CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In 1994, Ruth Humphrey, an American professor of Occupational Therapy wrote: “There are two arguments for the continued study of parents and caregivers of children with special needs. Firstly, identifying and adjusting services to different values and beliefs of individual parents is a critical step toward establishing a collaborative parent-therapist relationship and secondly, recognizing the importance of context on skill acquisition and performance intervention may lead to helping the caregiver identify and adopt different caregiving behaviours.” (p. 687)

In a country such as South Africa, where the gap between therapist and parent is even wider than it is in the USA, and where parents’ perceptions and expectations of therapy intervention have rarely been formally studied, the case for understanding parental participation in rehabilitation programmes becomes even stronger.

In this chapter, the literature is reviewed in an attempt to provide an overall view of factors that need to be taken into account when designing and implementing therapy programmes for children with CP living in disadvantaged settings. The chapter is divided into five main sections:

1. Disability, culture and coping with a child with CP.
2. Frameworks for structuring therapy services for children with CP.
3. An overview of current therapeutic interventions for children with CP.
4. Parental involvement in therapy programmes.
5. A review of outcome measures and issues surrounding the
development, translation and cross-cultural applicability of
measuring tools.

Figure 2.1 provides an outline of the aspects covered in this chapter.

Figure 2.1 Aspects covered in this literature review
The literature search was conducted on the following databases: Medline (Pubmed), CINAHL, PsychInfo and Pedro and included all English articles between 1980 and 2005. A hand search was also done and selected secondary references were followed up. Texts on related topics were also included. Keywords used were: cerebral palsy, family-centred services, developing countries, culture, therapy interventions, outcome measures and parents.

Whilst there is a large body of literature relating to therapy interventions, family-centred services and outcome measures in well-resourced settings, literature pertaining to these issues in disadvantaged settings is scanty. This literature review attempts to assimilate the available literature and describe the findings in an integrated manner. As there were very few studies directly comparable to the present study, the literature review is mostly descriptive in nature and critical comment is given on those papers where it is appropriate.

2.2 DISABILITY, CULTURE AND COPING WITH A CHILD WITH CEREBRAL PALSY

Whilst disability is a universal trait of human beings, the cultural environment affects the way in which people with disabilities perceive themselves, or are perceived by others, and this can influence their social well-being, economic status and health status. The concept of health and well-being is linked to the way in which people construct reality and is influenced by culturally defined belief systems and expectations (Brookins, 1993). Thus cultural sensitivity and affirmation are critical to delivering effective health and rehabilitation care.

This section explores the intersection between culture and disability, specifically regarding a diagnosis of cerebral palsy. Cerebral palsy is briefly described and factors which influence the health and well-being of caregivers of children with cerebral palsy are summarised.
2.2.1 Culture, disability and the family: acknowledging the influence of the cultural environment

In solving problems and managing family life when a child has a chronic illness or disability, the cultural environment of the family fundamentally influences the processes of adaptation to the disability (Groce and Zola, 1993; McCubbin et al., 1993). These processes of family life are the way in which families give “meaning” to having a child with a disability and they play a fundamental role in shaping the family’s responses to medical care, which includes rehabilitation therapy (McCubbin et al., 1993). Therefore it is important for health care providers to understand traditional beliefs, attitudes and practices pertaining to disability (Groce and Zola, 1993; McConkey 1995; Yousafzai et al., 2003).

Culture and ethnicity are defined as “the customary beliefs, integrated patterns of human behaviour (for example, thought, speech and action), social forms and traits of a group. They are nurtured, cultivated and transferred across generations and among family members through traditions and celebrations, as well as through problem solving efforts” (McCubbin et al., 1993, p. 1064). McGruder (1998, p.55) notes that “culture is invisible, especially to the one who carries it and participates in it. It is taken for granted. When we come in contact with cultural ways that are different from our own, we perceive the “otherness”, the strangeness of the other groups’ ways.” Individuals depend on familiar cultural cues, such as communication styles and customs, as they grow and develop, but may not be consciously aware of these cues (Trafford, 1996).

In the context of this study, the obvious question to ask is “What then is the ‘African’ perspective on disability and how is this shaped by culture?” However, this is clearly a naïve and unanswerable question (Marshall and Largo, 1999) and speaks to a lack of understanding of cultural diversity (Groce and Zola, 1993). The challenge for health professionals lies in exploring the diverse aspects of culture that shape family problem solving and adaptation without making global assumptions and generalisations.
In one of the few studies on culture and disability in Africa, Whyte and Ingstad (1995, p. 7) contend that: “The concept of disability itself cannot be taken for granted. In many cultures, one cannot be “disabled” for the simple reason that “disability” as a recognised category does not exist. There are blind people and lame people and “slow” people, but “the disabled” as a general term does not translate easily into many languages. The concepts of disability, handicap, and rehabilitation emerged in particular historical circumstances in Europe.” Thus they suggest that the social identity of being “disabled” is historically a European concept which does not easily translate into all African cultures. Similarly, the word “cerebral palsy” has no equivalent meaning in many African languages.

A cursory review of the literature on disability across ethnic groups often reveals meaningful but rather stereotypical descriptions of family beliefs and traditions. For example, there appears to be a widespread belief that the birth of a disabled child is linked to evil spirits and/or parental misconduct (Scheer and Groce, 1988 cited in McConkey, 1995). Other cultures may view disabled people as a curse resulting from a sin committed by an ancestor or by the affected person in a previous existence. Such explanations often result in parental feelings of shame or guilt with consequences such as hiding the affected child from neighbours. Consequently, families may seek assistance from traditional healers rather than from services based upon modern biomedical thinking and values (McConkey, 1995). In other families, there may be fatalistic acceptance of the disability with notions that they have been given a special responsibility. This can result in low expectations of the child and an over-emphasis on physical care and protection (McConkey, 1995).

It must be noted that these are broad generalisations and that variations in beliefs exist both across cultures and among families within a culture. In addition, these beliefs may be amenable to change (McConkey, 1995). Attempts to homogenise ethnic groups reinforces stereotyping and oversimplification (McCubbin et al., 1993; Groce and Zola 1993; Chiang and Carlson, 2003). This
masks the variability which exists within ethnic groups. However, as McCubbin et al. (1993) point out, the absence of research that attempts to understand the within-group diversity strengthens the dependence on these stereotypes. This supports the argument for the necessity of this study – to shed some light on how families in a disadvantaged South African setting adapt to taking care of a child who has CP.

A common stereotype is that children with disabilities living in poor traditional communities are often hidden away in their homes. Ingstad (1995; 1999), challenges the “myth of the hidden disabled” and suggests it was highlighted and strengthened through the mass media’s focus on cases of neglect and misery in the developing world in order to raise money in the “developed” countries.

Ingstad (1995) followed up eight cases of reported abuse, neglect or hiding of disabled people reported by rehabilitation workers in Botswana. When looked at more closely, only two proved to be so to some extent, and even here, the situation of the disabled person was mainly a reflection of the general hardship under which all household members were living. It was rather community attitudes to disability combined with an ignorance of all the facts that had prejudged the families’ behaviour labelling it as abuse, neglect or hiding the child. When families are unable to cope with the care of a disabled relative it is likely to be because of poverty, a lack of support and knowledge about what can be done to improve the situation rather than as a result of lack of love and negative attitudes (Ingstad, 1999).

Hartley et al. (2005) point out that baseline information is lacking about how families with a disabled child in resource-constrained settings cope. One consequence of this is that rehabilitation in these areas is often based on myths regarding attitudes towards, and care of, children with disabilities together with implementing simplified rehabilitation practice from income-rich countries. This may be at odds with local reality (Ingstad, 1999; Hartley et al., 2005).
To understand how families cope with the care of a disabled child, how disabled people cope with their life situation, and how people relate to disabled friends and relatives, living people are the starting point. Actual life situations need to be analysed in order to identify the constraints, possibilities, beliefs and values that generate patterns of coping with disability (Ingstad, 1995). Adopting this approach may avoid the risk of creating stereotypes (Ingstad, 1995).

As Groce (1999a, p. 38) observes “understanding socio-cultural models of disability is of more than academic interest. Unless programmes for individuals with disabilities are designed in a culturally appropriate way, the opportunity to make real and effective change is lost.” She continues: “Rehabilitation professionals are too often trained to concentrate on clinical goals – restoring function in a specific set of muscles or training an individual in daily living skills, while ignoring the larger social networks and culture matrix in which those with whom they work must live. Being aware of the weaknesses (and strengths) of the surrounding community enables rehabilitation professionals to work far more effectively with and advocate in partnership with those whom they serve.” (Groce 1999a, p. 38)

The potential for miscommunication and misunderstanding increases when the family and therapist come from different cultural backgrounds (Black and Purnell, 2002). This has consequences for rendering effective care, for example, a caregiver may not respond to a therapist’s advice and intervention if he or she does not agree with or understand the underlying rationale for the treatment (Black and Purnell, 2002). McCubbin et al. (1993) suggest that there are several factors which determine the ease with which health care professionals incorporate cultural or ethnic factors into their practice when dealing with caregivers and families of children with disabilities:

- The cultural or ethnic background of the health care professional.
- The sensitivity and competence of the health care professional to deal with cultural and ethnic factors.
• The degree of conflict between the family's paradigm for care and treatment and the type of intervention offered by the health care professional.

• The residual and often asymptomatic influence of racism, poverty and disempowerment that often accompanies cultural and ethnic consideration.

In summary, cultural and ethnic factors play a significant role in understanding how families of children with cerebral palsy cope, adapt and attach meaning to the diagnosis and to the concept of disability. When working in a multi-cultural setting, these factors cannot be ignored and generalisations and stereotypes should be avoided. These issues need to be explored and understood if therapy intervention strategies are to be appropriate and effective.

Mindful of this background, the term Cerebral Palsy, the disability that is the focus of this study, is explained in the following section.

2.2.2 Cerebral Palsy

Cerebral palsy describes "a group of disorders of the development of movement and posture causing activity limitation, which 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/or behaviour, and/or by a seizure disorder" (Rosenbaum et al., 2005, p. 572). Thus the hallmark of any person with CP is a disorder in the development of motor function (Rosenbaum et al., 2002).

Except in its mildest forms, CP can be recognised in the first 12 to 18 months of life (Rosenbaum, 2003). The condition presents when children fail to reach their motor milestones and when they show differences in the quality of their motor patterns and development, such as asymmetry, or unusual muscle stiffness or floppiness. CP is usually characterised clinically by the parts of the body affected,
that is the limbs and/or the trunk, and the predominant motor disorder is referred to as spastic, dystonic, athetoid or ataxic (Cans, 2000). The child’s gross motor functional status can be categorised by using the five levels of the Gross Motor Function Classification System for cerebral palsy (GMFCS), a reliable and valid system (Palisano et al., 1997, Wood and Rosenbaum, 2000).

Whilst it is a non-progressive disorder, CP is a life-long condition. Children with CP grow up to be adults with CP and in addition to their primary motor disability, they are often further disadvantaged by accompanying neurodevelopmental disorders as well as by the negative attitudes and ignorance of the people around them.

CP is the commonest childhood physical disability occurring in 2 to 2.5 per 1000 live births in industrialised countries (Hagberg et al., 1996; Stanley et al., 2000). Accurate estimates of the prevalence of childhood disability in developing countries are lacking but rates are expected to be higher than in more developed countries (Davidson et al., 2003). The only population-based South African study suggested that the prevalence of CP in a rural part of Kwazulu-Natal may be as high as 10 per 1000 (Couper, 2002).

2.2.3 The health and well-being of caregivers of children with cerebral palsy
Existing literature supports the concept that caring for a child with a disability can have implications for the physical and mental health of caregivers (Brehaut et al., 2004). Parental adaptation and caregiver stress in families of children with a disability has been the subject of many studies in well-resourced settings (Erickson and Upshur, 1989; Cadman et al., 1991; Knussen and Sloper, 1992; Sloper and Turner, 1993; Manuel et al., 2003). Recently, increasing attention has been focused on understanding and measuring the health and well-being of parents of children with disabilities, specifically children with cerebral palsy (Raina et al., 2004; 2005; Brehaut et al., 2004).
Caregivers of children with disabilities spend more time in child-care activities and less time on socialisation and leisure activities compared with caregivers of children without disabilities (Crowe and Florez, 2006; Crowe, 1993). There is evidence that caregivers of children with disabilities are more likely to experience depression and distress (Cadman et al., 1991; Manuel et al., 2003); to report poorer general emotional health (Dyson, 1993), to have increased levels of stress and feelings of pessimism regarding the future (Dyson, 1993; Raina et al., 2004) and to feel that caregiving interferes with having time for themselves (Raina et al., 2004), compared to caregivers of children without disabilities. However, mediating factors include feelings of mastery of the care-giving situation and high self-esteem (Dunst et al., 1986), specific coping strategies (Knussen and Sloper, 1992), social and family support (Dunst et al., 1986; Frey et al., 1989; Gowen 1989; Knussen and Sloper, 1992; Dyson, 1993) and formal support services (Dunst et al., 1994).

To overcome the limitation of many of the studies in this field that tend to use traditional analytic approaches (that is, linear regression) to examine the relationship between a factor and the outcome after adjusting for other variables, Raina et al. (2004; 2005) proposed a single multidimensional model which examined the direct and indirect effects of a comprehensive set of variables on the health and well-being of caregivers. These variables included socio-economic factors, child characteristics (that is, child behaviour and functional status), caregiving demands and caregiver perceptions about formal care, caregiver intra-psychic factors, social support, family function, stress management and caregivers’ psychological and physical health. Structural equation modelling was used to test specific hypotheses outlined in their conceptual model. Results from this study revealed that the most important predictors of caregivers’ well-being were child behaviour, care-giving demands and family function (Raina et al., 2005).
It is not known whether these findings hold true in poorly-resourced areas or in a cross-cultural situation where environmental factors may be very different.

2.3 FRAMEWORKS FOR STRUCTURING THERAPY SERVICES FOR CHILDREN WITH CP

A distinction needs to be made between therapy interventions, which are the technical component of therapy, and the structure of service delivery. As Rosenbaum states “Service providers need to be aware that how we work may be as important as what we actually prescribe, and may in fact enhance or detract from the best advice we have to offer” (Rosenbaum, 2004, p. 22). This section reviews two frameworks for structuring services – the International Classification of Functioning, Disability and Health (ICF) and Family-Centred Services (FCS).

2.3.1 International Classification of Functioning, Disability and Health (ICF)

The ICF, developed and adopted by the World Health Organization in 2001 (World Health Organization, 2001; Schneider, Hurst, Miller and Ustun, 2003), provides a very useful framework for structuring intervention services for children with disabilities. It uses a bio-psychosocial model which fuses together elements of both the medical and social models of disability.

The ICF conceptualises disability to have a medical or health condition as one of its core components together with one or more related impairments. The health condition can be expressed at three different but equally important levels: body function and structure level; person or activity level; and participation or societal level. The ICF is not a hierarchical system. Rather there is a dynamic interaction between these three levels and the context of the individual – which includes personal and environmental factors.
The health condition may be diagnosable but frequently may not be clearly identifiable. Examples of a diagnosable condition include epilepsy; brain damage (resulting in conditions such as CP and intellectual impairments); physical abnormalities such as underdeveloped or missing limbs; malformations of various body organs; and genetic syndromes like Down syndrome. Frequently, the health condition is assumed through indirect diagnosis. For example, autism, childhood depression, and intellectual impairment are generally diagnosed on the basis of observed behaviours and not from a direct test for the health condition. These observable behaviours provide an indication of the child's impairments – such as impairments in the domain of intellectual function or of muscle power and control.

This level of measurement involves the function and structure of individual body parts, organs or body systems. When there is a problem this is referred to as an impairment of body function or structure. Body function and structure are inherent features of an individual.

The person level of the ICF is concerned with activities such as walking, learning and playing. When a child is doing a task or activity, he or she is using his or her whole being in a complex set of actions that makes up that activity. This person level of human functioning is also an inherent feature of an individual. If a child has difficulty doing one or more activities, as determined by an assessment process, by observation or by report from the caregiver, this is called an activity limitation. This is what is usually referred to when using the term “persons with disabilities”.

A child with one or more activity limitations is at risk of being excluded from participating in a range of activities because of the impact of environmental and
other contextual factors. The extent to which a child does not participate in age-appropriate learning, recreation, socialization, mobility and communication will contribute to the extent and type of disadvantage experienced by that child. This is the participation or societal level of the ICF. For example, a child who does not participate in learning will experience a disadvantage in the level of educational attainment whilst a child who does not participate in communication and socialization will experience the disadvantage of social exclusion.

The ICF includes a “contextual” component which reflects the social construct of disability. The contextual component comprises two factors: environmental and personal factors. At the societal level of functioning, the impact of environment factors is critical. Environmental factors include products and technology, the natural and built environment, support and relationships (which include the immediate and extended family, friends and neighbours), attitudes, and services, systems and policies.

In a facilitative environment, the child may have significant activity limitations but may still be able to participate in daily life situations and activities such as learning and going to school. For example, consider a child in a wheelchair who is unable to walk but who is able to move around effectively if the physical environment is accessible for wheelchair users. Another child may have difficulty communicating but if family, friends and school teachers are supportive and allow the child time and space to communicate as well as providing a system for augmentative communication, this child will experience little disadvantage or exclusion. If the environment has many barriers, the same children could face significant disadvantages because of an inaccessible physical environment or a stressful and non-supportive social network.
The second contextual component, “personal factors” includes aspects such as gender, age, education, preferences and lifestyle. What might a child with CP be interested in doing? What does he or she like doing? The contextual components of the ICF influence and modify all the other components and need to be taken into account when considering the dimensions of “body function/structure”, “activity” and “participation.” However, these contextual factors are often overlooked when developing therapy interventions for the management of children with CP (Yousafzai et al., 2003). An understanding of the societal constructs regarding disability in a given culture contributes to developing strategies to meet the needs of children with disabilities and their families.

Thus in the context of disability, the ICF is helpful in understanding the interactive nature of the relationship between a child’s health condition (e.g., CP), activities, participation and a child’s context which includes personal and environmental factors. This framework is also useful in structuring and describing therapy interventions. Are the interventions primarily impairment-based, do they address function and activity limitation, or are they targeted at enhancing social engagement and participation (Rosenbaum and Stewart, 2004)?

2.3.2 Family-centred services (FCS)

In addition to establishing “what works best” regarding therapy interventions, a parallel body of emerging thinking and research has begun to explore issues in service delivery (Rosenbaum, 2004). The last decade has seen a move towards “family-centred service” (FCS) (Rosenbaum et al., 1998). This is a “process” rather than a content-based therapy approach that emphasises the needs, roles and well-being of the family as well as the child. The family becomes the focus of the intervention. Parents’ expertise regarding their child’s needs is recognised, the partnership between parents and therapists or service providers is encouraged and the family’s role in decision-making is acknowledged (Rosenbaum et al., 1998; King et al., 2004b).
Research indicates that providing services which are family-centred is associated with higher levels of parental satisfaction with services and lower parental stress (Rosenbaum et al., 1998; Law et al., 2003). Satisfaction with services is important because it has been related to increased adherence to treatment recommendations as well as the assessment of quality of care (Donabedian, 1988). Family-centred services are associated with fewer parental feelings of distress and depression and with improved well-being (Rosenbaum et al., 1998; King et al., 1999; Law et al., 2003). However, the assumption that the well-being of families will impact positively on the child’s development and function, whilst eminently sensible, still needs to be validated (Rosenbaum, 2003).

The environment around a child with CP involves the family (Rosenbaum and Stewart, 2004). In an “ecological” way of thinking, the family is the context in which children develop. When the family “environment” is recognised as contributing to children’s ultimate well-being, efforts to support families (e.g., implementing and practising family-centred services) are important corollaries of this thinking. In addition to the philosophical principles of FCS (Rosenbaum et al., 1998), and the established connection between FCS and overall parent satisfaction and mental health (King et al., 1999), it has been shown that the family can participate in identifying goals for their child’s therapy. In so doing, the family can help the child achieve greater functional gains, with less effort, than are seen with traditional impairment-based therapy (Ketelaar et al., 2001).

Is a FCS approach applicable in all settings? There is limited, if any, research around FCS in cross-cultural or resource-constrained environments. Humphrey (1994) suggests that, when working with families living in chronic poverty, the following factors may influence the implementation of FCS:

- Time orientation: whilst rehabilitation processes are based on the future (with intervention, the client will see improvement over time and into the future), for persons living in chronic poverty, present rather than future orientation is more salient. Thus for example caregivers may not see the
relevance of developing long-term goals if there is no certainty about how they will simply get through the next week.

• Difference in orientation toward the meaning of activities: a therapist may suggest certain activities as a way of helping the child to achieve or improve motor skills, whilst the parent may not see the value of these activities if the child is not interested in doing them.

• Family relationships: families living in chronic poverty often have to share resources with extended family members or neighbours. This results in a more collateral or collective group orientation whereas the dominant culture of a more affluent society usually emphasises the needs of the individual over the needs of the group, which is a more individualistic orientation.

• Control of nature: in the dominant culture of the USA, the value orientation leads people to assume that they will overcome and shape nature. Knowledge and technology are thus seen as tools to use against natural events such as disease or disability. On the other hand, for persons who experience chronic poverty, much of the world may seem to have control over them. Thus, a more subjugated orientation may emphasise the importance of accepting a disability and not expecting to change it.

Cultural, socio-economic and language differences may further complicate effective implementation of FCS. McGubbin et al. (1993) challenge the unspoken assumption that the existence of common symptoms leads to similar family reactions regardless of the ethnic or cultural associations of the child’s family. They stress the need for health care providers to be aware of those cultural beliefs, values and perspectives on illness and disability which would significantly influence the perceptions and reactions of families caring for a child with a disability.
Groce and Zola (1993) suggest three key points to consider when trying to comprehend underlying family beliefs and attitudes in a cross-cultural situation:

- Traditional beliefs about the cause of chronic illness or disability will play a significant role in determining family and community attitudes toward individuals with a disability and will influence how, when and where medical intervention is sought.
- The expectation of the child’s probability of survival, on the part of the parents and family, will affect the amount of time, energy and co-operation shown by the family for the child.
- The family’s expectations of the social role of the family member with a disability will affect a broad range of issues, including education, social participation and independence.

At the intersection of culture, poverty and the provision of services for families of children with a disability, there needs to be recognition of the interdependence of these factors (Brookins, 1993). Cultural sensitivity and competence can prevent health care providers working in cross-cultural settings from unintentionally alienating caregivers or families through miscommunication or what the family considers inappropriate and unacceptable suggestions and behaviour (McGubbin et al., 1993).

A recent comment from a South African occupational therapist sums up the situation well: “Personally, I believe effective communication between mothers and therapists is one of the most significant elements of parent-therapist collaboration and if language were one of the barriers to establishing FCS in addition to racial, ethnic as well as cultural differences, surely to have a collaborative relationship would be pretty difficult.” (Moja, 2004, p.11).

2.4 THERAPY INTERVENTIONS FOR CHILDREN WITH CP
As the research question in this study focuses on the outcome of therapy intervention, it is pertinent to review current therapy approaches and how these relate to current practice in South African public service hospitals. After summarising the aims of therapy interventions for children with CP, this section describes the main therapy approaches used in well-resourced settings and summarises the evidence base for these interventions. The section concludes with a review of studies conducted in poorly-resourced settings.

2.4.1 The aim of therapy intervention for children with CP
The approach to the management of the child with CP needs to be centred on the family’s needs and goals and to take into account the maintenance of muscle length, attention to muscle strength, and the importance of meaningful goals and self-generated activity (Mayston, 2004). The main aim of therapy for the child with CP should be to improve the quality of life for the individual child and his or her family and to prepare for an improved quality of life during adult years (Mayston, 2001a). Depending on the age of the child and severity of the disability, three general aims can be identified. For younger and more able children, the aim may be to increase or improve the skills repertoire, whilst for older children maintaining the current level of functional abilities is an important aim. For older and more severely involved or affected children, the aim of treatment may be general daily management and the minimisation of contractures and deformities, as well as support for the caregivers.

Damiano (2004) suggests that five potential therapeutic aims when working with a child with a chronic motor disorder are to:

1. Reduce the current musculoskeletal impairments so as to improve function and quality of life in the short and long-term.
2. Enable children to function optimally given their existing impairments.
3. Prevent or limit development of secondary impairments that may further limit function.
4. Alter the “natural” course of the disorder.
5. Promote wellness and fitness over the lifespan.

When viewed within the ICF framework, these aims of therapy for children with CP predominantly target the levels of body function and structure (or impairment) and activity limitations.

2.4.2 Therapy approaches for children with CP

Most children with CP living in well-resourced areas receive therapy of some type (physiotherapy, occupational therapy and/or speech therapy) (Koman et al., 2004). Ideally, treatment is multidisciplinary, involving a partnership between the patient and family, health professionals and the community to optimise functional mobility and health-related quality of life for each individual (Damiano, 2004).

There is an array of therapy approaches in current practice described in the literature. This is often confusing for new therapists and for parents and families, and the confusion is exacerbated by the fact that research has consistently failed to demonstrate that one approach is advantageous or more effective than another. Given the diversity of the nature of CP, it is not surprising that evidence to support the positive effects of any single intervention is lacking (Hur, 1995). Randomised controlled trials can be difficult to conduct, both because of the difficulty in obtaining adequate sample sizes and for ethical reasons, and where they have been done, overall results are often inconclusive (Hur, 1995). Despite this, therapy is widely advocated and desired, and therapy programmes are an integral part of the management of the child with CP (Mayston, 2001b)

Therapy interventions include a wide range of techniques and schools of thought. The most common are based on philosophies such as Bobath or Neurodevelopmental Therapy, Conductive Education (Peto) and Vojta, all of which in one way or another address the impairment level of the problem. Newer therapy approaches and modalities include Movement Opportunities via Education (MOVE), Functional Electrical Stimulation (FES) and Advanced
Neuromotor Rehabilitation (ANR). Complementary approaches include hyperbaric oxygen therapy, acupressure and osteocranialsacral therapy. Recent adjuncts to therapy include muscle strengthening, Lycra garments and treadmill training.

The Bobath approach to the therapeutic management of children with CP, today also known as Neurodevelopmental Therapy or NDT, was conceived in the 1940s in Europe by Dr. and Mrs. Bobath, a neurologist and a remedial gymnast, respectively. The Bobaths emphasized that their approach was a “concept” and not a method or technique. It is “primarily a way of observing, analysing and interpreting task performance” (Mayston, 2001a). Physiotherapists, occupational therapists and speech therapists train together and share “core skills” of assessment and management that enable them to work in both a multi- and transdisciplinary way. The aims of treatment are to influence muscle tone and improve postural alignment through specific handling techniques, and then to work for better active participation and practice of specific, relevant, functional skills (Mayston, 2001a ;2001b).

A study by Davidson and Waters (2000) found that 88% of neurological therapists in the United Kingdom use the Bobath/NDT approach. As this is the only approach for which training is available to graduate therapists in South Africa, it is likely that most therapists working with children with CP in this country would base their therapy on the Bobath/NDT approach.

2.4.3 Evidence base for therapy

Evaluating the effectiveness of therapy in the treatment of children with CP is very complicated for several reasons (Bower and McLellan, 1994; Hur, 1995; Butler and Darrah, 2001; Knox and Evans 2002; Tsorlakis et al., 2004) including that:

- Most therapy approaches are not specific treatments delivered in a standardised manner or in discrete dosages.
- Therapy often depends upon the therapist’s skill level.
- Specific aims and outcomes of therapy are difficult to define.
- Until recently there has been a lack of suitable validated outcome measures.
- The cerebral palsy population is diverse and heterogeneous, in terms of the type of cerebral palsy, age of child, and the associated problems.
- Therapy is dependent on personal interaction and active collaboration between the child and the therapist.

In a randomised controlled trial, Bower and coworkers (1996) demonstrated that over a two week period, significant improvements in motor function as measured by the Gross Motor Function Measure (GMFM) were obtained in children where specific measurable goals directed at motor skill acquisition were set. Over the same period, intensive physiotherapy produced a slightly greater effect than routine physiotherapy but this difference was not significant. In a subsequent randomised control trial, Bower et al., (2001) investigated whether intensive therapy or collaborative goal-setting enhanced motor function and performance. Fifty-six children with CP were treated by 56 therapists (one child each), 54 of whom described their therapy approach as eclectic whilst two followed the Bobath/NDT approach. The children were followed up for 18 months and changes in motor function and performance were assessed using the GMFM and the Gross Motor Performance Measure (GMPM). The study showed no statistically difference in the scores achieved between intensive and routine amounts of therapy or between aim-directed and goal-directed therapy in either motor function or performance.

In a systematic review of 21 studies which met strict criteria for inclusion in their review, Butler and Darrah (2001) concluded that Bobath/NDT did not confer any advantage over the alternative therapy methods to which it was compared. These 21 studies included only 416 children who varied considerably in the type
of CP and its severity, associated disabilities and age at treatment. Only 14 of the studies were relatively robust, providing results which could be regarded as definitely or tentatively valid (i.e., level I and II evidence). Butler and Darrah (2001) conclude that clearly defined, homogeneous participants, operationally defined treatment techniques and appropriate outcome measures in samples with adequate power are sorely needed.

Since the above review was published, two more studies have been reported (Knox and Evans, 2002; Tsorlakis et al., 2004). These two studies included a total of 49 children and both used the Gross Motor Function Measure, the “gold standard” for measuring motor function in children with CP to assess the outcome of intermittent periods of intensive Bobath/NDT. Both studies provide evidence for the effectiveness of NDT suggesting that shorter, more intensive periods of therapy are effective in changing gross motor function.

A comparative study of traditional therapy versus Conductive Education showed little difference between outcomes, but more contractures were present in the Conductive Education group (Bairstow et al., 1993). A study comparing Vojta and Bobath found no significant difference in developmental progress (d’Avignon et al., 1981). Studies examining the effectiveness of hyperbaric oxygen have found that it offers no advantage over pressurized air in children with CP and no significant benefits of hyperbaric oxygen have been demonstrated (Collett et al., 2001; Essex, 2003)

Relevance for South Africa
How useful and how relevant is this information for a public service setting in South Africa? None of the studies reviewed were conducted in resource poor settings where therapy is usually only available on a monthly basis. In addition, living in a well-resourced setting means that it was likely that most of the children included in the studies not only received regular weekly therapy, but also had received intervention from an early age. Neither of these are likely occurrences in
disadvantaged South African settings. Early intervention has been demonstrated to confer advantage and benefits (Simeonsson, 1982; Shonkoff and Hauser-Cram, 1987).

2.4.4 Therapy interventions for children with CP in developing countries

Only a handful of studies of rehabilitation therapy intervention have been conducted in resource poor settings. These studies were mainly conducted in the Asian sub-continent (McConachie et al., 2000, Goldbart and Mukerjee, 2001) and only one African study was found (Jelsma and Zhanje, 1999). All these studies describe service delivery and structure as opposed to the type or the content of therapy intervention offered to children.

In a non-randomised study, Goldbart and Mukherjee (2001) compared two models of service delivery for families with a child with CP – a fortnightly out-patient service which involved carrying out home exercises taught by physiotherapists and self-help programmes devised by teachers; and a Parent Involvement Service (PIP). The latter involved three sessions a week, each session lasting 1.5 to 2.5 hours, during which parents took on the responsibility of working with one another’s children on programmes devised by staff and parents. They also attended workshops run by the project’s teachers, the physiotherapist and the social worker.

The purpose of the study was to ascertain the extent to which the two models of service delivery served different types of family and whether the two groups differed with regard to parents’ knowledge of CP. The study showed that families with higher income and higher parental education levels were more likely to attend the higher intensity service. There was no significant difference between the two groups in terms of the parents’ knowledge of CP as measured by a 15-item multiple choice test. The study did not examine the impact of therapy on the child’s functional skills; parents’ satisfaction or perceptions of the service; or parental stress levels. The service combined education and therapy ("exercises")
without details of what was meant by “exercises”. Because most of the higher income parents were in the more intensive service, it is not known whether all parents, if they had had the financial means, would have preferred the more intensive service, particularly as none of the children were at school.

In a Bangladeshi study comparing alternative modes of service provision for young children with cerebral palsy, 85 children were randomly allocated to one of two intervention groups – daily centre-based mother-child group versus a distance training package for urban children; and a health advice versus distance training package for rural children (McConachie et al., 2000). The mother-child group received daily intervention in the form of a stimulation group led by a therapist. Mothers in the distance training package attended a monthly training session with a special education teacher and received a pictorial guidance manual which provided ideas and suggestions on what to do at home. The mothers and children in the health advice group were only seen at the beginning of the study where a paediatrician gave them advice about the child’s health and a box of simple local toys and books for their children to play with at home.

Outcome measures included changes in children’s adaptive skills as measured by the Independent Behaviour Assessment Scale which was developed and standardised for Bangladesh; maternal stress and adaptation to the child as measured by the Judson Maternal Self-rating Scale; satisfaction with social support as measured by the Family Support Scale; knowledge of handling a physically disabled child as measured by Parental Knowledge Test which was specially developed for this study; and maternal stress as measured by the Self Report Questionnaire. The Judson Maternal Self-rating Scale, the Family Support Scale and the Self Report Questionnaire were not modified or validated for use in Bangladesh.

All 85 children received initial assessments and 58 (68%) were successfully followed up and assessed approximately nine months later. Among the rural
children, those in the health advice group showed the least progress. This was as expected as this group of children had received the least amount of intervention. The perceptions of helpfulness of formal sources of support (as measured on the Family Support Scale) increased significantly in the group of mothers in the distance training package. Both rural groups reported increased maternal adaptation to the child but there was no change in parental knowledge and apparent reductions in maternal stress did not reach significance, possibly because of the low power of the study to detect these changes.

For the children in the urban arm of the study, mothers in the centre-based mother-child group showed a significant increase in knowledge and both urban groups showed a significant increase in maternal adaptation to the child.

Findings from the Bangladeshi study showed that paradoxically, participation may have increased stress for some mothers, particularly those attending the centre-based mother-child clinic (i.e., higher intensity of intervention). Although maternal adaptation increased in all the groups, it was greatest in the health advice group who had received the least intervention. This might perhaps have been because this kind of intervention had a low emphasis on the child’s disability which mothers found reassuring, thus perhaps providing a false sense of security.

The study also revealed an erratic pattern of therapy attendance. In the monthly distance training packages, mothers attended a mean of six out of nine possible sessions. Where children had attended a programme at least four times, their skills improved and the mothers’ adaptation increased.

Although the power of the above study was low, it highlighted several useful factors service providers need to be aware of when planning intervention services. In areas where few support networks exist, parental stress needs to be minimised. The positive effects of the service such as improvements in the child’s
adaptive skills need to be weighed against the negative effects like the increased emotional burden on parents. The authors advocate a community-based rehabilitation service combined with outreach developmental services with support for the family. Similarly to the Goldbart and Mukherjee (2001) study, this paper does not provide sufficient detail regarding the content of the intervention provided.

A Zimbabwean study evaluated the impact of parent groups for children with a disability and sought to establish caregiver satisfaction with the service (Jelsma and Zhanje, 1999). Caregivers of 50 children attending parent groups in Harare were interviewed using a structured questionnaire with open-ended questions. The parent groups were run by rehabilitation technicians and met two to four times a month at decentralised locations in Harare. When necessary, the children were referred back to a central institution for further assessment or more intensive therapy intervention by a physiotherapist.

Results showed that each caregiver attended approximately 30% of all meetings and 21 (42%) had been referred back to the central institution for additional therapy. All the caregivers felt that they had benefited from attending the parent groups. The majority of caregivers were highly satisfied with the rehabilitation workers’ ability to help them, but the problem of limited “hands-on” treatment time was a cause for dissatisfaction. The caregivers all wanted more individual therapy for their children.

Although no standardised or validated outcome measures were used in the study, it underlines the relationship between service delivery (in this case parent groups) and “hands-on” therapy and how this balance is a critical issue in therapy intervention services in poorly-resourced settings.

The lack of suitable reliable and valid tools to measure outcomes in a poorly-resourced area is striking in all of the above studies. Tools were usually
developed specifically for the study and only one study included a validation of the new tool. Where existing tools were used, they were not validated for use in the new setting.

In addition, in all the studies from developing countries, the distinction between service provision and therapy intervention is blurred. As highlighted earlier, this is an important distinction to make because how the service is organised is as important as what is prescribed (Rosenbaum, 2004). Studies describing the content of therapy programmes and what works best in a poorly-resourced area were not found. This may in part be ascribed to the fact that many therapists working in resource-constrained settings adopt an eclectic approach to therapy (Levitt, 1982) rendering it impossible to evaluate the effectiveness or advantage of the technical aspects of any one kind of therapy approach over another.

Most studies from developing countries focus on models for intervention and prevention of impairment and disability from the service providers' perspective and relatively few obtain families' views about support (Brodin and Molosiwa, 2000). As the role of the parents in therapy intervention programmes is an integral part of all the above studies and a focus of the present study, the next section examines parental involvement in therapy programmes.

2.5 PARENTAL INVOLVEMENT IN THERAPY PROGRAMMES

The role of parents in therapy programmes for children with disabilities has long been debated and discussed (Bazyk, 1989; Hinojosa and Anderson, 1991; Sloper and Turner, 1992; Law et al., 1993; Jansen et al., 2003). The emphasis in much of the research has been on the effects of parental participation on child functioning. Although it is generally acknowledged that parental participation has a positive effect on child-related outcomes, the effect of parental participation on parents themselves has received relatively little attention (Jansen et al., 2003). Parental involvement in therapy programmes may also have negative
consequences in that it may impose an additional stress factor for parents who already have to deal with the difficulties of raising a child with a disability (Sloper and Turner, 1992; Crowe, 1993; Crowe et al, 1997; McConachie et al., 2001; Jansen et al., 2003; Rosenbaum, 2004;). The services themselves may impose extra demands on the family by expecting parents to concentrate on the child with the disability to the exclusion of other problems (Sloper and Turner, 1992; Crowe, 1993).

There are few studies from developing countries which have either formally examined the role of parents in therapy intervention programs or attempted to establish parents’ needs and expectations of a therapy service and its outcome. In reviewing these studies, it is often difficult to separate out the issue of parental involvement and stress in caring for a child with a disability from that of parental involvement in a therapy programme.

O’Toole (1989), in his evaluation of the appropriateness of applying Western models of care to a Guyanese sample, poses a pertinent question: “Is parental involvement a practical proposition in a developing country?” (p. 330). He suggests that overwork, poverty, severe social tensions and sheer exhaustion can make parental involvement a demanding proposition. This view is supported by McConkey (1995) who warns that early intervention schemes in developing countries are more often constrained by what is possible for families to cope with than the possibilities envisaged by service workers.

In a study on the appropriateness of Western models of parental involvement in Calcutta, Goldbart and Mukherjee (1999a) point out that whilst in developed countries parent involvement is partly driven by the principle that intervention which includes partnership with parents optimises outcomes, in India and other less-developed countries parental involvement is often needs-driven. This is mainly the result of limited availability of teachers and therapists experienced in working with children with special needs. Goldbart and Mukherjee (1999b) also
stress that issues such as family constellation (i.e., nuclear, extended and joint family structures), traditional hierarchies within families, and women's roles and responsibilities may necessitate specific adjustments to the delivery of intervention programmes.

Anderson and Venter (1997) explored parental experiences and expectations of a cerebral palsy clinic in a poor urban community in Soweto, South Africa. Interviews conducted with 55 parents of children with cerebral palsy revealed that the majority of parents' expectations were for a "normal" child and the hope that therapy would help their children to "become like other children." Almost all the children in this study were under the age of five years with over half being under the age of three years, which may have explained the parents' unrealistic expectations for a normal outcome.

An unexpected finding of this study was that 84% of parents said they would still continue to attend the clinic even if they thought that therapy was not beneficial. The authors interpreted this finding as an indication of the paucity of community-based services and resources offering appropriate support to families of children with disabilities and the important subsidiary role the clinic played in providing emotional help and support to parents. Another interesting finding from this study was that over 50% of the parents wanted more "hands on" therapy for their children, a finding similar to Jelsma and Zhanje's study (1999) in Harare, Zimbabwe.

In a study conducted in Lesotho, McConkey and Mphole (2000) held a series of consultation sessions with six groups of mothers of children with intellectual impairments. A total of 68 parents and friends attended the sessions, the aims of which were to determine the priorities caregivers had for themselves and for their children, and their views on how this might best be achieved. The dominant themes emerging from this process were that mothers wanted their children to become independent in daily living activities, have a chance of employment and
attend school. The wishes parents expressed for themselves were mainly for the protection of the child’s rights and to have training in looking after their children.

A survey of 47 caregivers of children with intellectual impairments in Botswana revealed that the caregivers’ main expressed needs were for financial, transport, health and educational support (Brodin and Molosiwa, 2000). Few caregivers mentioned the need for rehabilitation; this was most likely because this kind of support had never been available and so caregivers were unaware that therapy might have been necessary or useful.

An in-depth qualitative study involving 52 caregivers of children with disabilities was conducted recently in Uganda (Hartley et al., 2005). This is the only published paper from Africa which provides a deep understanding of how families cope with children with disabilities in their own communities. Data from this study suggested that although most families were coping, the main challenges they faced were the burden of care for the child; poverty (resulting in lack of money for basic items such as food and clothing as well as for transport and treatment); the impact of the child’s disability on the carer in the form of stress; and difficulties in communicating with the child. Adequate knowledge, information and skills that would assist caregivers in caring for their own children and thus reducing their own stress levels were the main needs identified by the caregivers. Comments from the carers suggested that the children’s three main needs were physical, the need for assistive devices such as wheelchairs and hearing aids, and the need for company. In keeping with the findings of Anderson and Venter (1997), McConkey and Mphole (2000), and Brodin and Molosiwa (2000), access to education for their children was also an important priority for caregivers.

**Summary**
The issue of parental participation in therapy programmes in developing countries and what constitutes an appropriate model of service delivery remains poorly described. Although attempts have been made to establish caregivers’
needs and expectations both for themselves and their children, none of this has been translated into practice or evaluated. Parental participation in therapy programmes is widely advocated but in poorly-resourced areas it is important to recognise that many families are barely coping under the strain of lack of material resources and environmental hardships. Consequently, imposing additional responsibilities on a caregiver in terms of carrying out therapy programmes at home may simply increase his or her stress levels and burden of care. In disadvantaged settings, greater parent participation in therapy programmes is driven by a lack of trained therapists – thus, paradoxically, the most vulnerable caregivers in need of the greatest amount of support are often given the most responsibility for caring for their child.

Research is needed to assist service providers in disadvantaged areas to develop suitable and appropriate intervention programmes and to evaluate the impact of these programmes on the child’s family and caregiver. The goal is not to add one more demand on already overburdened parents, but to enhance the quality of interaction between caregivers and children in the time which is available (O’Toole, 1989). Intervention programmes need to take into account cultural and environmental factors such as poverty and styles of parenting as well as the needs and expectations of caregivers. In poorly-resourced areas, these needs and expectations often extend far beyond just the need for traditional therapy.

2.6 OUTCOME MEASURES AND ISSUES SURROUNDING THE DEVELOPMENT, TRANSLATION AND CROSS-CULTURAL APPLICABILITY OF MEASURING TOOLS

Having outlined approaches to therapy intervention as well as models of service provision and parental participation, this section reviews ways in which therapy intervention and service delivery can be evaluated and outcomes measured.
Psychometric properties of scales are briefly described and a brief overview of some of the outcome measures for children with CP is given.

2.6.1 Measuring change in children with CP – what outcomes should be measured?

Evaluation of the outcomes of therapy intervention programmes is complex because programmes usually have several objectives. Traditionally, therapy programmes have concentrated on skill acquisition and improving functional abilities of the child (Haley et al., 1991; Campbell, 1996; Msall et al., 1997). As mentioned earlier in this chapter, functional outcomes of therapy programmes are very difficult to measure because CP is a highly heterogeneous condition and therapy is not delivered in a standardised manner (Butler and Darrah, 2001).

There is, however, a growing awareness of the need to look beyond the child’s impairment during therapy sessions and when establishing outcomes. Service providers often place too much emphasis on the technical quality of the service as opposed to enhancing participation of families and evaluating the process of providing care (Dunst and Trivette, 1996; Rosenbaum et al., 1998). The ICF has shifted the emphasis of intervention beyond “impairment” towards the promotion of “activity” and “participation” (WHO, 2001). In this model the goals of functional capacity and independence, leading to enhanced “participation” in life, become the primary objectives of intervention rather than the assumed end results of improvements in function based on improvements in impairments.

The ICF provides a useful framework for planning intervention strategies and for evaluating outcomes. Interventions can be focused at the level of impairment (body structures and function); activities and participation; environmental factors; and personal factors. Tools measuring therapy intervention and service delivery can be similarly organised.
2.6.2 Development of measurement scales and tools

Kirshner and Guyatt (1985) have provided a methodological framework for assessing health measures or tools. Within this framework, measures are classified according to their purpose. However, measures may be used for one or more purposes.

A **discriminative** index distinguishes between individuals with and without a particular characteristic or function. It is used to distinguish individuals at a single point on some feature of interest (Boyce et al., 1991). A **predictive** index classifies people into categories based on what is believed or expected will be their future status. This is used when an accepted criterion exists to determine whether an individual has been classified correctly (Boyce et al., 1991). An **evaluative** index is used to measure the magnitude of change in function over time or after treatment (Rosenbaum et al., 1990; Ketelaar et al., 1998). Measures are generally developed and validated specifically to fulfil one of these functions. A measure cannot automatically be used for a purpose other than the one for which it was designed or applied to a population dissimilar to that for which it was developed and validated (Rosenbaum et al., 1990; Ketelaar et al., 1998).

The **reliability** and **validity** of a measure should be established before a measure is used. **Reliability** refers to the ability of a measure to give consistent responses on repeated assessments in the absence of change in the characteristic being evaluated (Mitchell, 1979). Potential sources of variability that contribute to unreliability of a measure include those related to observers, subjects, environments, timing, and the index itself. These potential sources of variability should be quantified and controlled as fully as possible. Reliability of a measure is established through assessing test-retest consistency (repeated assessments over a short period of time using the same rater); inter-rater reliability of observations made by different people of the same phenomena; intra-rater reliability of people against their own observations; and the internal consistency as measured by co-efficient alpha (Boyce et al., 1991; Streiner and Norman,
The internal consistency of a measure refers to the level of correlation of the scores between the items in the measure, based on a single administration of the measure (Streiner and Norman, 2003).

Validity refers to the appropriateness (truth) of inferences made when interpreting a measure, a score, or the results of a test (Cronbach, 1971, cited in Rosenbaum et al., 1990). It has been defined as the extent to which an instrument measures what it is intended to measure (Carmines and Zeller 1979, cited in Boyce et al., 1991). Thus validity is directly related to the purpose of the measure (Ketelaar et al., 1998).

Validity is generally categorised into three types: content, criterion and construct validity (Nunnally, 1978). Content validity is a judgment call and means that the scale has enough items and adequately covers the domain under investigation. It is a non-statistical subjective evaluation of the scale, usually by a panel of experts in the area. The higher the content validity of a measure, the broader are the inferences that can be drawn about the subject under a variety of conditions and in different situations (Streiner and Norman, 2003).

Criterion validity refers to the correlation of the scale with another measure of the trait or disorder of interest, ideally the “gold standard” that has been widely used and accepted in the field. It assesses how a person who scores at a certain level on the new score will do on some criterion measure. Criterion validity is usually divided into two types: concurrent validity and predictive validity. To establish concurrent validity, the new scale is correlated with the criterion measure by administering both scales simultaneously. Predictive validity refers to a scale’s success in predicting some important future state or behaviour and so the measurement is correlated to the criterion at a later point in time. Obviously this criterion needs to be one which is recognised as valid in its own right (Streiner and Norman, 2003).
Construct validity refers to the hypothetical construct or mini-theory used to explain the relationships among various behaviours or attitudes. Multi-trait scaling and convergent and discriminative validity are two of the statistical methods used to establish construct validity (Streiner and Norman, 2003).

Some publications argue that these distinctions amongst content, criterion and construct validity are less important than the underlying purpose of all validity testing which is to make inferences (Streiner and Norman, 2003). Thus, the validity of a scale should provide a measure of the degree of confidence that can be placed in the inferences drawn from the scores on the scales (Streiner and Norman, 2003).

2.6.3 Available outcome measures for children with CP

There are many outcome measures for children with disabilities. Amongst these are a number of measures specifically designed for children with motor impairments which ideally should include children with CP. However, there are very few measures specifically developed for children with CP; most are generic and have been developed for use with children with special needs and their families.

It is not the intention here to provide an exhaustive list and description of all available outcome measures for children with disabilities. Only those that are relevant to this study are described in Tables 2.1 – 2.5. Table 2.1 summarises measures of motor function in children with motor impairments. Table 2.2 presents measures of functional abilities for children with CP. Although motor and functional performance of the child are not the focus of the study, a description of the scales pertaining to these aspects is included as they are so widely used in studies involving children with CP. When reviewing results of functional measurement scales, it is pertinent to remember that they may show variations in different countries because of differences in socio-cultural
behaviours, including feeding, bathing, grooming and toilet habits (Erkin et al., 2005).

Table 2.3 describes some of the measures available to assess caregivers’ physical and mental health and quality of life, while Table 2.4 reflects measures of family support. The final table, Table 2.5 contains measures of parental perceptions and experiences of care-giving and services.
<table>
<thead>
<tr>
<th>MEASURES OF MOTOR FUNCTION USED FOR CHILDREN WITH MOTOR IMPAIRMENTS</th>
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<tbody>
<tr>
<td><strong>REFERENCE</strong></td>
</tr>
<tr>
<td>GROSS MOTOR FUNCTION MEASURE</td>
</tr>
<tr>
<td>ALBERTA INFANT MOTOR SCALES (AIMS)</td>
</tr>
<tr>
<td>BAYLEY SCALES OF INFANT DEVELOPMENT - II</td>
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<tr>
<td>BRUININKS-OSERETSKY TEST OF MOTOR PROFICIENCY</td>
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</table>
## TABLE 2.2: MEASURES OF FUNCTIONAL ABILITIES IN CHILDREN WITH CP

<table>
<thead>
<tr>
<th>TOOL</th>
<th>REFERENCE</th>
<th>PURPOSE</th>
<th>RELIABILITY AND VALIDITY</th>
<th>COMMENT</th>
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<tbody>
<tr>
<td>PEDIATRIC EVALUATION OF DISABILITY INVENTORY (PEDI)</td>
<td>Haley et al., 1992</td>
<td>Discriminative and evaluative standardised measure of functional limitations in children 6 months to 7 ½ years. Developed for children with chronic illnesses and disabilities.</td>
<td>Excellent test-retest and interrater reliability. Content validation by expert group. Excellent concurrent validity with Battelle and WeeFIM. Responsiveness to change over a six month period in children with CP has been confirmed.</td>
<td>Most widely used tool for assessing activities and participation in children with CP. Was developed in a well-resourced setting and thus not suitable in poorly resourced areas e.g., reference to cars, wheelchairs, bath, toilets, etc.</td>
</tr>
<tr>
<td>FUNCTIONAL INDEPENDENCE MEASURE FOR CHILDREN (WeeFIM)</td>
<td>Msall et al., 1994</td>
<td>Discriminative and evaluative measure of consistent performance of functional skills in children aged 6 months to 8 years, and children through adolescence</td>
<td>Excellent test-retest and interrater reliability. Content validation by expert group. Concurrent validity with VABS and Battelle. Reliability and validity for discriminative purposes have been established. Responsiveness to change has not been evaluated.</td>
<td>Commonly used method of paediatric functional evaluation for both healthy children and children with disabilities, including CP. Developed in a well-resourced setting; no published studies on its use in poorly-resourced settings</td>
</tr>
<tr>
<td>VINELAND ADAPTIVE BEHAVIOUR SCALE (VABS)</td>
<td>Sparrow et al., 1984</td>
<td>Descriptive measure of communication, daily living, socialisation, and motor skills for children from birth to 18 years, disabled and non-disabled</td>
<td>Excellent test-retest and interrater reliability. Excellent correlation with IQ and other adaptive measures. Responsiveness to change not established.</td>
<td>Not standardised for use in poorly resourced settings. Has to be administered by a psychologist.</td>
</tr>
</tbody>
</table>

- 56 -
<p>| SCALES OF INDEPENDENT BEHAVIOUR (SIB) | Bruininks et al., 1984 | Descriptive measure of adaptive skills and problem behaviours from birth to 40 years. | Split-half and interrater reliability are excellent. Test-retest is good-to-excellent. Excellent construct validity. Responsiveness to change not established. | Not standardised for use in poorly resourced settings. |</p>
<table>
<thead>
<tr>
<th>TOOL</th>
<th>REFERENCE</th>
<th>PURPOSE</th>
<th>RELIABILITY AND VALIDITY</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>PARENTING STRESS INVENTORY (PSI)</td>
<td>Abidin, 1989</td>
<td>Discriminative measure of caretaker stress</td>
<td>Internal reliability; child, parent and total stress alpha excellent. Excellent concurrent validity with social and family stress in children with cerebral palsy and other developmental disabilities.</td>
<td>Developed for use in children with chronic illness and behaviour problems</td>
</tr>
<tr>
<td>MEDICAL OUTCOMES STUDY (MOS) SHORT-FROM GENERAL HEALTH SURVEY</td>
<td>Stewart et al., 1988, 1989</td>
<td>Designed as a general outcome measure in clinical studies and as a health status measure in population studies. Covers five domains: physical, social and role functioning, mental health, pain and health perceptions</td>
<td>Excellent reliability and validity.</td>
<td>Has been successfully used in adults in a disadvantaged South African setting</td>
</tr>
<tr>
<td>EUROPEAN QUALITY OF LIFE-5 (EQ-5D)</td>
<td>Bakker and van der Linde, 1995</td>
<td>Generic single index measure describing health-related quality of life in terms of five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression</td>
<td>Excellent reliability and validity.</td>
<td>Has been translated into several European languages and into Shona. Has been used on adults with a variety of medical conditions.</td>
</tr>
<tr>
<td>COPING HEALTH INVENTORY FOR PARENTS (CHIP)</td>
<td>McCubbin and Thompson, 1991</td>
<td>Discriminative measure of caretaker stress and coping for children with chronic illness</td>
<td>Good inter-item reliability with coping patterns. Excellent concurrent validity with low-conflict and high-conflict families with a child with cerebral palsy.</td>
<td>Developed for parents of children with serious or chronic illness that leads to disability. More useful for families of preschool children</td>
</tr>
<tr>
<td><strong>SHORT-FORM 36 (SF-36)</strong></td>
<td>Ware et al., 1993</td>
<td>Widely used generic measure of health related quality of life for any population</td>
<td>Excellent reliability and validity</td>
<td>Requires purchase of licence for use</td>
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<tr>
<td><strong>PERSONAL QUALITY OF LIFE SCALE</strong></td>
<td>Westaway et al., 1999a</td>
<td>Measures well-being satisfaction with the personal domain of quality of life</td>
<td>Good reliability and validity.</td>
<td>Has been used in a poorly resourced South African setting. Has not been used for caregivers of children with a disability</td>
</tr>
<tr>
<td><strong>GENERIC LIFESTYLE ASSESSMENT QUESTIONNAIRE (LAQ-G)</strong></td>
<td>Jessen et al., 2003</td>
<td>Descriptive and discriminative measure of the impact of impairment and disability on the lives of children with disability and their families</td>
<td>Acceptable reliability and validity has been established.</td>
<td>Not designed to measure change over time. Not widely used. Has not been used in a poorly resourced setting.</td>
</tr>
<tr>
<td>TOOL</td>
<td>REFERENCE</td>
<td>PURPOSE</td>
<td>RELIABILITY AND VALIDITY</td>
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<tr>
<td>FAMILY RESOURCE SCALE (FRS)</td>
<td>Dunst et al., 1988</td>
<td>Adequacy of different resources in households with young children. Resources include income, housing, health resources, interpersonal support and time.</td>
<td>Reliability has not been tested. Significant correlation with personal well being and maternal commitment to implement child level interventions.</td>
<td>More useful for families of pre-school children</td>
</tr>
<tr>
<td>FAMILY SUPPORT SCALE (FSS)</td>
<td>Dunst et al., 1994</td>
<td>Descriptive measure of sources of support available to the family</td>
<td>Good reliability and validity.</td>
<td>Widely used for families of children with a chronic illness or disability. Has been used with mothers of children with CP in a poorly-resourced setting</td>
</tr>
<tr>
<td>QUESTIONNAIRE ON RESOURCES AND STRESS (QRS)</td>
<td>Holroyd, 1974</td>
<td>Measure of resources, coping and stress reactions of families with children of all ages with disabilities</td>
<td>Kuder Richardson internal consistency excellent for long and short forms. Excellent construct validity. Other criterion validity not studied.</td>
<td>Has not been used in poorly resourced settings</td>
</tr>
</tbody>
</table>
### TABLE 2.5: MEASURES OF PARENTAL PERCEPTIONS AND EXPERIENCES OF CAREGIVING AND SERVICES

<table>
<thead>
<tr>
<th>TOOL</th>
<th>REFERENCE</th>
<th>PURPOSE</th>
<th>RELIABILITY AND VALIDITY</th>
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<tbody>
<tr>
<td>MEASURE OF PROCESSES OF CARE (MPOC-20)</td>
<td>King et al., 2004a</td>
<td>Evaluative measure of family-centred behaviours by health care providers</td>
<td>Excellent consistency and retest reliability. Good validity with parental stress.</td>
<td>Widely used in North America and Europe by service-providers working with children with special needs.</td>
</tr>
<tr>
<td>JUDSON MATERNAL SELF-RATING SCALE</td>
<td>Judson and Burden, 1980</td>
<td>Measure of adaptation to the child. Designed to measure maternal acceptance and adjustment towards a child with a disability.</td>
<td>Factor analysis has failed to reveal a clear factor structure. Reliability has been established.</td>
<td>Developed for use with children with disabilities. Has been used with mothers of children with CP in a disadvantaged setting</td>
</tr>
</tbody>
</table>
2.6.4 Language and cultural translation of questionnaires and outcome measures

Health status measures developed in one country cannot simply be translated for use in a different cultural context (Wagner et al., 1998; Ustun et al., 2001). The standard procedure for making a document cross-culturally applicable is to run it through a translation and back-translation process in order to identify any problems with language. However, this process has been shown to be only partially effective (Ustun et al., 2001). Spielberger and Sharma (1976) and Streiner and Norman (2003) suggest that there are four stages to the translation process: preliminary translation into the second language; evaluation of the preliminary translation; establishment of the cross-cultural equivalence between the original and translated versions; and establishment of the reliability and validity of the translated questionnaire.

Jelsma et al., (2000) point out that the translation process should ensure that the target version is not only semantically equivalent to the source version but also conceptually equivalent. Semantic equivalence is concerned with the transfer of meaning across languages and with achieving a similar effect on respondents in different languages. The translation should reflect not only the correct linguistic interpretation of the source but, if the instrument is to be useful, it should also reflect the domains that the target culture regards as important (Herdman, 1998, cited in Jelsma et al., 2000). Establishing conceptual equivalence involves determining whether people in the two cultures view the concept in the same way (Streiner and Norman, 2003).

2.6.5 Cross-cultural applicability of scales

When doing cross-cultural work in the disability field, a fundamental dilemma is whether the experience of taking care of a child with cerebral palsy is a universal one, or to what extent it is influenced by a complex combination of factors, from personal and emotional characteristics to differences in the physical, social and cultural context in which the caregiver and child live. Thus the question becomes
“How appropriate is it simply to take an instrument developed in one culture and assume that it will be applicable in another culture?”

This is an issue which has attracted a large amount of debate in the medical anthropology literature. Much of this discussion falls beyond the scope of this study. Whilst numerous studies argue against the possibility of a universal transcultural classification of disability and suggest that many health and illness concepts are variable across cultures and sub-cultures (Bice and Kalima, 1971; Scheer and Groce, 1988; Ingstad and Whyte, 1995), Ustun et al. (2001) suggest that a universal understanding of disability is plausible. The same argument could be applied to the experiences of caring for a child with cerebral palsy. The challenge is to identify the commonalities without losing sight of the cultural and linguistic differences and to integrate these into the instruments.

The process of establishing the cross-cultural applicability of instruments such as the ICF and the International Quality of Life Assessment (IQOLA) (Wagner et al., 1998; Ustun et al., 2001) provide practical guidelines on how cross-cultural ability can be achieved.

Ustun et al. (2001) suggests four steps:

1. **Key informant interviews and focus groups** to provide a detailed understanding of the knowledge and beliefs surrounding a diagnosis of cerebral palsy in each cultural setting. Key informants include cultural experts who have in-depth knowledge in a particular area of culture or who are judged to be knowledgeable about cultural conceptions. The focus groups provide information on the collective views about particular cultural conditions.

2. **Linguistic analysis and translation and back translation protocols.** This linguistic protocol includes three types of equivalence: semantic, conceptual and technical equivalence. This process assists in identifying problematic terms.
3. **Concept mapping.** This strategy reveals how people think about concepts and assists with establishing the cultural applicability of each item. Ten questions are asked about each item, for example, “Does this item need clarification?”; “Can this concept be used without any difficulty in your culture?”; “Is this item culturally sensitive (difficult to talk about, taboo, embarrassing, etc)?”

4. **Pile sorting.** This technique indicates how natural groupings of concepts are made by people. Respondents are given a set of cards, each of which contains an item from the scale, and asked to place them in piles according to what they feel makes them alike. Respondents then have to give each pile a name and a reason for placing the items together.

It could be argued that the above steps are a laborious process involving almost as much, if not more, work as the initial development of the original scale. In addition, re-establishing the reliability and validity within the new context requires exactly the same steps as those followed when developing a new scale (Streiner and Norman, 2003). The question that therefore arises is whether translating a scale is worth the effort. An alternative to translating the scale is to administer the questionnaire in its original format but this would restrict respondents to those fluent in that language. Interpreters may also be used in an interviewer administered questionnaire; however, this may result in a change in the meaning of the question, which may bias the results (Del Greco et al., 1987).

Streiner and Norman (2003) point out that although many scales have been translated, problems still remain particularly when making comparisons of the same phenomenon across cultures. It is not always clear whether differences observed are due to cultural and other factors, or whether they reflect subtle variations in the instruments used to measure them. Besides, if true differences do exist between language and population groups, will the translated version identify them?
The complexity of issues surrounding the decision about whether or not to translate an instrument and what translation protocol to follow therefore clearly depends on the nature, the type and the sensitivity of the data being collected (Streiner and Norman, 2003). Furthermore, when comparisons are made with other studies, both similarities and differences found should be interpreted with extreme caution.

2.7 SUMMARY

Little information exists as to how to incorporate ethnic and cultural definitions of, and meanings attached to, disability such as cerebral palsy into appropriate health care provision and even more so, into tools which can be used to measure the outcome of therapeutic interventions. These factors influence how families cope and are currently poorly understood in disadvantaged South African settings.

The literature reveals that whilst family-centred services and parental participation in therapy programmes are generally advocated and found to be beneficial in well-resourced settings, parents and families in poorly-resourced settings face additional hardships making it inappropriate to transplant Western models without taking environmental considerations into account.

Measuring the outcomes of therapy intervention for children with motor impairments has received substantial attention in the literature with a variety of tools available to measure both child and family-related outcomes. However, few if any of these tools have been developed or validated in disadvantaged settings. Thus, existing tools need to be adapted to suit local conditions without changing their conceptual basis. In addition, careful attention needs to be paid to cross-cultural applicability and the process of translating the scales. Reliability and validity need to be re-established before they can be used in the new setting.