipuni uma edla ngaphandle kokufuna usizo)		✓					✓	
	Dressing								
	Functional Mobility Associated with Dressing								
1	Assists, such as pushing legs through pants (Uyasiza, okufana nokushutheka imilenze ingene ebhulukweni)	✓				✓		✓	
2	Holds out arms and pushes them through sleeves (Uyazelula izandla bese ezishutheka zingene emkhonweni)	✓						✓	
3	Obtains clothing from closet or drawer (Uyazithatha izingubo ekhabetheni noma ediloweni)					✓		✓	

	Washing Items								
	Functional Mobiliy Associated with Washing								
	Toileting Items	Ambiguous	Repetition	Inappropriate for under 7 years	Culturally inappropriate	Difficult to observe	Edit wording	Discard	Changed to
1	Indicates when nappy needs to be changed (Uyasho uma inabukeni selidinga ukushintshwa)					✓		✓	
2	Takes self to the toilet or outside to urinate (daytime) (Uyaziyela egumbini lokuyochama (emini))					✓		✓	
3	Consistently stays dry day and night (Ngokulandelanayo uhlala omile emini nasebusuku)					✓		✓	
4	Asks to go to the toilet or goes regularly without asking (Uyacela uma eya ethoyilethi noma uvamise ukuya engacelanga)					✓		✓	
5	Indicates need to urinate with time to get to the toilet during the day (Ngokulandelanayo uyasho uma edinga ukuchama ngesikhathi esanele sokuthi afike ethoyilethi (emini))					✓		✓	
6	Bladder control during the day, but has to go quite often (Uyakwazi ukuwubamba umchamo emini, kodwa kumele achame kaningana)					✓		✓	

7	"Toilet trained" with infrequent accidents ("Ufundisekile ngokusebenzisa ithoyilethi" kube nokuphunyuka okungavamisile)					✓		✓	
8	Distinguishes between the need for urination and bowel movements (Uyawukhombisa umehluko phakathi kwesidingo sokuyochama kanye nesokuzikhulula)					✓		✓	
9	Tells parent or other adult when he or she needs to use the toilet (Uyamtshela umzali noma omunye omdala uma edinga ukuya ethoyilethi)					✓		✓	
10	Bowel movements generally regular (Ukuya ethoyilethi kuvamise ukuhamba kahle)					✓		✓	
11	Indicates the need to use the toilet for bowel movements with time to get to the toilet during the day (Ngokulandelanayo uyasho uma edinga ukuya ethoyilethi khona ezozikhulula ngesikhathi esanele sokuthi aze afike ethoyilethi (emini))					✓		✓	
12	Takes self to the toilet for bowel movements, has no bowel accidents (Uyaziyela yena uqobo ethoyilethi ukuyozikhulula, akabi nazo izingozi zokuzikakela)					✓		✓	
	Functional mobility associated with Toileting								
	Grooming Items								
1	Brushes own teeth with little fussing when told by an adult (Uyazixubha amazinyo akhe ngaphandle kwenkinga uma etsheliwe ngumuntu omdala)					✓		✓	
2	Brushes teeth regularly (Uyazixubha amazinyo njalo)					✓		✓	

	Functional Mobility Associated with Grooming								
	Sleeping Items								
1	Sleeps through most of the night, waking no more than one or two times (Uyalala ubusuku bonke, avuke hhayi ngaphezulu kwesikhathi esisodwa noma ezimbili)					✓		✓	
2	Sleeps through the entire night without waking (Uyalala ubusuku bonke ngaphandle kokuvuk)					✓		✓	
3	Goes to bed with few or no complaints (Uyaziyela kolala embhedeni ekhononda okuncane noma engakhonondi)					✓		✓	
	Functional Mobility Associated with Sleeping								
	General functional mobility Items								
1	Gets in and out of car with no assistance or instruction (Uyazingenela futhi aziphumele emotweni ngaphandle kosizo noma umyalelo)					✓		✓	
2	Gets in and out of car and opens and closes car door (Uyazingenela futhi aziphumele emotweni abuye avule futhi avale izicabha zemoto)					✓		✓	

Appendix O: Items' scoring modified post field test

	Eating Items	Ambiguous	Difficult to observe	Edited scoring	Edit wording	Discard	Changed to

1	Uses fingers for eating, but does not chew (Usebenzisa iminwe uma edla, kodwa akahlafuni)	✓			✓		Uses fingers for eating (Usebenzisa iminwe uma edla)
2	Lifts cup to drink, but cup may tip (Uphakamisa inkomishi khona ezophuza, kodwa kungenzeka inkomishi iwe)	✓		✓	✓		Lifts cup to drink (Uphakamisa inkomishi khona ezophuza); All ages received 4s
3	Feeds himself or herself crackers, carrot sticks or other finger foods (Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe)			✓			5-year-old score: 4 - able to finger feed
4	Takes spoon filled with food to mouth (Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni)			✓			5-year-old score 4 - able to use spoon
5	Pours himself or herself a glass or cup of juice (Uzithelela yena uqobo ingilazi noma inkomishi yejusi)			✓			2-year-old score: 2; 3-year-old score 3
6	Feeds self entire meal using spoon (Uzidlela konke ukudla esebenzisa isipuni kanye)			✓			2-year-old score: 2
	Functional mobility associated with Eating						
1	Returns spoon to bowl (Ubuyisela isipuni endishini)			✓			5-year-old score: 4
	Dressing						
1	Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners) (Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa))			✓			5-year-old score: 4
2	Removes pants including unfastening (Uyazikhumula ibhulukwe, elinga fasiwe)			✓			5-year-old score: 4
3	Puts on and removes a front opening shirt, not including fasteners (Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa)			✓			3-year-old score: 4
4	Manages velcro fasteners (Asebenzise kahle okokokufasa ukungamavelikho)			✓			3-year-old score: 3

5	Zips and unzips without help (Uyazifasa abuye aqaqe uziphu, engasizwa)			✓			3-year-old score: 4
	Functional Mobility Associated with Dressing						
	Washing Items						
1	Washes hands with soap (Uyazigeza izandla ngensipho)			✓			5-year-old score: 4
2	Dries hands with towel (Uyazesula izandla ngethawula)			✓			3-year-old score 4
	Functional Mobiliy Associated with Washing						
	Toileting Items						
	Functional mobility associated with Toileting						
1	Gets on and off potty (Uyakwazi ukuzihlalela abuye azisukumele ethoyilethi elifushane noma epoweni)			✓			3-year-old score: 3
	Grooming Items						
1	Opens mouth for teeth to be brushed (Uyawuvula umlomo khona uzomxubha amazinyo)			✓			5-year-old score: 4
2	Brushes or combs hair (Uyazibhulasha noma azikame izinwele)			✓			3-year-old score: 4
	Functional Mobility Associated with Grooming						
1	Puts toothpaste on toothbrush (Uyawufaka umuthi wokuxubha esixubheni)			✓			3-year-old score 2
	Sleeping Items						
	Functional Mobility Associated with Sleeping						
	General functional mobility Items						
1	Moves objects along the floor (Uyazihudula izinto phansi)			✓			5-year-old score: 4
2	Stands on tip toes to reach objects (Uyacokama ukuze afinyelele ezintweni)			✓			5-year-old score: 4
3	Picks up things from the floor (Uyazicosha izinto phansi)			✓			5-year-old score 4

Appendix P: Individual differences detailed for all domains of SCICP except for eating.

Dressing and Functional Mobility Associated With Dressing

The percentages of independence demonstrated by participants with CP within the dressing and dressing functional mobility section decreased as the level of CP severity increased but the scores varied as dressing is a learnt skill and the older participants scored better than the younger participants even if their GMFCS level indicated more severe CP. (Figure P1).

Participant CP5 (GMFCS V, MACS IV) Zipping and unzipping - score 2 (needs a lot of help)

Participant CP4 (GMFCS IV, MACS II) managing velcro fasteners - score 4 (Independent)

Participant CP 3 (GMFCS III, MACS III) taking off a front opening shirt, not including fasteners – score 4 (Independent)

Participant CP2 (GMFCS II, MACS II) removing a pullover garment with no fasteners – score 4 (Independent)

Participant CP 1 (GMFCS I, MACS III) untying his shoes - score 4 (Independent)

Figure P1: Participants with GMFCS V to GMFCS I engaging in dressing items

Figure P1 showed Child participants with CP performing a range of dressing items.

Washing and Functional Mobility Associated With Washing

The percentages of independence demonstrated by participants with CP within the washing and washing functional mobility section demonstrate decreased independence from levels GMFCS II to V. (Figure P2)

Participant CP5 (GMFCS V, MACS IV) drying his face with a towel – score 2 (needs a lot of help)

Participant CP4 (GMFCS IV, MACS II) sitting without support in the basin - score 4 (Independent)

Participant CP3 (GMFCS III, MACS III) climbing into the basin - score 4 (Independent)

Participant CP2 (GMFCS II, MACS II) climbing into the basin score 4 (Independent)

Participant CP1 (GMFCS I, MACS III) climbing into the basin, score 4 (Independent)

Figure P2: Participants with GMFCS V to GMFCS I engaging in washing items

Figure P2 shows child participants engaging in washing and functional mobility associated with washing items.

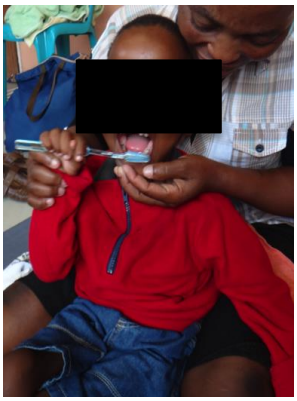
Toileting and Functional Mobility Associated With Toileting

The percentages of independence demonstrated by participants with CP within the toileting and toileting functional mobility section demonstrate highest independence (score 4) with the child with GMFCS levels II and III (Figure P3).

Figure P3: Participant with CP (GMFCS III) climbing onto an adult sized toilet

Grooming and Functional Mobility Associated With Grooming

The percentages of independence demonstrated by participants with CP within the grooming and grooming functional mobility section demonstrate decreasing independence from GMFCS III to GMFCS V. Figure P4 shows participants engaging in tooth brushing items. Within the functional mobility items, the participants with GMFCS II and III levels score the highest percentage of independence, with decreasing independence in the GMFCS IV and V level.



Participant CP5 (GMFCS V, MACS IV) brushing his teeth - holding the toothbrush, - score a 2 (needs a lot of help) and opening his mouth score a 4 (independent)

Participant CP4 (GMFCS IV, MACS II) brushing his teeth- holding toothbrush - score 4 (independent)

Participant CP3 (GMFCS III, MACS III) brushing her teeth – holding toothbrush score 4 (independent), brushing teeth thoroughly score 2 (needs a lot of help)

Participant CP2 (GMFCS II, MACS II) putting toothpaste on his toothbrush- score 4 (independent) takes top off toothpaste – score 3 (needs a little help)

Participant CP1 (GMFCS I, MACS III) brushing his teeth holding toothbrush score 4 (independent), brushing teeth thoroughly, score 2 (needs a lot of help)

Figure P4: Participant with GMFCS V to GMFCS I engaging in grooming items

Functional Mobility Associated With Sleeping

The participants with GMFCS levels I to III achieve 100% independence in functional mobility associated with sleeping. The participants with GMFCS IV and V levels achieve lower scores.

General Functional Mobility

The percentages of independence demonstrated by participants with CP within the general functional mobility section demonstrate decreasing independence from GMFCS I to GMFCS

V. CP5 scored 1 (dependent) for all but one item. Figure P5 shows participants GMFCS III, II and I completing general functional mobility items.

Participant CP3 (GMFCS III, MACS III) moving an object along the floor, score 4 (independent)

Participant CP2 (GMFCS II, MACS II) leaning forward to reach an object, score 4 (independent)

Participant, CP1 (GMFCS I, MACS III) picking up an object from the floor, score 4 (independent)

Figure P5: Participants performing general functional mobility

The performance that was observed in all domains of the SCICP highlighted that age and severity of CP play a role in development of independence in self-care. Observations highlighted the variety in the manner in which the items were completed and how age, classification levels on MACS and GMFCS and associated impairments have an influence on the scores of the SCICP.

Appendix Q: Self Care Inventory for Children with Cerebral Palsy (SCICP) with scoring and administration instructions

Administration

- Ask parent or caregiver whether their child can perform each item independently.
- If the child is unable to perform the item independently, ask the parent or caregiver how much help the child needs to perform this task and what kind of help the child needs to complete this task.
- Observe the child perform each item.
- Score based on observation, using table below.
- If the performance and caregiver report differs make notes in the comments section.

Scoring

Score Number	Score Description
1	Child is unable to do the task at all Ingane ayikwazi nhlobo ukwenza umsebenzana
2	Child is almost able to do the task, but needs a lot of help Ingane iyakwazi ukwenza umsebenzana kodwa idinga ukusizwa kakhulu • Help is from caregiver; environmental support and adaptations; standing frame; chair; walker; facilitation • Okuvela kumnakekeli, ukusekela futhi ukuguqula isimo sendawo ekuyo, uhlaka lokuma, isihlalo, insiza yokuhamba, ukumsiza
3	Child is almost able to do the task on its own, but requires a little bit of help Ingane icishe yakwazi ukwenza umsebenzana kodwa idinga ukusizwa kancane • Help is from built up spoon; modified Velcro fastenings; extra time; universal cuff • Kusukela esipunini esakhiweyo, okokufasa okujikwe kwafaneleka, isikhathi esithe xaxa, okufakwa esihlakaleni okujwayelekileyo
4	Child is able to do the task without any help Ingane iyakwazi ukwenza lo msebenzana ngaphandle kosizo

	Items	Scoring				
	Eating/Ukudla	**1**	**2**	**3**	**4**	**Comments**
1	**Ugwinya uketshezi ngaphandle khwehlela;** Swallows liquids without coughing					

2	**Udla ukudla okubushelelezi okuthambile;** Eats smooth soft foods					
3	**Udla ukudla okugayiwe/izigaxa;** Eats ground/lumpy foods					
4	**Usebenzisa iminwe uma edla;** Uses fingers for eating					
5	**Uyaliluma iqhuzwana lokudla;** Bites off piece of food					
6	**Uphakamisa ibhodlela bese eziphuzela engasizwa muntu;** Picks up bottle and drinks independently					
7	**Uphakamisa inkomishi khona ezophuza;** Lifts cup to drink					
8	**Uyakuhlafuna ukudla okuqinileyo;** Chews solid food					
9	**Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe;** Feeds crackers, carrot sticks or other finger foods					
10	**Udla ukudla okusikiwe kwaba yizicucwana/izigaxana/amadayisana;** Eats cut up/chunky/diced foods					
11	**Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni;** Takes spoon filled with food to mouth					
12	**Uphuza ngenkomishi ngaphandle kosizo;** Drinks from a cup without help					
13	**Uyakukhotha ukudla okuzungeze umlomo;** Licks food from around mouth					
14	**Uzithelela yena uqobo ingilazi noma inkomishi yejusi;** Pours himself or herself a glass or cup of juice					

15	**Uhluba ukudla oku-3 (ubhanana, inantshi, neqanda elibilisiweyo);** Peels 3 foods (banana, naartjie, boiled egg)					
16	**Usebenzia ummese khona "ezogcoba" ibhotela, ujamu njll;** Uses a knife for "spreading" butter, jam etc.					
17	**Usika ukudla okuthambile ngommese (ubhanana, izambane elibhakiweyo);** Cuts soft foods with knife (banana, baked potato)					
18	**Usika inyama noma okunye ukudla kube izingcucwana ezizolumeka;** Cuts meat or other food into bite-sized pieces					
19	**Uzidlela konke ukudla esebenzisa isipuni kanye;** Feeds self entire meal using spoon					
	TOTAL EATING SCORE:				**/76**	
	Functional mobility associated with Eating/Ukunyakaza okwanele okuhambisana nokudla	**1**	**2**	**3**	**4**	**Comments**
1	**Ufinyelela ebhodleleni noma enkomishini;** Reaches for bottle or cup					
2	**Uyalugoqoza uketshezi ngesipuni;** Stirs liquid with a spoon					
3	**Uyasula lapho kuchitheke khona, azithathele indwangu yakhe;** Cleans up spills, getting own cloth					
4	**Uphathe ipuleti elinokudla ngaphandle kokuchitha, waliyise etafuleni;** Carries a plate with food on it without spilling, to the table					
5	**Uyazelula ukuze afinyelele eshalofini eliphezulu;** Stretches to reach a high shelf					
6	**Ubuyisela isipuni endishini;** Returns spoon to bowl					
7	**Uyayiphakamisa futhi ayibuyisele inkomishi ihlale iqonde etafuleni;** Picks up and replaces cup upright on the table					

8	**Uphatha inkomishi egcwaliswe ujusi ngaphandle kokuchitheka;** Carries cup filled with juice without spilling					
9	**Uyalivula ibhokisi lobisi okanye lejusi;** Opens milk or juice box					
10	**Ulungisa isemeshi noma esinye isinekhi;** Prepares sandwich or other snack					
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH EATING SCORE:				**/40**	
	Dressing/Ukuggoka	**1**	**2**	**3**	**4**	**Comments**
1	**Uyazikhumula amasokisi kanye nezicathulo ezingafaswa;** Removes socks and unfastened shoes					
2	**Uyazifaka izicathulo ezingafaswa;** Puts on unfastened shoes					
3	**Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa);** Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners)					
4	**Uyazigqokisa isikibha,ingubo noma ijezi okuxegayo;** Puts on loose T-shirt, dress or jersey					
5	**Uyazikhumula ibhulukwe elinelastiki okhalo;** Removes pants with elastic waist					
6	**Uyaziqaqa izintambo zezicathulo;** Unties shoes					
7	**Uyazikhumula ibhantshi uma lingafasiwe;** Takes off Jacket when unfastened					
8	**Uyazigqokisa isigqoko;** Puts on a hat					
9	**Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa;** Puts on and removes a front opening shirt, not including fasteners					

10	**Uyazigqokisa noma azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa;** Puts on and removes front opening shirt, including fasteners					
11	**Uyazigqokisa ibhulukwe elinelastiki okhalo;** Puts on pants with elastic waist					
12	**Uyazikhumula ibhulukwe, elinga fasiwe;** Removes pants including unfastening					
13	**Uyalikhumula ibhande;** Unbuckles belt					
14	**Uyazigqokisa ibhulukwe , okuhlanganisa ukulifasa;** Puts on pants, including fastening					
15	**Uyazigqokisa amasokisi;** Puts on socks					
16	**Uyazigqokisa izicathulo onyaweni okuyilo;** Puts shoes on the correct feet					
17	**Asebenzise kahle okokokufasa ukungamavelikho;** Manages velcro fasteners					
18	**Uyazibopha ibhande;** Buckles belt					
19	**Uyazifasa izinkinobho abuye aziqaqe izinkinobho;** Buttons and unbuttons					
20	**Uyazibopha izintambo zezicathulo;** Ties shoelaces					
21	**Uyazigqokisa ibhande alifake emalupheni;** Puts belt through belt loops					
22	**Uyazifasa abuye aqaqe uziphu, engasizwa;** Zips and unzips without help					

23	**Uyazigqokisa amagilavu;** Puts on gloves					
	TOTAL DRESSING SCORE				**/92**	
	Functional Mobility Associated with Dressing/Ukunyakaza okwanele okuhambisana nokuggoka	**1**	**2**	**3**	**4**	**Comments**
1	**Uyalibona ingemuva lezingubo;** Finds back of clothing					
2	**Uyazigoqa izingubo ezilula (izikipha, amahembe);** Folds simple clothing (T-Shirts, shirts)					
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH DRESSING SCORE				**/8**	
	Washing/Ukugeza	**1**	**2**	**3**	**4**	**Comments**
1	**Uyazihlikihla izandla zombili khona ezozihlanza;** Rubs hands together to clean					
2	**Uyazesula ubuso bakhe uma enikezwe indwangu ngumuntu omdala;** Wipes own face when given a cloth by an adult					
3	**Uyazigeza izandla ngensipho;** Washes hands with soap					
4	**Uyazigezisisa kahle izandla;** Washes hands thoroughly					
5	**Uyazesula izandla ngethawula;** Dries hands with towel					
6	**Uyazigeza ubuso cishe ngokwanele (kodwa hhayi ngemuva kwezindebe);** Washes face more or less adequately (not necessarily behind ears)					
7	**Uyabomisa ubuso ngethawula;** Dries face with a towel					
8	**Uyawugezisisa kahle umzimba, ungabuhlanganisi ubuso;** Washes body thoroughly, not including face					

9	**Uyawomisisa kahle umzimba;** Dries body thoroughly					
10	**Uyazigeza umzimba wonke kahle engasizwa;** Washes using the basin without help					
	TOTAL WASHING SCORE:				**/40**	
	Functional Mobility Associated with Washing/Ukunyakaza okwanele okuhambisana nogeza	**1**	**2**	**3**	**4**	**Comments**
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli ebhavini noma endishini;** Sits if supported by equipment or caregiver in a tub or basin					
2	**Uyazihlalela engasekeliwe futhi anyakaze kubhavu;** Sits unsupported and moves in the basin					
3	**Uyazilula izandla khona zizogezwa;** Holds hands out to be washed					
4	**Uyazigibelela noma azishushuluzela ngezinqe engena noma ephuma kubhavu;** Climbs or slides on his or her bottom in and out of the basin					
5	**Uyazihlalela phansi abuye azisukumele ephakathi endishini;** Sits down and stands up from inside the basin					
6	**Uyazitholela insipho (kanye nendwangu yensipho, uma isetshenziswa);** Obtains soap (and soaps washcloth, if used)					
7	**Uyazithathela amanzi endishini ukuze ageze;** Fills up a basin with water for washing					
8	**Uyazichithela amanzi endishini emuva kokugeza, ayihlanze endishi;** Empties basin after washing, cleans the basin					
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH WASHING SCORE:				**/32**	
	Toileting/Ezethoyilethi	**1**	**2**	**3**	**4**	**Comments**
1	**Uyalisebenzisa ipowa uma ebekwe kulo;** Uses potty/chamber pot when placed on it					

2	**Uyakwenza adinga ukukwenza ethoyilethi engasizwa ngaphandle uma esedinga ukusulwa izinqe;** Attends to toilet needs without help, except wiping					
3	**Ulisebenzisile iphepha eliwulwelwesi lasethoyilethi futhi waliphonsa ethoyilethi walishaya lahamba;** Uses the toilet paper and throws it into the toilet					
4	**Uyazinakekela uma esethoyilethi, azisule kahle futhi ageze nezandla;** Cares for himself at the toilet, cleans himself and washes hands					
5	**Uyalisebenzisa ithoyilethi ngaphandle kosizo;** Uses toilet without help					
	TOTAL TOILETING SCORE:				**/20**	
	Functional mobility associated with Toileting/Ukunyakaza okwanele okuhambisana nezethoyilethi	**1**	**2**	**3**	**4**	**Comments**
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli;** Sits if supported by equipment or caregiver					
2	**Uyazihlalela engasekeliwe noma esihlalweni esinepowa;** Sits unsupported on potty chair					
3	**Uyakwazi ukuzihlalela abuye azisukumele elifushane noma epoweni;** Gets on and off potty					
4	**Uyakwazi ukuzihlalela abuye azisukumele labantu abadala;** Gets on and off adult sized toilet					
5	**Uya kwazi ukuzi thathela iphepha lasethwayelethi;** Gets toilet paper					
6	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to undo clothing fastenings, pulling down pants and underpants					
7	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to pull pants and underpants back up and redo fastenings					

8	**Uyazisulisisa kahle emuva kokukaka;** Wipes self thoroughly after bowel movements					
9	**Uyakwazi ukuzihlalela abuye azisukele ethoyilethi, angadingi ukusebenzisa izingalo zakhe ukuze zimesekele uma ethwayiletile;** Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet					
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH TOILETING SCORE:				**/36**	
	Grooming/Ukuzicwala	**1**	**2**	**3**	**4**	**Comments**
1	**Uyawuvula umlomo khona uzomxubha amazinyo;** Opens mouth for teeth to be brushed					
2	**Uyavuma ukusulwa amafinyila;** Allows nose to be wiped					
3	**Uyafinya ebanjelwe ulwelwesana lwephepha;** Blows nose into held tissue					
4	**Uyazisula amafinyila esebenzisa ulwelwesana lwephepha uma eceliwe;** Wipes nose using tissue on request					
5	**Uyazibhulasha noma azikame izinwele;** Brushes or combs hair					
6	**Uyaliqinisa ikhanda lime kahle ngesikhathi umkama izinwele;** Holds head in place while hair is combed					
7	**Uyazigeza izinwele zakhe;** Washes his or her own hair					
8	**Uyazifinyisa futhi azisule amafinyila ngaphandle kokucelwa;** Blows and wipes nose without request					
9	**Uyazixubhisisa kahle amazinyo;** Thoroughly brushes teeth					
	TOTAL GROOMING SCORE:				**/36**	
	Functional Mobility Associated with Grooming/Ukunyakaza okwanele	**1**	**2**	**3**	**4**	**Comments**

	okuhambisana nokuzicwala					
1	**Uyasibamba isixubho;** Holds toothbrush					
2	**Uyawufaka umuthi wokuxubha esixubheni;** Puts toothpaste on toothbrush					
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH GROOMING SCORE:				**/8**	
	Functional Mobility Associated with Sleeping/Ukunyakaza okwanele okuhambisana nokulala	**1**	**2**	**3**	**4**	**Comments**
1	**Uyaphakama ahlale embhedeni noma;** Raises to a sitting position in bed					
2	**Alale phansi emuva kokuhlala osebeni lombhede;** Lies down from sitting at the edge of bed					
3	**Uyazingenela futhi aziphumele embhedeni;** Gets in and out of bed					
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH SLEEPING SCORE:				**/12**	
	General Functional mobility/Okujwayelekile	**1**	**2**	**3**	**4**	**Comments**
1	**Uyeluleka abambe into ebekwe eduzane;** Reaches out and grasps an object placed nearby					
2	**Uyeluleka athathe izinto ngokugoba aye phambili;** Reaches for objects by leaning forward					
3	**Uyayinyakazisa into ayiyise emuva naphambili esebenzisa isandla esisodwa ayiyise kwesinye;** Moves an object back and forth from one hand to another					
4	**Uyazihudula izinto phansi;** Moves objects along the floor					
5	**Ukuphatha izinto ezinkulu ngokwanele ezidinga ukuphathwa ngezandla ezimbili;** Carries objects large enough to require two hands					

6	**Ukuphatha izinto ezincane ngokwanele eziphatheka ngesandla esisodwa;** Carries objects small enough to be held in one hand					
7	**Uyacokama ukuze afinyelele ezintweni;** Stands on tip toes to reach objects					
8	**Uyazicosha izinto phansi;** Picks up things from the floor					
9	**Uyaziphatha izinto ezichobokayo noma ezichithekayo;** Carries fragile or spillable objects					
	TOTAL GENERAL FUNCTIONAL MOBILITY SCORE:				**/36**	

Scoring Form

Domain	Total Score	Percentage
Eating	/76	
Functional mobility associated with eating	/40	
Dressing	/92	
Functional mobility associated with dressing	/8	
Washing	/40	
Functional mobility associated with washing	/32	
Toileting	/20	
Functional mobility associated with toileting	/36	
Grooming	/36	
Functional mobility associated with grooming	/8	
Functional mobility associated with sleeping	/12	
General functional mobility items	/36	
Overal Total Point Score:	/436	

Appendix R: Comparison of age of independence as determined during discussion groups and field test

	Eating Items	Age Range-discussion grp (months)	Pilot Average (Months)	Difference (Months)
1	**Ugwinya uketshezi ngaphandle khwehlela;** Swallows liquids without coughing	0	5	-5
2	**Udla ukudla okubushelelezi okuthambile;** Eats smooth soft foods	4	5	-1
3	**Udla ukudla okugayiwe/izigaxa;** Eats ground/lumpy foods	6	10	-4
4	**Usebenzisa iminwe uma edla;** Uses fingers for eating	6	6	0
5	**Uyaliluma iqhuzwana lokudla;** Bites off piece of food	8	17	-9
6	**Uphakamisa ibhodlela bese eziphuzela engasizwa muntu;** Picks up bottle and drinks independently	8	19	-11
7	**Uphakamisa inkomishi khona ezophuza;** Lifts cup to drink	10	13	-3
8	**Uyakuhlafuna ukudla okuqinileyo;** Chews solid food	12	19	-7
9	**Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe;** Feeds crackers, carrot sticks or other finger foods	12	24	-12
10	**Udla ukudla okusikiwe kwaba yizicucwana/izigaxana/amadayisana;** Eats cut up/chunky/diced foods	14	20	-6
11	**Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni;** Takes spoon filled with food to mouth	18	24	-6

12	**Uphuza ngenkomishi ngaphandle kosizo;** Drinks from a cup without help	24	22	2
13	**Uyakukhotha ukudla okuzungeze umlomo;** Licks food from around mouth	36	21	15
14	**Uzithelela yena uqobo ingilazi noma inkomishi yejusi;** Pours himself or herself a glass or cup of juice	36	31	5
15	**Uhluba ukudla oku-3 (ubhanana, inantshi, neqanda elibilisiweyo);** Peels 3 foods (banana, naartjie, boiled egg)	36	36	0
16	**Usebenzia ummese khona "ezogcoba" ibhotela, ujamu njll;** Uses a knife for "spreading" butter, jam etc.	48		/
17	**Usika ukudla okuthambile ngommese (ubhanana, izambane elibhakiweyo);** Cuts soft foods with knife (banana, baked potato)	48		/
18	**Usika inyama noma okunye ukudla kube izingcucwana ezizolumeka;** Cuts meat or other food into bite-sized pieces	48		/
19	**Uzidlela konke ukudla esebenzisa isipuni kanye;** Feeds self entire meal using spoon	72	30	42
	TOTAL EATING SCORE:			
	<u>Functional mobility associated with Eating</u>			
1	**Ufinyelela ebhodleleni noma enkomishini;** Reaches for bottle or cup	6	6	0
2	**Uyalugoqoza uketshezi ngesipuni;** Stirs liquid with a spoon	6	18	-12
3	**Uyasula lapho kuchitheke khona, azithathele indwangu yakhe;** Cleans up spills, getting own cloth	10	39	-29
4	**Uphathe ipuleti elinokudla ngaphandle kokuchitha, waliyise etafuleni;** Carries a plate with food on it without spilling, to the table	24	30	-6

5	**Uyazelula ukuze afinyelele eshalofini eliphezulu;** Stretches to reach a high shelf	24	18	6
6	**Ubuyisela isipuni endishini;** Returns spoon to bowl	36	29	7
7	**Uyayiphakamisa futhi ayibuyisele inkomishi ihlale iqonde etafuleni;** Picks up and replaces cup upright on the table	36	33	3
8	**Uphatha inkomishi egcwaliswe ujusi ngaphandle kokuchitheka;** Carries cup filled with juice without spilling	36	39	-3
9	**Uyalivula ibhokisi lobisi okanye lejusi;** Opens milk or juice box	48	43	5
10	**Ulungisa isemeshi noma esinye isinekhi;** Prepares sandwich or other snack	72		/
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH EATING SCORE:			
	Dressing			
1	**Uyazikhumula amasokisi kanye nezicathulo ezingafaswa;** Removes socks and unfastened shoes	8	19	-11
2	**Uyazifaka izicathulo ezingafaswa;** Puts on unfastened shoes	12	19	-7
3	**Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa);** Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners)	14	33	-19
4	**Uyazigqokisa isikibha,ingubo noma ijezi okuxegayo;** Puts on loose T-shirt, dress or jersey	24	42	-18
5	**Uyazikhumula ibhulukwe elinelastiki okhalo;** Removes pants with elastic waist	24	27	-3
6	**Uyaziqaqa izintambo zezicathulo;** Unties shoes	24	32	-8

7	**Uyazikhumula ibhantshi uma lingafasiwe;** Takes off Jacket when unfastened	24	29	-5
8	**Uyazigqokisa isigqoko;** Puts on a hat	24	27	-3
9	**Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa;** Puts on and removes a front opening shirt, not including fasteners	36	46	-10
10	**Uyazigqokisa noma azikhumule ihembe elivuleka ngaphambili, okuhlanganisa okokufasa;** Puts on and removes front opening shirt, including fasteners	36	50	-14
11	**Uyazigqokisa ibhulukwe elinelastiki okhalo;** Puts on pants with elastic waist	36	37	-1
12	**Uyazikhumula ibhulukwe, elinga fasiwe;** Removes pants including unfastening	36	46	-10
13	**Uyalikhumula ibhande;** Unbuckles belt	48	44	4
14	**Uyazigqokisa ibhulukwe , okuhlanganisa ukulifasa;** Puts on pants, including fastening	48	45	3
15	**Uyazigqokisa amasokisi;** Puts on socks	48	40	8
16	**Uyazigqokisa izicathulo onyaweni okuyilo;** Puts shoes on the correct feet	48	40	8
17	**Asebenzise kahle okokokufasa ukungamavelikho;** Manages velcro fasteners	48	31	17
18	**Uyazibopha ibhande;** Buckles belt	48	56	-8
19	**Uyazifasa izinkinobho abuye aziqaqe izinkinobho;** Buttons and unbuttons	60	44	16

20	**Uyazibopha izintambo zezicathulo;** Ties shoelaces	60	60	0
21	**Uyazigqokisa ibhande alifake emalupheni;** Puts belt through belt loops	60	60	0
22	**Uyazifasa abuye aqaqe uziphu, engasizwa;** Zips and unzips without help	72	36	36
23	**Uyazigqokisa amagilavu;** Puts on gloves	72	48	24
	TOTAL DRESSING SCORE			
	Functional Mobility Associated with Dressing			
1	**Uyalibona ingemuva lezingubo;** Finds back of clothing	48	38	10
2	**Uyazigoqa izingubo ezilula (izikipha, amahembe);** Folds simple clothing (T-Shirts, shirts)	48	/	/
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH DRESSING SCORE			
	Washing Items			
1	**Uyazihlikihla izandla zombili khona ezozihlanza;** Rubs hands together to clean	24	36	-12
2	**Uyazesula ubuso bakhe uma enikezwe indwangu ngumuntu omdala;** Wipes own face when given a cloth by an adult	24	30	-6
3	**Uyazigeza izandla ngensipho;** Washes hands with soap	36	36	0
4	**Uyazigezisisa kahle izandla;** Washes hands thoroughly	60	42	18
5	**Uyazesula izandla ngethawula;** Dries hands with towel	60	37	23

6	**Uyazigeza ubuso cishe ngokwanele (kodwa hhayi ngemuva kwezindebe);** Washes face more or less adequately (not necessarily behind ears)	60		/
7	**Uyabomisa ubuso ngethawula;** Dries face with a towel	60		/
8	**Uyawugezisisa kahle umzimba, ungabuhlanganisi ubuso;** Washes body thoroughly, not including face	96		/
9	**Uyawomisisa kahle umzimba;** Dries body thoroughly	96	/	/
10	**Uyazigeza umzimba wonke kahle engasizwa;** Washes using the basin without help	120	/	/
	TOTAL WASHING SCORE:			
	Functional Mobiliy Associated with Washing			
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli ebhavini noma endishini;** Sits if supported by equipment or caregiver in a tub or basin	0	1	-1
2	**Uyazihlalela engasekeliwe futhi anyakaze kubhavu;** Sits unsupported and moves in the basin	4	10	-6
3	**Uyazilula izandla khona zizogezwa;** Holds hands out to be washed	18	12	6
4	**Uyazigibelela noma azishushuluzela ngezinqe engena noma ephuma kubhavu;** Climbs or slides on his or her bottom in and out of the basin	18	14	4
5	**Uyazihlalela phansi abuye azisukumele ephakathi endishini;** Sits down and stands up from inside the basin	24	12	12
6	**Uyazitholela insipho (kanye nendwangu yensipho, uma isetshenziswa);** Obtains soap (and soaps washcloth, if used)	36	36	0
7	**Uyazithathela amanzi endishini ukuze ageze;** Fills up a basin with water for washing	60	60	0

8	**Uyazichithela amanzi endishini emuva kokugeza, ayihlanze endishi;** Empties basin after washing, cleans the basin	72	50	22
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH WASHING SCORE:			
	Toileting Items			
1	**Uyalisebenzisa ipowa uma ebekwe kulo;** Uses potty/chamber pot when placed on it	12	31	-19
2	**Uyakwenza adinga ukukwenza ethoyilethi engasizwa ngaphandle uma esedinga ukusulwa izinqe;** Attends to toilet needs without help, except wiping	36	29	7
3	**Ulisebenzisile iphepha eliwulwelwesi lasethoyilethi futhi waliphonsa ethoyilethi walishaya lahamba;** Uses the toilet paper and throws it into the toilet	60		/
4	**Uyazinakekela uma esethoyilethi, azisule kahle futhi ageze nezandla;** Cares for himself at the toilet, cleans himself and washes hands	60		/
5	**Uyalisebenzisa ithoyilethi ngaphandle kosizo;** Uses toilet without help	60		/
	TOTAL TOILETING SCORE:			
	Functional mobility associated with Toileting			
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli;** Sits if supported by equipment or caregiver	8	2	6
2	**Uyazihlalela engasekeliwe noma esihlalweni esinepowa;** Sits unsupported on potty chair	24	21	3
3	**Uyakwazi ukuzihlalela abuye azisukumele elifushane noma epoweni;** Gets on and off potty	24	28	-4
4	**Uyakwazi ukuzihlalela abuye azisukumele labantu abadala;** Gets on and off adult sized toilet	48	18	30
5	**Uya kwazi ukuzi thathela iphepha lasethwayelethi;** Gets toilet paper	48	42	6

6	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to undo clothing fastenings, pulling down pants and underpants	60	48	12
7	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to pull pants and underpants back up and redo fastenings	60	48	12
8	**Uyazisulisisa kahle emuva kokukaka;** Wipes self thoroughly after bowel movements	60	48	12
9	**Uyakwazi ukuzihlalela abuye azisukele ethoyilethi, angadingi ukusebenzisa izingalo zakhe ukuze zimesekele uma ethwayiletile;** Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet	72	36	36
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH TOILETING SCORE:			
	Grooming Items			
1	**Uyawuvula umlomo khona uzomxubha amazinyo;** Opens mouth for teeth to be brushed	24	34	-10
2	**Uyavuma ukusulwa amafinyila;** Allows nose to be wiped	24	25	-1
3	**Uyafinya ebanjelwe ulwelwesana lwephepha;** Blows nose into held tissue	36	18	18
4	**Uyazisula amafinyila esebenzisa ulwelwesana lwephepha uma eceliwe;** Wipes nose using tissue on request	48	29	19
5	**Uyazibhulasha noma azikame izinwele;** Brushes or combs hair	60	48	12
6	**Uyaliqinisa ikhanda lime kahle ngesikhathi umkama izinwele;** Holds head in place while hair is combed	84	36	48
7	**Uyazigeza izinwele zakhe;** Washes his or her own hair	84	/	/

8	**Uyazifinyisa futhi azisule amafinyila ngaphandle kokucelwa;** Blows and wipes nose without request	84	42	42
9	**Uyazixubhisisa kahle amazinyo;** Thoroughly brushes teeth	84	/	/
	TOTAL GROOMING SCORE:			
	Functional Mobility Associated with Grooming			
1	**Uyasibamba isixubho;** Holds toothbrush	36	29	7
2	**Uyawufaka umuthi wokuxubha esixubheni;** Puts toothpaste on toothbrush	48	50	-2
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH GROOMING SCORE:			
	Functional Mobility Associated with Sleeping			
1	**Uyaphakama ahlale embhedeni noma;** Raises to a sitting position in bed	12	29	-17
2	**Alale phansi emuva kokuhlala osebeni lombhede;** Lies down from sitting at the edge of bed	48	34	14
3	**Uyazingenela futhi aziphumele embhedeni;** Gets in and out of bed	60	40	20
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH SLEEPING SCORE:			
	General functional mobility Items			
1	**Uyeluleka abambe into ebekwe eduzane;** Reaches out and grasps an object placed nearby	4	15	-11
2	**Uyeluleka athathe izinto ngokugoba aye phambili;** Reaches for objects by leaning forward	6	16	-10
3	**Uyayinyakazisa into ayiyise emuva naphambili esebenzisa isandla esisodwa ayiyise kwesinye;** Moves an object back and forth from one hand to another	18	11	7

4	**Uyazihudula izinto phansi;** Moves objects along the floor	24	14	10
5	**Ukuphatha izinto ezinkulu ngokwanele ezidinga ukuphathwa ngezandla ezimbili;** Carries objects large enough to require two hands	24	29	-5
6	**Ukuphatha izinto ezincane ngokwanele eziphatheka ngesandla esisodwa;** Carries objects small enough to be held in one hand	24	19	5
7	**Uyacokama ukuze afinyelele ezintweni;** Stands on tip toes to reach objects	24	23	1
8	**Uyazicosha izinto phansi;** Picks up things from the floor	24	20	4
9	**Uyaziphatha izinto ezichobokayo noma ezichithekayo;** Carries fragile or spillable objects	60	27	33
	TOTAL GENERAL FUNCTIONAL MOBILITY SCORE:			

Appendix S: Comparison of age of independence as determined during discussion groups and field test actual performance

	Eating Items	Age Range-discussion grp		
1	**Ugwinya uketshezi ngaphandle khwehlela;** Swallows liquids without coughing	birth	Indep by 2 years of age	Same
2	**Udla ukudla okubushelelezi okuthambile;** Eats smooth soft foods	4m	Indep by 2 years of age	Same
3	**Udla ukudla okugayiwe/izigaxa;** Eats ground/lumpy foods	6m	Indep by 2 years of age	Same
4	**Usebenzisa iminwe uma edla;** Uses fingers for eating	6m	Indep by 2 years of age	Same
5	**Uyaliluma iqhuzwana lokudla;** Bites off piece of food	8m	Indep by 2 years of age	Same
6	**Uphakamisa ibhodlela bese eziphuzela engasizwa muntu;** Picks up bottle and drinks independently	8m	Indep by 2 years of age	Same
7	**Uphakamisa inkomishi khona ezophuza;** Lifts cup to drink	10m	Indep by 2 years of age	Same
8	**Uyakuhlafuna ukudla okuqinileyo;** Chews solid food	12m	Indep by 2 years of age	Same
9	**Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe;** Feeds crackers, carrot sticks or other finger foods	12m	Indep by 2 years of age	Same
10	**Udla ukudla okusikiwe kwaba yizicucwana/izigaxana/amadayisana;** Eats cut up/chunky/diced foods	14m	Indep by 2 years of age	Same
11	**Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni;** Takes spoon filled with food to mouth	18m	Indep by 5 years of age	Later

12	**Uphuza ngenkomishi ngaphandle kosizo;** Drinks from a cup without help	2yr	Indep by 2 years of age	Same
13	**Uyakukhotha ukudla okuzungeze umlomo;** Licks food from around mouth	3yr	Indep by 2 years of age	Earlier
14	**Uzithelela yena uqobo ingilazi noma inkomishi yejusi;** Pours himself or herself a glass or cup of juice	3yr	Indep by 5 years of age	Later
15	**Uhluba ukudla oku-3 (ubhanana, inantshi, neqanda elibilisiweyo);** Peels 3 foods (banana, naartjie, boiled egg)	3yr	Indep by 5 years of age	Later
16	**Usebenzia ummese khona "ezogcoba" ibhotela, ujamu njll;** Uses a knife for "spreading" butter, jam etc.	4yr	Independent ABOVE 5 years of age	Later
17	**Usika ukudla okuthambile ngommese (ubhanana, izambane elibhakiweyo);** Cuts soft foods with knife (banana, baked potato)	4yr	Indep by 5 years of age	Same
18	**Usika inyama noma okunye ukudla kube izingcucwana ezizolumeka;** Cuts meat or other food into bite-sized pieces	4yr	Indep by 5 years of age	Same
19	**Uzidlela konke ukudla esebenzisa isipuni kanye;** Feeds self entire meal using spoon	6yr	Indep by 5 years of age	Earlier
	TOTAL EATING SCORE:			
	Functional mobility associated with Eating			
1	**Ufinyelela ebhodleleni noma enkomishini;** Reaches for bottle or cup	6m	Indep by 2 years of age	Same
2	**Uyalugoqoza uketshezi ngesipuni;** Stirs liquid with a spoon	6m	Indep by 3 years of age	Later
3	**Uyasula lapho kuchitheke khona, azithathele indwangu yakhe;** Cleans up spills, getting own cloth	8-12m	Indep by 5 years of age	Later
4	**Uphathe ipuleti elinokudla ngaphandle kokuchitha, waliyise etafuleni;** Carries a plate with food on it without	2yr	Indep by 3 years of age	Later

	spilling, to the table			
5	**Uyazelula ukuze afinyelele eshalofini eliphezulu;** Stretch to reach a high shelf	2 yr	Indep by 2 years of age	Same
6	**Ubuyisela isipuni endishini;** Returns spoon to bowl	3yr	Indep by 3 years of age	Same
7	**Uyayiphakamisa futhi ayibuyisele inkomishi ihlale iqonde etafuleni;** Picks up and replaces cup upright on the table	3yr	Indep by 5 years of age	Later
8	**Uphatha inkomishi egcwaliswe ujusi ngaphandle kokuchitheka;** Carries cup filled with juice without spilling	3yr	Indep by 5 years of age	Later
9	**Uyalivula ibhokisi lobisi okanye lejusi;** Opens milk or juice box	4yr	Indep by 5 years of age	Same
10	**Ulungisa isemeshi noma esinye isinekhi;** Prepares sandwich or other snack	6yr	Indep by 5 years of age	Earlier
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH EATING SCORE:			
	Dressing			
1	**Uyazikhumula amasokisi kanye nezicathulo ezingafaswa;** Removes socks and unfastened shoes	8m	Indep by 3 years of age	Later
2	**Uyazifaka izicathulo ezingafaswa;** Puts on unfastened shoes	12m	Indep by 2 years of age	Same
3	**Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa);** Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners)	14m	Indep by 3 years of age	Later
4	**Uyazigqokisa isikibha,ingubo noma ijezi okuxegayo;** Puts on loose T-shirt, dress or jersey	2yr	Indep by 5 years of age	Later
5	**Uyazikhumula ibhulukwe elinelastiki okhalo;** Removes pants with elastic waist	2yr	Indep by 3 years of age	Later

6	**Uyaziqaqa izintambo zezicathulo;** Unties shoes	2yr	Indep by 3 years of age	Later
7	**Uyazikhumula ibhantshi uma lingafasiwe;** Takes off Jacket when unfastened	2yr	Indep by 3 years of age	Later
8	**Uyazigqokisa isigqoko;** Puts on a hat	2yr	Indep by 2 years of age	Same
9	**Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa;** Puts on and removes a front opening shirt, not including fasteners	3yr	Indep by 5 years of age	Later
10	**Uyazigqokisa noma azikhumule ihembe elivuleka ngaphambili, okuhlanganisa okokufasa;** Puts on and removes front opening shirt, including fasteners	3yr	Indep by 5 years of age	Later
11	**Uyazigqokisa ibhulukwe elinelastiki okhalo;** Puts on pants with elastic waist	3yr	Indep by 3 years of age	Same
12	**Uyazikhumula ibhulukwe, elinga fasiwe;** Removes pants including unfastening	3yr	Indep by 3 years of age	Same
13	**Uyalikhumula ibhande;** Unbuckles belt	4yr	Indep by 5 years of age	Same
14	**Uyazigqokisa ibhulukwe , okuhlanganisa ukulifasa;** Puts on pants, including fastening	4yr	Independent ABOVE 5 years of age	Later
15	**Uyazigqokisa amasokisi;** Puts on socks	4yr	Indep by 3 years of age	Earlier
16	**Uyazigqokisa izicathulo onyaweni okuyilo;** Puts shoes on the correct feet	4yr	Indep by 3 years of age	Earlier
17	**Asebenzise kahle okokokufasa ukungamavelikho;** Manages velcro fasteners	4yr	Indep by 3 years of age	Earlier
18	**Uyazibopha ibhande;** Buckles belt	4yr	Indep by 5 years of age	Same

19	**Uyazifasa izinkinobho abuye aziqaqe izinkinobho;** Buttons and unbuttons	5yr	Indep by 5 years of age	Same
20	**Uyazibopha izintambo zezicathulo;** Ties shoelaces	5yr	Indep by 5 years of age	Same
21	**Uyazigqokisa ibhande alifake emalupheni;** Puts belt through belt loops	5yr	Indep by 5 years of age	Same
22	**Uyazifasa abuye aqaqe uziphu, engasizwa;** Zips and unzips without help	6yr	Indep by 3 years of age	Earlier
23	**Uyazigqokisa amagilavu;** Puts on gloves	6yr	Indep by 5 years of age	Earlier
	TOTAL DRESSING SCORE			
	Functional Mobility Associated with Dressing			
1	**Uyalibona ingemuva lezingubo;** Finds back of clothing	4yr	Indep by 5 years of age	Same
2	**Uyazigoqa izingubo ezilula (izikipha, amahembe);** Folds simple clothing (T-Shirts, shirts)	4yr	Indep by 5 years of age	Same
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH DRESSING SCORE			
	Washing Items			
1	**Uyazihlikihla izandla zombili khona ezozihlanza;** Rubs hands together to clean	2yr	Indep by 3 years of age	Later
2	**Uyazesula ubuso bakhe uma enikezwe indwangu ngumuntu omdala;** Wipes own face when given a cloth by an adult	2yr	Indep by 3 years of age	Later
3	**Uyazigeza izandla ngensipho;** Washes hands with soap	3yr	Indep by 3 years of age	Same
4	**Uyazigezisisa kahle izandla;** Washes hands thoroughly	5yr	Indep by 5 years of age	Same

5	**Uyazesula izandla ngethawula;** Dries hands with towel	5yr	Indep by 3 years of age	Earlier
6	**Uyazigeza ubuso cishe ngokwanele (kodwa hhayi ngemuva kwezindebe);** Washes face more or less adequately (not necessarily behind ears)	5yr	Indep by 5 years of age	Same
7	**Uyabomisa ubuso ngethawula;** Dries face with a towel	5yr	Indep by 5 years of age	Same
8	**Uyawugezisisa kahle umzimba, ungabuhlanganisi ubuso;** Washes body thoroughly, not including face	8yr	Indep by 5 years of age	Earlier
9	**Uyawomisisa kahle umzimba;** Dries body thoroughly	8yr	Independent ABOVE 5 years of age	Same
10	**Uyazigeza umzimba wonke kahle engasizwa;** Washes using the basin without help	10yr	Independent ABOVE 5 years of age	Same
	TOTAL WASHING SCORE:			
	Functional Mobiliy Associated with Washing			
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli ebhavini noma endishini;** Sits if supported by equipment or caregiver in a tub or basin	birth	Indep by 2 years of age	Same
2	**Uyazihlalela engasekeliwe futhi anyakaze kubhavu;** Sits unsupported and moves in the basin	4m	Indep by 2 years of age	Same
3	**Uyazilula izandla khona zizogezwa;** Holds hands out to be washed	18m	Indep by 2 years of age	Same
4	**Uyazigibelela noma azishushuluzela ngezinqe engena noma ephuma kubhavu;** Climbs or slides on his or her bottom in and out of the basin	18m	Indep by 2 years of age	Same
5	**Uyazihlalela phansi abuye azisukumele ephakathi endishini;** Sits down and stands up from inside the basin	2yr	Indep by 2 years of age	Same
6	**Uyazitholela insipho (kanye nendwangu yensipho, uma isetshenziswa);** Obtains soap (and soaps washcloth, if used)	3yr	Indep by 3 years of age	Same

7	**Uyazithathela amanzi endishini ukuze ageze;** Fills up a basin with water for washing	5yr	Indep by 5 years of age	Same
8	**Uyazichithela amanzi endishini emuva kokugeza, ayihlanze endishi;** Empties basin after washing, cleans the basin	6yr	Indep by 5 years of age	Earlier
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH WASHING SCORE:			
	Toileting Items			
1	**Uyalisebenzisa ipowa uma ebekwe kulo;** Uses potty/chamber pot when placed on it	1yr	Indep by 2 years of age	Same
2	**Uyakwenza adinga ukukwenza ethoyilethi engasizwa ngaphandle uma esedinga ukusulwa izinqe;** Attends to toilet needs without help, except wiping	3yr	Indep by 3 years of age	Same
3	**Ulisebenzisile iphepha eliwulwelwesi lasethoyilethi futhi waliphonsa ethoyilethi walishaya lahamba;** Uses the toilet paper and throws it into the toilet	5yr	Indep by 5 years of age	Same
4	**Uyazinakekela uma esethoyilethi, azisule kahle futhi ageze nezandla;** Cares for himself/herself at the toilet, cleans himself/herself and washes hands	6yr	Indep by 5 years of age	Earlier
5	**Uyalisebenzisa ithoyilethi ngaphandle kosizo;** Uses toilet without help	6yr	Indep by 5 years of age	Earlier
	TOTAL TOILETING SCORE:			
	Functional mobility associated with Toileting			
1	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli;** Sits if supported by equipment or caregiver	8m	Indep by 2 years of age	Same
2	**Uyazihlalela engasekeliwe noma esihlalweni esinepowa;** Sits unsupported on potty chair	2yr	Indep by 2 years of age	Same
3	**Uyakwazi ukuzihlalela abuye azisukumele elifushane noma epoweni;** Gets on and off potty	2yr	Indep by 3 years of age	Later

4	**Uyakwazi ukuzihlalela abuye azisukumele labantu abadala;** Gets on and off adult sized toilet	4yr	Indep by 3 years of age	Earlier
5	**Uya kwazi ukuzi thathela iphepha lasethwayelethi;** Gets toilet paper	4yr	Indep by 3 years of age	Earlier
6	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to undo clothing fastenings, pulling down pants and underpants	5yr	Indep by 3 years of age	Earlier
7	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to pull pants and underpants back up and redo fastenings	5yr	Indep by 3 years of age	Earlier
8	**Uyazisulisisa kahle emuva kokukaka;** Wipes self thoroughly after bowel movements	5yr	Indep by 3 years of age	Earlier
9	**Uyakwazi ukuzihlalela abuye azisukele ethoyilethi, angadingi ukusebenzisa izingalo zakhe ukuze zimesekele uma ethwayiletile;** Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet	6yr	Independent ABOVE 5 years of age	Same
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH TOILETING SCORE:			
	Grooming Items			
1	**Uyawuvula umlomo khona uzomxubha amazinyo;** Opens mouth for teeth to be brushed	2yr	Indep by 2 years of age	Same
2	**Uyavuma ukusulwa amafinyila;** Allows nose to be wiped	2yr	Indep by 2 years of age	Same
3	**Uyafinya ebanjelwe ulwelwesana lwephepha;** Blows nose into held tissue	3yr	Indep by 2 years of age	Earlier
4	**Uyazisula amafinyila esebenzisa ulwelwesana lwephepha uma eceliwe;** Wipes nose using tissue on request	4yr	Indep by 2 years of age	Earlier

5	**Uyazibhulasha noma azikame izinwele;** Brushes or combs hair	5yr	Indep by 3 years of age	Earlier
6	**Uyaliqinisa ikhanda lime kahle ngesikhathi umkama izinwele;** Holds head in place while hair is combed	7yr	Indep by 3 years of age	Earlier
7	**Uyazigeza izinwele zakhe;** Washes his or her own hair	7yr	Indep by 5 years of age	Earlier
8	**Uyazifinyisa futhi azisule amafinyila ngaphandle kokucelwa;** Blows and wipes nose without request	7yr	Independent ABOVE 5 years of age	Same
9	**Uyazixubhisisa kahle amazinyo;** Thoroughly brushes teeth	7yr	Independent ABOVE 5 years of age	Same
	TOTAL GROOMING SCORE:			

	Functional Mobility Associated with Grooming			
1	**Uyasibamba isixubho;** Holds toothbrush	3yr	Indep by 3 years of age	Same
2	**Uyawufaka umuthi wokuxubha esixubheni;** Puts toothpaste on toothbrush	4yr	Indep by 5 years of age	Same
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH GROOMING SCORE:			
	Functional Mobility Associated with Sleeping			
1	**Uyaphakama ahlale embhedeni noma;** Raises to a sitting position in bed	1yr	Indep by 2 years of age	Same
2	**Alale phansi emuva kokuhlala osebeni lombhede;** Lies down from sitting at the edge of bed	4yr	Indep by 3 years of age	Earlier
3	**Uyazingenela futhi aziphumele embhedeni;** Gets in and out of bed	5yr	Indep by 5 years of age	Same
	TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH SLEEPING SCORE:			

	General functional mobility Items			
1	**Uyeluleka abambe into ebekwe eduzane;** Reaches out and grasps an object placed nearby	4m	Indep by 2 years of age	Same
2	**Uyeluleka athathe izinto ngokugoba aye phambili;** Reaches for objects by leaning forward	6m	Indep by 3 years of age	Later
3	**Uyayinyakazisa into ayiyise emuva naphambili esebenzisa isandla esisodwa ayiyise kwesinye;** Moves an object back and fort271-279h from one hand to another	18m	Indep by 3 years of age	Later
4	**Uyazihudula izinto phansi;** Moves objects along the floor	2yr	Indep by 2 years of age	Same
5	**Ukuphatha izinto ezinkulu ngokwanele ezidinga ukuphathwa ngezandla ezimbili;** Carries objects large enough to require two hands	2yr	Indep by 3 years of age	Later
6	**Ukuphatha izinto ezincane ngokwanele eziphatheka ngesandla esisodwa;** Carries objects small enough to be held in one hand	2yr	Indep by 2 years of age	Same
7	**Uyacokama ukuze afinyelele ezintweni;** Stands on tip toes to reach objects	2yr	Indep by 3 years of age	Later
8	**Uyazicosha izinto phansi;** Picks up things from the floor	2yr	Indep by 2 years of age	Same
9	**Uyaziphatha izinto ezichobokayo noma ezichithekayo;** Carries fragile or spillable objects	5yr	Independent ABOVE 5 years of age	Later
	TOTAL GENERAL FUNCTIONAL MOBILITY SCORE:			

Appendix T: Final version of the Self Care Inventory for Children with Cerebral Palsy (SCICP) with scoring and administration instructions

Administration

- Ask parent or caregiver whether their child can perform each item independently.
- If the child is unable to perform the item independently, ask the parent or caregiver how much help the child needs to perform this task and what kind of help the child needs to complete this task.
- Observe the child perform each item.
- Score based on observation, using table below.
- If the performance and caregiver report differs make notes in the comments section.

Scoring

Score Number	Score Description
1	Child is unable to do the task at all Ingane ayikwazi nhlobo ukwenza umsebenzana
2	Child is almost able to do the task, but needs a lot of help Ingane iyakwazi ukwenza umsebenzana kodwa idinga ukusizwa kakhulu • Help is from caregiver; environmental support and adaptations; standing frame; chair; walker; facilitation • Okuvela kumnakekeli, ukusekela futhi ukuguqula isimo sendawo ekuyo, uhlaka lokuma, isihlalo, insiza yokuhamba, ukumsiza
3	Child is almost able to do the task on his own, but requires a little bit of help Ingane icishe yakwazi ukwenza umsebenzana kodwa idinga ukusizwa kancane • Help is from built up spoon; modified Velcro fastenings; extra time; universal cuff • Kusukela esipunini esakhiweyo, okokufasa okujikwe kwafaneleka, isikhathi esithe esithe xaxa, okufakwa esihlakaleni okujwayelekileyo
4	Child is able to do the task without any help Ingane iyakwazi ukwenza lo msebenzana ngaphandle kosizo

		Items	Scoring				
	Age of Independence (years)	**Eating Items**	**1**	**2**	**3**	**4**	**Comments**
1	2	**Ugwinya uketshezi ngaphandle khwehlela;** Swallows liquids without coughing					
2	2	**Udla ukudla okubushelelezi okuthambile;** Eats smooth soft foods					
3	2	**Usebenzisa iminwe uma edla;** Uses fingers for eating					
4	2	**Udla ukudla okugayiwe/izigaxa;** Eats ground/lumpy foods					
5	2	**Uphakamisa inkomishi khona ezophuza;** Lifts cup to drink					
6	2	**Uyaliluma iqhuzwana lokudla;** Bites off piece of food					
7	2	**Uphakamisa ibhodlela bese eziphuzela engasizwa muntu;** Picks up bottle and drinks independently					
8	2	**Uyakuhlafuna ukudla okuqinileyo;** Chews solid food					

9	2	**Udla ukudla okusikiwe kwaba yizicucwana/izigaxana/amadayisana;** Eats cut up/chunky/diced foods					
10	2	**Uyakukhotha ukudla okuzungeze umlomo;** Licks food from around mouth					
11	2	**Uyazidlela yena amakhrekhazi, izindukwana zezaqathi noma okunye ukudla okudleka ngeminwe;** Feeds crackers, carrot sticks or other finger foods					
12	2	**Uthatha isipuni esigcwaliswe ukudla asiyise emlonyeni;** Takes spoon filled with food to mouth					
13	5	**Uphuza ngenkomishi ngaphandle kosizo;** Drinks from a cup without help					
14	5	**Uzidlela konke ukudla esebenzisa isipuni kanye;** Feeds self entire meal using spoon					
15	5	**Uzithelela yena uqobo ingilazi noma inkomishi yejusi;** Pours himself or herself a glass or cup of juice					

16	5	**Usebenzia ummese khona "ezogcoba" ibhotela, ujamu njll;** Uses a knife for "spreading" butter, jam etc.					
17	5	**Usika ukudla okuthambile ngommese (ubhanana, izambane elibhakiweyo);** Cuts soft foods with knife (banana, baked potato)					
18	5	**Usika inyama noma okunye ukudla kube izingcucwana ezizolumeka;** Cuts meat or other food into bite-sized pieces					
19		**Uhluba ukudla oku-3 (ubhanana, inantshi, neqanda elibilisiweyo);** Peels 3 foods (banana, naartjie, boiled egg)					
		TOTAL EATING SCORE:				**/76**	
		Functional mobility associated with Eating	**1**	**2**	**3**	**4**	**Comments**
1	2	**Ufinyelela ebhodleleni noma enkomishini;** Reaches for bottle or cup					
2	2	**Uphathe ipuleti elinokudla ngaphandle kokuchitha, waliyise etafuleni;** Carries a plate with food on it without spilling, to the table					
3	3	**Uyalugoqoza uketshezi ngesipuni;** Stirs liquid with a spoon					

4	3	**Ubuyisela isipuni endishini;** Returns spoon to bowl					
5	3	**Uyayiphakamisa futhi ayibuyisele inkomishi ihlale iqonde etafuleni;** Picks up and replaces cup upright on the table					
6	5	**Uyazelula ukuze afinyelele eshalofini eliphezulu;** Stretches to reach a high shelf					
7	5	**Uyasula lapho kuchitheke khona, azithathele indwangu yakhe;** Cleans up spills, getting own cloth					
8	5	**Uphatha inkomishi egcwaliswe ujusi ngaphandle kokuchitheka;** Carries cup filled with juice without spilling					
9	5	**Uyalivula ibhokisi lobisi okanye lejusi;** Opens milk or juice box					
10	5	**Ulungisa isemeshi noma esinye isinekhi;** Prepares sandwich or other snack					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH EATING SCORE:				**/40**	
		Dressing	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyazifaka izicathulo ezingafaswa;** Puts on unfastened shoes					

2	2	**Uyazikhumula, impahla noma ijezi okuxegayo (impahla engena mkhono okokufasa);** Removes loose T-shirt skipper, dress or jersey (pullover garment without fasteners)					
3	3	**Uyazikhumula amasokisi kanye nezicathulo ezingafaswa;** Removes socks and unfastened shoes					
4	3	**Uyazikhumula ibhulukwe elinelastiki okhalo;** Removes pants with elastic waist					
5	3	**Uyazikhumula ibhantshi uma lingafasiwe;** Takes off Jacket when unfastened					
6	3	**Asebenzise kahle okokokufasa ukungamavelikho;** Manages velcro fasteners					
7	3	**Uyaziqaqa izintambo zezicathulo;** Unties shoes					
8	3	**Uyazigqokisa amasokisi;** Puts on socks					
9	3	**Uyazigqokisa izicathulo onyaweni okuyilo;** Puts shoes on the correct feet					
10	3	**Uyazifasa izinkinobho abuye aziqaqe izinkinobho;** Buttons and unbuttons					

11	3	**Uyazigqokisa ibhulukwe , okuhlanganisa ukulifasa;** Puts on pants, including fastening					
12	3	**Uyazikhumula ibhulukwe, elinga fasiwe;** Removes pants including unfastening					
13	3	**Uyazibopha izintambo zezicathulo;** Ties shoelaces					
14	5	**Uyazigqokisa isigqoko;** Puts on a hat					
15	5	**Uyazifasa abuye aqaqe uziphu, engasizwa;** Zips and unzips without help					
16	5	**Uyazigqokisa ibhulukwe elinelastiki okhalo;** Puts on pants with elastic waist					
17	5	**Uyazigqokisa isikibha,ingubo noma ijezi okuxegayo;** Puts on loose T-shirt, dress or jersey					
18	5	**Uyazigqokisa futhi azikhumule ihembe elivuleka ngaphambili, ayivulele okokufasa;** Puts on and removes a front opening shirt, not including fasteners					
19	5	**Uyazigqokisa amagilavu;** Puts on gloves					

20	5	**Uyazigqokisa noma azikhumule ihembe elivuleka ngaphambili, okuhlanganisa okokufasa;** Puts on and removes front opening shirt, including fasteners					
21	5	**Uyazibopha ibhande;** Buckles belt					
22	5	**Uyazigqokisa ibhande alifake emalupheni;** Puts belt through belt loops					
23		**Uyalikhumula ibhande;** Unbuckles belt					
		TOTAL DRESSING SCORE				**/92**	
		Functional Mobility Associated with Dressing	**1**	**2**	**3**	**4**	**Comments**
1	5	**Uyalibona ingemuva lezingubo;** Finds back of clothing					
2	5	**Uyazigoqa izingubo ezilula (izikipha, amahembe);** Folds simple clothing (T-Shirts, shirts)					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH DRESSING SCORE				**/8**	
		Washing Items	**1**	**2**	**3**	**4**	**Comments**
1	3	**Uyazesula ubuso bakhe uma enikezwe indwangu ngumuntu omdala;** Wipes own face when given a cloth by an adult					

2	3	**Uyazihlikihla izandla zombili khona ezozihlanza;** Rubs hands together to clean					
3	3	**Uyazigeza izandla ngensipho;** Washes hands with soap					
4	3	**Uyazigezisisa kahle izandla;** Washes hands thoroughly					
5	5	**Uyazesula izandla ngethawula;** Dries hands with towel					
6	5	**Uyazigeza ubuso cishe ngokwanele (kodwa hhayi ngemuva kwezindebe);** Washes face more or less adequately (not necessarily behind ears)					
7	5	**Uyabomisa ubuso ngethawula;** Dries face with a towel					
8	5	**Uyawugezisisa kahle umzimba, ungabuhlanganisi ubuso;** Washes body thoroughly, not including face					
9		**Uyawomisisa kahle umzimba;** Dries body thoroughly					
10		**Uyazigeza umzimba wonke kahle engasizwa;** Washes using the basin without help					
		TOTAL WASHING SCORE:				**/40**	

		Functional Mobiliy Associated with Washing	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli ebhavini noma endishini;** Sits if supported by equipment or caregiver in a tub or basin					
2	2	**Uyazihlalela engasekeliwe futhi anyakaze kubhavu;** Sits unsupported and moves in the basin					
3	2	**Uyazilula izandla khona zizogezwa;** Holds hands out to be washed					
4	2	**Uyazihlalela phansi abuye azisukumele ephakathi endishini;** Sits down and stands up from inside the basin					
5	2	**Uyazigibelela noma azishushuluzela ngezinqe engena noma ephuma kubhavu;** Climbs or slides on his or her bottom in and out of the basin					
6	3	**Uyazitholela insipho (kanye nendwangu yensipho, uma isetshenziswa);** Obtains soap (and soaps washcloth, if used)					

7	5	**Uyazichithela amanzi endishini emuva kokugeza, ayihlanze endishi;** Empties basin after washing, clean the basin					
8	5	**Uyazithathela amanzi endishini ukuze ageze;** Fills up a basin with water for washing					
		TOTA FUNCTIONAL MOBILITY ASSOCIATED WITH WASHING SCORE:				**/32**	
		Toileting Items	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyakwenza adinga ukukwenza ethoyilethi engasizwa ngaphandle uma esedinga ukusulwa izinqe;** Attends to toilet needs without help, except wiping					
2	3	**Uyalisebenzisa ipowa uma ebekwe kulo;** Uses potty/chamber pot when placed on it					
3	5	**Ulisebenzisile iphepha eliwulwelwesi lasethoyilethi futhi waliphonsa ethoyilethi walishaya lahamba;** Uses the toilet paper and throws it into the toilet					

4	5	**Uyazinakekela uma esethoyilethi, azisule kahle futhi ageze nezandla;** Cares for himself at the toilet, cleans himself and washes hands					
5	5	**Uyalisebenzisa ithoyilethi ngaphandle kosizo;** Uses toilet without help					
		TOTAL TOILETING SCORE:				**/20**	
		Functional mobility associated with Toileting	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyazihlalela uma esekelwe ngento ethile noma ngumnakekeli;** Sits if supported by equipment or caregiver					
2	2	**Uyakwazi ukuzihlalela abuye azisukumele labantu abadala;** Gets on and off adult sized toilet					
3	3	**Uyazihlalela engasekeliwe noma esihlalweni esinepowa;** Sits unsupported on potty chair					
4	3	**Uyakwazi ukuzihlalela abuye azisukumele elifushane noma epoweni;** Gets on and off potty					

5	3	**Uyakwazi ukuzihlalela abuye azisukele ethoyilethi, angadingi ukusebenzisa izingalo zakhe ukuze zimesekele uma ethwayiletile;** Gets on and off toilet, not needing his or her arms to support himself or herself on the toilet					
6	3	**Uya kwazi ukuzi thathela iphepha lasethwayelethi;** Gets toilet paper					
7	3	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to undo clothing fastenings, pulling down pants and underpants					
8	3	**Uyakwazi ukuqaqa okokokufasa, ukwehlisa amabhulukwe kanye nokwangaphansi, nokuwagqoka kanye nokufasa;** Manages to pull pants and underpants back up and redo fastenings					
9	5	**Uyazisulisisa kahle emuva kokukaka;** Wipes self thoroughly after bowel movements					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH TOILETING SCORE:				**/36**	
		Grooming Items	**1**	**2**	**3**	**4**	**Comments**

1	2	**Uyafinya ebanjelwe ulwelwesana lwephepha;** Blows nose into held tissue					
2	2	**Uyavuma ukusulwa amafinyila;** Allows nose to be wiped					
3	2	**Uyazisula amafinyila esebenzisa ulwelwesana lwephepha uma eceliwe;** Wipes nose using tissue on request					
4	2	**Uyawuvula umlomo khona uzomxubha amazinyo;** Opens mouth for teeth to be brushed					
5	3	**Uyaliqinisa ikhanda lime kahle ngesikhathi umkama izinwele;** Holds head in place while hair is combed					
6	3	**Uyazifinyisa futhi azisule amafinyila ngaphandle kokucelwa;** Blows and wipes nose without request					
7	5	**Uyazibhulasha noma azikame izinwele;** Brushes or combs hair					
8		**Uyazigeza izinwele zakhe;** Washes his or her own hair					
9		**Uyazixubhisisa kahle amazinyo;** Thoroughly brushes teeth					
		TOTAL GROOMING SCORE:				**/36**	

		Functional Mobility Associated with Grooming	**1**	**2**	**3**	**4**	**Comments**
1	3	**Uyasibamba isixubho;** Holds toothbrush					
2	5	**Uyawufaka umuthi wokuxubha esixubheni;** Puts toothpaste on toothbrush					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH GROOMING SCORE:				**/8**	
		Functional Mobility Associated with Sleeping	**1**	**2**	**3**	**4**	**Comments**
1	2	**Uyaphakama ahlale embhedeni noma;** Raises to a sitting position in bed					
2	3	**Alale phansi emuva kokuhlala osebeni lombhede;** Lies down from sitting at the edge of bed					
3	5	**Uyazingenela futhi aziphumele embhedeni;** Gets in and out of bed					
		TOTAL FUNCTIONAL MOBILITY ASSOCIATED WITH SLEEPING SCORE:				**/12**	

		General functional mobility Items	1	2	3	4	Comments
1	2	**Uyayinyakazisa into ayiyise emuva naphambili esebenzisa isandla esisodwa ayiyise kwesinye;** Moves an object back and forth from one hand to another					
2	2	**Uyeluleka athathe izinto ngokugoba aye phambili;** Reaches for objects by leaning forward					
3	2	**Uyazicosha izinto phansi;** Picks up things from the floor					
4	2	**Uyaziphatha izinto ezichobokayo noma ezichithekayo;** Carries fragile or spillable objects					
5	3	**Uyazihudula izinto phansi;** Moves objects along the floor					
6	3	**Uyeluleka abambe into ebekwe eduzane;** Reaches out and grasps an object placed nearby					
7	3	**Ukuphatha izinto ezincane ngokwanele eziphatheka ngesandla esisodwa;** Carries objects small enough to be held in one hand					

8	3	**Uyacokama ukuze afinyelele ezintweni;** Stands on tip toes to reach objects					
9		**Ukuphatha izinto ezinkulu ngokwanele ezidinga ukuphathwa ngezandla ezimbili;** Carries objects large enough to require two hands					
		TOTAL GENERAL FUNCTIONAL MOBILITY SCORE:				**/36**	

Scoring Form

Domain	Total Score	Percentage
Eating	/76	
Functional mobility associated with eating	/40	
Dressing	/92	
Functional mobility associated with dressing	/8	
Washing	/40	
Functional mobility associated with washing	/32	
Toileting	/20	
Functional mobility associated with toileting	/36	
Grooming	/36	
Functional mobility associated with grooming	/8	
Functional mobility associated with sleeping	/12	
General functional mobility items	/36	
Overall Total Point Score:	/436	