CHAPTER ONE: INTRODUCTION

1.1 Introduction
One in four hundred children born in Australia have cerebral palsy (Stanley, Blair & Alberman, 2000). With ever increasing shortage in health resources (Baume, 1998), the pressure on health professionals to find and utilise cost effective treatments for these children is growing (Christiansen & Baum, 1991; Lloyd-Smith, 1997). Evidenced based health care has also necessitated clinicians to justify the efficacy of interventions (Lloyd-Smith, 1997). This chapter will provide a background to the research problem and the rationale for its investigation. It will also discuss how this study will expand the occupational therapy body of knowledge about treatment for children with cerebral palsy.

1.2 Background
During the last century, the value of families, particularly the value of parents of children with disabilities, and their role in paediatric health care, has undergone significant transformation (Dunst et al, 1988; Winton & Bailey, 1997). Changes to US law mandating ‘least restrictive’ education to school-aged children with disabilities have reinforced the philosophy of parental involvement in therapy (Anderson & Schoelkopf, 1996; Bazyk, 1989; Hopkins & Smith, 1988). This trend has also occurred in Australia; policies have been developed to endorse early intervention services, which involve and value the whole family, as best practice (Hanna & Rodger, 2002). Children with disabilities were historically institutionalised because they were deemed to require ‘special’ care beyond the capabilities of parents (Christiansen & Baum, 1991; Rosenbaum et al, 1998). These same children are now living at home, as active members of their local community, in the ‘expert’ care of their parents (Dunst et al, 1988; Hopkins & Smith, 1988). This is a major shift in practical terms, but it also reflects a significant change in the assumptions underlying care. Winton and Bailey (1997), referred to this dramatic shift in philosophical thinking, which gives greater recognition to the centrality and expertise of families in the care of their own children, as a "revolution". Now families, rather than health professionals, are viewed as the best people to make decisions about their child’s health care, prioritise interventions and plan their child’s future (Winton & Bailey, 1997). In some Australian health settings, parental expertise has been so
embraced that parents, along with professionals, are recognised as vital for achieving desired health outcomes in children with disabilities. Australian policy encourages families to care for their relatives with disabilities at home (Thompson, 1998). When this family member is a child with a disability, it has been proposed that the definition of parental ‘caregiving’ expands to include, providing ‘specialist’ services to help the child (Thompson, 1998). This is particularly the case in Australia, where there is less of a regulatory framework to mandate the provision of professional services to children and their families than other countries, for example, the United States of America. Parents are now considered ‘team members’ in their child’s care (Rosenbaum, 1998). Conceptually the approach of including parents as team members is known as ‘family-centred practice’ (Dormans & Pellegrino, 1998).

Family-centred practice is defined as an approach where,

“professionals become agents of family priorities… families determine the interventions that are appropriate based on their knowledge of their child and their own circumstances…. Family-centred care gives appropriate emphasis to the parental right to determine what is best for the child, regardless of professional opinions that might differ” (Dormans & Pellegrino, 1998 p.61).

This definition of the approach clearly includes parents as intervention team members. Indeed the inclusion of families within intervention is what fundamentally sets family-centred intervention apart from former philosophical approaches,

“If services for children with special needs or developmental problems are to be family-centred, the needs and involvement of all family members should be encouraged and supported” (Rosenbaum et al, 1998, p.7).

Dormans and Pellegrino (1998) and others (Ahmann, 1994; Roberts & Magrab, 1991) have for some time recognised family-centred practice, by means of interdisciplinary collaboration as the ‘gold standard’ for services to children with a disability, including children with cerebral palsy. Occupational therapy is one of the health professions routinely involved in services to children with cerebral palsy (Dormans & Pellegrino, 1998). Occupational therapists address the occupational engagement and occupational performance of children with cerebral palsy, commonly focussing on fine motor skills; functioning of the upper extremities; self-care skills; prescription of splints and seating equipment, with
the aim of improving the child’s independence (Miller & Bachrach, 1995). These clinical interventions are provided through a variety of service delivery options, one of these being a home program. Family-centred practice is the most recent philosophical approach within which home programs intervention for children with cerebral palsy occur (Dormans & Pellegrino, 1998; Hinojosa et al, 2002).

The implementation of the family-centred approach has led professionals to place a greater emphasis on the home environment as a treatment context (Law & King, 1993). Deinstitutionalisation coupled with parental recognition has meant that treatment programs for children with cerebral palsy now need to be designed to be implemented in the home, at least in part by family members themselves rather than solely by health professionals. The practice of home based therapy treatment has thus been broadly embraced by early intervention service providers (Bazyk, 1989), including occupational therapists. Occupational therapy assumes a ‘whole person’ approach, which makes it ideally suited to intervention within the home environment (Anderson & Schoelkopf, 1996) and occupational therapists are known to use home programs extensively with children who have cerebral palsy (Hinojosa & Anderson, 1991). The home program aspect of therapy is considered an important aspect of child rearing by the mothers of children with cerebral palsy (Hinojosa, 1990). It has been recommended that,

“The treatment of a child with cerebral palsy is a 24 hour a day process…home programs are an essential part of the treatment process” (Howison, 1988, p.683-684).

The term ‘home program’ in early intervention literature, universally describes therapeutic activities or exercises, to be practised by the child with the assistance and overseeing of their parent, in the home environment, for the goal of achieving desired health outcomes (Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Law & King, 1993; Molineux, 1993; Schreiber et al, 1995). Home programs have been defined in the paediatric occupational therapy literature as,

“one consisting of activities / exercises and / or paper and pencil worksheets completed at home by the child with parental supervision, between treatment sessions” (Molineux, 1993, p.23).
Home programs are nowadays thought of more broadly than just exercises supervised by parents. Occupational therapists believe that, working with parents in reviewing home instructions and teaching therapy techniques has a greater impact on a child with a disability than any other aspect of intervention (Hinojosa et al, 2002). In the cerebral palsy occupational therapy literature, home programs have been referred to as,

“therapeutic regimens to be carried out by the parents and children at home” (Law & King, 1993, p.983).

Key to these definitions is that therapeutic activities are completed at home with parental involvement. Nevertheless, the extent of the parent’s role in the home program appears to differ between health professionals and countries. In the paediatric physiotherapy literature, the home program is described as addressing the child’s health needs and also the parent’s caregiving skills (Schreiber et al, 1995).

The core essence of home program definitions are the same for all early intervention service providers, ‘therapeutic activities practised at home with parental input’, with the emphasis on mode of delivery (eg. exercises versus paper and pencil activities etc), varying dependent on the child’s individual needs.

Home programs have long been seen as important by occupational therapists and physiotherapists for children with cerebral palsy (Finnie, 1975; Hinojosa & Anderson, 1991; Mayo, 1981; Moersch, 1985; Schreiber et al, 1995) but their role and function has changed as philosophy about practice has changed. Home programs were once seen as the mechanism “between treatment sessions” to support the expert care provided by health professionals (Gajdosik, 1991). The trend towards ‘parent training’, which was prevalent in the 1980’s, expanded the roles of parents in therapy (Bazyk, 1989). Therapists were no longer the sole providers of intervention; parents became responsible for assuming the role of ‘therapist at home’ (Bazyk, 1989). Now, when home programs are embedded within an Australian family-centred practice scaffold, the daily caregiving of parents is viewed as an opportunity for therapy (Thompson, 1998). The Australian interpretation of the family-centred approach has assumed that, “supporting families in their caregiving role promote[s] the functional development of the child” (Thompson, 1998).

A qualitative study showed that Australian mothers of children with disabilities believe that,
“the development of their child was unquestionably linked to their efforts as the primary caregivers… [and] the more time they were able to spend repeating and reinforcing therapy sessions at home, the more likely it was that their child would progress and develop” (Thompson, 1998).

The adoption of the family-centred practice approach, within an Australian context, necessitates changes to approaches used by therapists (Thompson, 1998) and therefore to the composition and structure of home programs.

Health professionals are increasingly prescribing home programs as a substitute for regular ‘direct’ therapy intervention because of health funding shortages (Law & King, 1993). As a consequence, increased numbers of parents of children with disabilities are involved in home programs. In spite of the greater incidence of home program use, there is currently no evidence-based guideline or “best-practice” description of a home program for children with cerebral palsy in the literature. In addition to concerns about ‘what’ should be done in a home program, parents are naturally also asking health care providers questions such as, ‘how much therapy is enough?’, operating from the belief that more is better (Hinojosa, 1990). There are currently no definitive answers to questions of home program intensity in the research literature. Indeed, there is surprisingly little investigation of home programs in the area of cerebral palsy treatment. What is known about home programs is limited to one non-randomised, experimental study that found children with autism who received a home program in addition to formal intervention made bigger developmental gains (Ozonoff & Cathcart, 1998).

Apart from issues of efficacy and intensity, parents experiencing a perceived shortage of therapist provided services for their child with cerebral palsy, are also asking questions of service providers, about the relative efficacy of home programs as against institutionally based services. These include questions such as ‘is my child missing out?’, ‘if my child had therapy, would they do better?’ (Miller & Bachrach, 1995). Again the research literature provides few answers.

There are suggestions by many authors, that a number of features in home based therapy, raise a greater likelihood of success than traditional institutional based therapy programs. Firstly, parents have
the capacity to carry out home-based therapy programs (Bazyk, 1989; Dormans & Pellegrino, 1998; Humphrey & Case-Smith, 1996; Moersch, 1985; Rosenbaum, 1998; Tyler & Kogan, 1977). Secondly, the home environment is most likely to increase a child’s ability to perform a specific task as the environment is familiar and non-threatening (Anderson & Schoelkopf, 1996; Clarke & Allen, 1985). This assumes that children inherently perform better in familiar contexts (Anderson & Schoelkopf, 1996; Clarke & Allen, 1985). Thirdly, therapy embedded in everyday activities is easier to carry out and can be learnt and generalised more quickly (Dormans & Pellegrino, 1998; Humphrey & Case-Smith, 1996; Moersch, 1985; Rosenbaum, 1998). These assumptions however, in relation to home programs, have not been tested in research studies.

In spite of this, authors continue to recommend using home programs, for children with disabilities, including cerebral palsy, as an essential tool for translating new skills into ‘meaningful functional change’ within daily routines (Hinojosa et al, 1988; Howison, 1988; Humphrey & Case-Smith, 1996). The concept of ‘meaningful functional change within daily activities’ has remarkable synergy with principles in family-centred intervention, which is also commonly based in the child’s home. One key aspect of family-centred intervention which has similarity with home programs, is that therapeutic activities are designed to help caregivers develop effective ways to communicate and interact with their child while carrying out their usual daily routine (Kwok, 1993). Thus, home programs whilst they have been used within various philosophical paradigms, can be designed to fit within a family-centred intervention framework. This is because home programs, just like ‘hands-on’ family-centred intervention, can recognise the expert caregiving of parents in children’s daily lives (Kwok, 1994).

Home program intervention in an Australian family-centred context may significantly increase the parent’s ‘workload’ within the intervention team. This is because ‘direct’ therapy services may not always be readily available at the parent’s desired intensity level (Thompson, 1998) and therefore a greater reliance may be placed on outcomes that can be achieved by parents “providing” intervention at home. Whilst family-centred practice recognises family’s individual needs and promotes flexibility and adaptability in service delivery options, the range of service options and intensities available to families
is often limited by the constraints of the health care system (Humphrey & Case-Smith, 1996). Placing a greater emphasis on what parents can achieve at home when using a family-centred approach, ought not to be confused with a 1970’s-1980’s notion of training parents to become their child’s therapist:

“The goal is not for parents to become quasi-professionals” (Humphrey & Case-Smith, 1996, p.86).

Rather the goal, which can be achieved through home programs, is to enhance the caregiving competency of parents, to thereby improve their child’s health and development. Caregiving competency is defined as,

“the mother’s ability to meet her child’s needs, which may include needs related to safety, health, physical, social and emotional status” (Washington & Schwartz, 1996).

The rationale for this position on home programs is that the approach to practice (in this case family-centred practice) provides guiding principles to decide how therapy and home programs in particular should be provided.

While principles underpinning choice of therapy service model are important, most parents, children and therapists are interested in the effect of therapy programs. Few studies have measured the impact of home programs on desired therapy outcomes for children with cerebral palsy, such as improvements in upper limb function or the development of independence in activities of daily living. There has been little research, for example, on whether participation with home programs, affects the rate and magnitude of improvement in desired treatment outcomes.

Given the lack of research to support the efficacy of home programs for children with cerebral palsy, but the persistent popularity of home programs in the literature and in practice, the question which inevitably faces occupational therapists in this field is: whether or not home programs actually work? This study aims to contribute to the answer. First by exploring what a “best practice” home program for children with cerebral palsy (based on literature and best available evidence) might look like, as this has not previously been described in literature. Second by investigating what attributes of home programs appear to be related to clinically meaningful outcomes: for example what intensity, duration, and frequency of home programs significantly impacts on the desired health outcomes.
1.3 **Aim of the Study**

The aim of this study is to describe and evaluate the effectiveness of an occupational therapy home program within a family-centred framework, for children with cerebral palsy in achieving desired health outcomes.

1.4 **Objectives of the Study**

The purpose of this study is to:

a) Develop on the basis of evidence in literature a description of a “best practice” home program for children with cerebral palsy who have upper limb dysfunction and identify and describe measurable components and outcomes of these programs;

b) Implement the “best practice” home program;

c) Measure and describe outcomes of the “best practice” home program implemented in the study;

d) Explore the impact of program components on intervention outcomes: specifically, changes made to independence in: activities of daily living; and quality of upper limb movement.

e) Explore parental participation in the home program as a factor possibly related to clinical outcome; specifically the level of parental participation in terms of intensity, frequency and duration.
1.5 Theoretical Perspective for the Study

The family-centred practice framework is the theoretical basis for this study. Family-centred practice is understood to lead to better health outcomes for children with physical disabilities. The evidence for this was reviewed by Rosenbaum et al (1998). His literature review revealed five robust randomised controlled trials, as well as other supporting evidence of a lower quality level. These studies demonstrated that family-centred practice leads to: (a) increased parent participation in intervention (Moxley-Haegert & Serbin, 1983); (b) greater parental acquisition of health knowledge (Moxley-Haegert & Serbin, 1983); (c) greater achievement of motor and developmental skills by children (Moxley-Haegert & Serbin, 1983; Parker et al, 1992); (d) greater parental satisfaction (Davis & Getinger, 1995; Stein & Jessop, 1984); and (e) better psychological adjustment in the child (Pless et al, 1994; Stein & Jessop, 1984).

Collectively the research literature in this area (Rosenbaum et al, 1998) is proposed to demonstrate that family-centred practice leads to better health outcomes than do other models of practice. This study therefore first adopted, family-centred practice as the theoretical perspective to help achieve better health outcomes for families involved. Second, the study used a family-centred practice framework because therapy service provider organisation in the study had formally adopted this approach as the model for practice.

Home programs are not necessarily intrinsically family-centred and can be used in a variety of philosophical frameworks. Consequently, the a priori adoption of the family-centred practice model for the home program was an important foundation for the development of the programs used in this study. In this study, family-centred home programs were achieved by: (a) collaborative goal setting and information sharing with families; (b) recognising parents as experts in their child’s daily life and empowering them to direct, adjust and modify intervention to suit family routines, resources and the child’s preferences; and (c) recognising that the parental care-giving role will naturally influential the child’s health outcome; with parenting skill levels and expectations for their child being major contributing factors. Therefore the parent’s goals and interests drove the quantity and focus of home
program activities. At the same time, clinical reasoning was utilised by the therapist to determine specific intervention frameworks and techniques. As defined by Schell (1988) clinical reasoning is “the process used by practitioners to plan, direct, perform, and reflect on client care” (Schell, 1998, p.90). This led the researcher to collaboratively work with parents to develop an individualised home program for each child.

Occupational therapy home programs for children with hemiplegic cerebral palsy, based upon families’ goals, typically include: (1) strength and active movement exercises for improving use and control of the affected arm; (2) self care skills training; and (3) the wearing of hand splints to improve hand function and reduce muscle contracture development. The theoretical perspective underpinning these interventions is the ‘upper limb retraining’ model (Copley & Kuipers, 1999). The underlying assumption of this approach is that, impaired use of the arms and hands significantly affects the achievement of daily activities and roles and subsequently reduces quality of life (Copley & Kuipers, 1999). Therefore, the aim of intervention is to increase the quality and quantity of hand use to facilitate acquisition of functional skills. Use of a combination of treatment approaches is recommended for achieving the most successful outcomes (Carmick, 1997; Copley & Kuipers, 1999). Recommended approaches include: active movement and strength training; the prescription and manufacture of functional hand splints and upper limb casting intervention (Copley & Kuipers, 1999). Consequently, the individualised home programs in this study referred to earlier, included an upper limb and functional training program, with the wearing of functional hand splints.

In summary, within this study, home programs were viewed as a fundamental aspect of occupational therapy intervention for children with cerebral palsy, and were delivered in such a way that they were family-centred. Therapeutic activities founded in evidence were implemented by the therapist and the parent in collaboration using a home program framework. It is the evaluation of the effectiveness of this style of service delivery that makes this study unique. Terms used throughout the study are defined in Appendix A.
1.6 Delimitations and Limitations

1.6.1 Scope:

The scope was restricted to the evaluation of an occupational therapy home program designed and implemented by the researcher, based on evidence from literature. The program investigated the effectiveness of home programs in achieving desired therapeutic outcomes in children with hemiplegic cerebral palsy, aged 2-8 years. The home programs consisted of upper limb training and regular functional splint wear. The effect of the home programs was investigated in terms of clinical outcomes, measured by selected standardised instruments, namely the Goal Attainment Scaling (GAS); Paediatric Evaluation of Disability Inventory (PEDI); and Quality of Upper Extremity Skills Test (QUEST). The selection of instruments to evaluate the program was made on the basis of evidence of their rigour and relevance in the literature, further explored in chapters two and three.

The narrow age range studied and the decision to investigate one particular type of cerebral palsy limit the generalisation of these results to broader paediatric diagnostic groups. Narrowing the sample attributes was however necessary in order to minimise the number of extraneous variables being measured. It is recognised that the motor co-ordination abilities of children with cerebral palsy vary greatly (Miller & Bachrach, 1995) and that the severity of cerebral palsy will impact on the likelihood of achievement of desired outcomes. Thus generalisations about children with cerebral palsy only have meaning when children with the same recognised subgroup of cerebral palsy are compared (Miller & Bachrach, 1995). It was therefore considered important to study a homogenous sample group. This ensured that conclusions could be drawn from the data about the ‘effectiveness’ of home program treatment, rather than being confounded by comparing children whose motor abilities and potential for achieving the desired outcomes were disparate.

1.6.2 Design:

The study is a non-experimental pre-post single group design. It was non-experimental in the strict sense of the word ‘experimental’, as the investigator did not actively manipulate the intervention
Intensity level. The decision about how much time to spend implementing the program was directed by parents, as this was inherently family-centred in nature. Consequently, intensity was measured by the researcher, rather than controlled by the study design. However, when parents requested guidance or advice about the amount of home program participation time they ought to engage in, all families were given the same information. That is, there is currently no research to inform practice about what home program intensity is optimal. This approach allowed parents to adopt their own preferred intensity, reflecting what worked best for them as a family. It also recognised and respected their diversity and caregiving competence. The generalisability of findings is thus limited given the methodology adopted.

The lack of a controlled comparison group in this study limits the strength of the findings. Such a design was not feasible at the time of the study because of the service provider organisation constraints and lack of guiding literature precedents. Given the design selected, it is thus not possible to detect the contributing effect of developmental maturation, over the duration of the research. In spite of this limitation, the study will provide a solid basis of information relating to the nature of an evidence-based ‘best-practice’ program, and it’s effect on one group. This will be useful information for further work using more rigorous designs (such as randomised controlled trials) where protocol description and implementation must be of a precise nature.

1.6.3 Instruments:

The home program participation data was collected via self-report on a ‘log calendar’, designed and provided by the researcher, at the commencement of the study. Self report log calendars or journals have been shown to be the most accurate data collection method for evaluating parent participation in home programs (Law & King, 1993). Law and King (1993) cautioned that whilst this is the most accurate measure, there is still the possibility that parents may over-estimate their engagement (Law & King, 1993).
Clinical change in response to the home program was captured via a collection of standardised paediatric outcome measures, recommended in literature for recording response to therapy in children with cerebral palsy. See table 4 in chapter three.

### 1.7 Significance of the Study

This study has the potential to improve clinical practice for children with cerebral palsy by describing a program on the basis of evidence, and by furthering what is known about the effectiveness of home program intervention through empirical investigation.

The practice of prescribing home programs for children with cerebral palsy is commonplace (Hinojosa & Anderson, 1991; Law & King, 1993) and is thought to be an essential part of intervention (Howison, 1988). In a recent American survey (n=199), more than three quarters of paediatric occupational therapists respondents indicated that they believed working with parents had a greater impact on the child than any other aspect of occupational therapy intervention (Hinojosa et al, 2002). This same group of therapists also reported, firstly, spending two thirds of their intervention time instructing parents about the care of their child and secondly, that the time they did have was insufficient (Hinojosa et al, 2002). Of the range of therapy activities these therapists carried out with parents, the practice of reviewing home program intervention was estimated to take the most time (Hinojosa et al, 2002). Yet there is no literature to describe a ‘best-practice’ approach to the activity that therapists report as constituting 66.4% of their interaction time with families. The term ‘best-practice’ is used here to mean, “a continuous, collaborative, and systematic process for measuring and examining internal program’s strengths and weaknesses” (Lewis & Latney, 2002, p.25)

Strategies for developing, delivering and evaluating home program intervention is currently assumed knowledge, as no body of literature or systematic process appears to exist to guide clinicians in this principal area of practice. There is therefore a pressing need for a ‘gold standard’ home program, that encompasses family-centred thinking, to be developed.
In addition to the lack of a ‘best-practice’ program description, none of the literature, which recommends the use of home programs for children with cerebral palsy, has empirically measured the outcomes achieved through home programs. The recommendation to use home program intervention for children with cerebral palsy is based solely on expert opinion. To date, the focus of home program research has been on: whether parents perform home programs; how best to measure parental participation; and the effect of home programs on parent-child interactions. Whilst these studies have made an important contribution to the body of knowledge about home program intervention, there is a paucity of evidence regarding the efficacy of family-centred home programs, in reaching desired intervention outcomes for children with cerebral palsy. Arguably, the most fundamental question in this area of practice has not yet been asked by researchers, ‘do home programs work?’ This study has been designed to begin addressing this knowledge gap identified in the literature.

The results of this study, will add to the paediatric research literature by:

(1) describing a “best practice” home program for children with cerebral palsy;
(2) furthering what is known about home programs and parental participation;
(3) providing information about what constitutes home programs for children with cerebral palsy who have hemiplegia;
(4) describing potential program outcomes; and
(5) exploring what program or child attributes may be associated with program outcomes.

The results of this study have implications for health professionals who prescribe home programs to families who have a child with cerebral palsy. It will provide: an understanding of what ‘best practice’ home programs look like for children with cerebral palsy; a framework for developing home programs with families; and a description of the clinical outcomes that might be expected from implementation. The results of this study will also have applications for the consumers of home programs, parents and children. It will provide an understanding of what a home program for a child with upper limb dysfunction resulting from hemiplegic cerebral palsy may be like; what home program outcomes can be
expected; and what is required to achieve these outcomes. It will also provide a basis for examining whether home programs are an effective and realistic method of service delivery for families.

1.8 Synopsis

This chapter provided a background for the study, by defining the problem, presenting the purpose of the study, its delimitations and examining its potential significance. The next chapter provides an in-depth examination of the literature pertaining to the study.
CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Over the past fifty years there has been a revolutionary shift in the approach to paediatric health care; from professionals determining children's needs coupled with institutional care, to parents being recognised as central and expert caregivers (Dunst et al, 1988; Winton & Bailey, 1997). This transformation recognises that families are better positioned than health professionals, to direct, plan and prioritise their child’s health care (Winton & Bailey, 1997). The adoption of this value has necessitated change in the way services are delivered. A greater emphasis is now placed on the home environment as a treatment context (Law & King, 1993). In particular, home programs carried out by family members, are used extensively as an intervention strategy for achieving desired health outcomes (Hinojosa & Anderson, 1991; Howison, 1988). Within this study, home programs are perceived as one possible strategy for increasing parental caregiving competence, not as a replacement of professional’s responsibilities. The reliance on home programs as a substitute for direct ‘hands on’ intervention has become commonplace due to health resource shortages (Law & King, 1993) and the problems associated with Australian health resource shortfalls are acknowledged by parents of children with disabilities (Thompson, 1998). Despite well-documented academic and clinician consensus on the clinical importance of prescribing home programs, there is a paucity of evidence to support their efficacy.

This chapter describes the impact of cerebral palsy on children’s development, the use of occupational therapy home programs in a family-centred framework for children with cerebral palsy, and a review of current clinical practice for developing function in children with cerebral palsy. The chapter is extensive as it provides the foundation for the development of the study intervention – a ‘best-practice’ occupational therapy home program, which itself is a key contribution and outcome of this study. It will also demonstrate that there are gaps in the literature evidence presented and that a need exists for a study to evaluate the effectiveness of occupational therapy home programs that use a family-centred approach.
2.2 Children with Cerebral Palsy

Cerebral palsy is a commonly occurring childhood disability. The reported incidence varies from country to country but in Australia it is generally accepted to be 1 in 400 live births (Manning et al, 1998; Stanley & Watson, 1988; Stanley et al, 2000). Cerebral palsy is a disorder of muscle control and posture, which results from damage to the motor cortex of the brain. There are many types of cerebral palsy, each one classified by the type of abnormal movement patterns present and the region of the body affected (Bax, 1964; Bleck, 1987; Howison, 1998; Stanton, 1992). The most common type of cerebral palsy is spasticity. This classification is given when muscles are overactive and display a “stiff” or “tight” quality, which impedes normal or smooth, controlled movement (Katz & Rymer, 1989). When only the leg and arm on one side of the body are affected by spasticity, this is referred to as ‘spastic hemiplegia’ (Bleck, 1997; Dormans & Pellegrino 1998). Spastic hemiplegic cerebral palsy is the mildest form of the disorder as independent walking, speech and normal intellectual capacity is present (Bleck, 1987; Molnar & Gordon, 1976; Stanton, 1992). In the majority of cases, children with spastic hemiplegia have normal academic potential and are likely to mature to live and work independently as adults (Bleck, 1987).

Cerebral palsy can be understood from the perspective of the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF, 2001). The ICF is a multipurpose classification system designed to provide a scientific basis for understanding and studying health and establishing a common language (WHO, 2001). It is therefore a useful tool for developing an awareness of the multiple implications cerebral palsy may have on a person’s life. The ICF is described as having

“two parts, each with two components: Part 1. Functioning and Disability, (a) body functions and structures; (b) activities and participation. Part 2. Contextual factors, (a) environmental factors; (b) personal factors” (WHO, 2001, p.10).

Children with cerebral palsy have by nature of their diagnosis have changes in body function and body structure, eg. motor cortex damage causing spasticity with secondary physical limitations such as joint contractures. The body function changes experienced in cerebral palsy often affect the child’s ability to accomplish activities (e.g. fastening buttons, eating with utensils, writing their name) and participate in
meaningful life activities (e.g. playing community sport, attending mainstream school). Occupational therapists are vital members of the health team that support children with cerebral palsy and their families (Dormans & Pellegrino, 1998). Occupational therapy intervention addresses the body function impairments and activity limitations associated with cerebral palsy to enhance the child’s ability to experience and participate in life (WHO, 2001).

2.3 Intervention Needs of Children with Cerebral Palsy

Each child with cerebral palsy has individual and unique needs (Case-Smith, 1996). A comprehensive assessment is necessary to ensure that intervention is devised accurately to meet specific, individual needs. The assessment needs to include identification of the child’s strengths and limitations during their functional performance of every day activities, within different environments (Case-Smith, 1996). By definition, all people with cerebral palsy experience difficulties in the control of movement and posture (Bax, 1964; Bleck, 1987; Howison, 1998; Stanton, 1992). Associated deficits in language, intelligence, vision and hearing are also common, along with a high prevalence of epilepsy (Bax, 1964; Bleck, 1987; Howison, 1998; Stanton, 1992). The motor abnormalities of cerebral palsy, coupled with associated impairment, impact on a child’s function (Bleck, 1987; Case-Smith, 1996). The focus of intervention with children who have cerebral palsy is to improve the child’s functional performance and to enhance the child’s ability to interact with his or her physical and social environment (Case-Smith, 1996). Treatment goals for the team of health professionals who provide intervention services to children with cerebral palsy have been described as being,

“to maximise function and minimise the development of secondary problems such as joint contracture, thereby delaying or obviating the need for surgical intervention” (Russman et al, 1997, p.S182).

This could also be viewed as seeking to minimise the impact of impairments and disabilities, which can lead to handicaps.
Occupational therapy has had a long history of providing assessment and intervention to children with hemiplegic cerebral palsy (Powell, 1985). The occupational therapy approach has been broadly described by Erhardt and Merrill (1998):

“The occupational therapy practitioner working with young children who have cerebral palsy recognises the importance of encouraging them at an early age to take responsibility, be self-reliant and eventually become assertive in directing their own lives” (Erhardt & Merrill, 1998, p.589).

Occupational therapists are trained to develop a child’s functional abilities. When working with a child who has cerebral palsy, functional independence may be achieved through various means, which include: skills training; specialist equipment to enhance or promote self-help skills; environmental adaptations to facilitate independence; and assisting the child to adapt to their own environment (Ketelaar et al, 2001; Stanton, 1992). Recent research has demonstrated that targeted functional skill training is more effective at improving a child with cerebral palsy’s independence than traditional generic movement skills therapy (Ketelaar et al, 2001).

Many factors influence the ability of a child with cerebral palsy to become independent, but predominantly it is the motor deficit associated with cerebral palsy that can be detrimental (Erhardt & Merrill, 1998). Skilled, functional movement requires complex motor coordination, which in turn depends on a foundation of sound and basic movement patterns developed early in life. Occupational therapy plays an important role in assisting a child to develop skilful foundational movement patterns though the practice at everyday functional tasks (Case-Smith, 1996). For children with cerebral palsy, the quality of movement development is as important or even more important than the rate of development (DeMatteo et al, 1993; Erhardt & Merrill, 1998; Hickey & Ziviani, 1998).

Of particular interest to occupational therapists working with children who have hemiplegic cerebral palsy, is the child’s ability to use their affected arm and hand (Bleck, 1987; Erhardt & Merrill, 1998; Exner, 1996). For the majority of children with hemiplegia their hand is more affected than their leg (Stanley et al, 2000; Miller & Bachrach, 1995). Since the lower limb is used for walking, the child may
concentrate on the leg to gain increased independence and thereby disregard the hand, which is difficult
to use (Bleck, 1987; Bobath, 1967). The underlying concern for occupational therapists is that,
“Impaired use of one’s arms and hands …can affect the fulfilment of one’s life roles and subsequent

Hand function is far more necessary for independence than walking as wheelchairs can assist mobility
but it is proposed by Stanton (1992) that no mechanical aids can take over the fine motor role played by
the hands (Stanton, 1992). Consequently, a large focus of occupational therapy intervention for children
with hemiplegia is improving the use of the upper limbs. This approach is driven by the supposition that
increased quality and quantity of hand use leads to increased functional skill acquisition. The heavy
emphasis on upper limb therapy was evident even in Paisley’s early (1929) occupational therapy work
in schools with children who had hemiplegia. Paisley’s intervention focus was on bilateral tasks,
positioning and the undertaking of activities that required the use of weak muscles (Powell, 1985).

2.4 Intervention Approaches with Children who have
Cerebral Palsy

Historically, children with disabilities, including cerebral palsy, were institutionalised and received
“around the clock” expert care from professionals. This was based on the belief that their parents were
incapable of providing the specialist care they required (Rosenbaum et al, 1998). Mattingly and Lawlor
(1998) identified three key assumptions, which underpinned this traditional ‘medical approach’ to
treatment.

(1) Disability belongs to the individual. A pervasive notion in health care has been that it is the
professional’s task to ‘treat the pathology’. This framework loses the essence of treating a
person, who has a disabling condition (Mattingly & Lawlor, 1998).

(2) The professional is the expert. The biomedical approach where the professional is the ‘healer’
promotes the professional to the role of ‘expert’. The expert determines what is wrong and
what should be done and the patient’s role is one of submission (Mattingly & Lawlor, 1998).
The client is the recipient of care. When health professionals deliver treatment ‘to’ a person with a disease, the child or family become a passive recipient. Their role is to receive a ‘cure’ (Mattingly & Lawlor, 1998).

Intervention approaches and ‘best practice’ (Driever, 2002) in the care of children with disabilities has undergone significant change and evolution over the past fifty years (Bailey et al, 1992; Dormans & Pellegrino, 1998; Dunst, 1991; King et al, 1998; Leviton et al, 1992; Rosenbaum, 1998; Winton & Bailey, 1997). In the 1940’s and 1950’s parents formed advocacy groups, which began a gradual departure from professionals, controlling the destiny of children with disabilities (Rosenbaum et al, 1998). The efforts of parents and the United States inclusive education legislation began to reshape the approach to health care for school-aged children with disabilities, including those with cerebral palsy (Rosenbaum et al, 1998). This had flow on effects in Australia (Llewellyn et al, 1996; Thompson, 1998) where there has been a shift away from a medical approach to a family-centred one (Hanna & Rodger, 2002).

The key medical treatment assumptions as described above by Mattingly and Lawlor (1998) have been eroded and replaced over time, through active parental lobbying and consumer participation in health care. The term ‘disability experience’ was coined to encompass the person first and the disability second. This was done in an attempt to understand what the disability may mean to the person (Good, 1993; Kleinman, 1988; Mattingly & Lawlor, 1998). ‘Child with cerebral palsy’ has replaced phases such as the ‘cerebral palsied child’. This change is more than one of semantics it acknowledges a person before the disease or disorder. In addition to placing the person first, there has also been a shift towards collaboration with health care consumers (Mattingly & Lawlor, 1998; Rosenbaum et al, 1998). The potential contribution consumers could make to their own health care has gained valued status.

Collaborative partnerships are now sought between professionals and parents to enable family participation in health care, as it was recognised that the ‘expert model’ created barriers to parental contribution (Mattingly & Lawlor, 1998). The role of the family in the child’s life has received increased recognition and has led to the realisation that the family is a valuable resource within the health care
system (Rosenbaum et al, 1998). This understanding has fundamentally changed the approach to intervention for children with disabilities.

2.5 Family-Centred Practice Approach to Intervention for Children with Cerebral Palsy

The National Centre for Family-Centred Care (Bethesda USA) (1990) has put forward this definition of family-centred practice:

“Family-centred care is the name that has been given to a constellation of new philosophies, attitudes and approaches to care for children with special health service needs. At the very heart of family-centred care is the recognition that the family is the constant in a child’s life. For this reason, family-centred care is built on partnerships between parents and professionals” (National Centre for Family-centred Care, 1990).

This definition and the National Centre for Family-centred Care’s contribution to policy development concerning family-centred care, is widely referred to by professionals working in paediatric health care (Rosenbaum et al, 1998). However, eight years later the members of PROSPECTS (A family support and advocacy group for children with special needs in Peterborough Ontario) refined the definition further,

“The family-centred approach is one that begins with the child’s and family’s strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage and enhance the competence of parents in their role as caregivers” (Viscardis, 1998, p.44).

This definition shifts the focus of care squarely onto the family and thereby established a new standard.

Central to the idea of family-centred care is the belief that, families are capable of making informed decisions concerning the welfare of their child with a disability. Not only that, but parents are able to work as partners with professionals and have the right and responsibility to be so involved with their child (Viscardis, 1998). Dormans and Pellegrino (1998) describe this facet of family-centred care as:
“professionals become agents of family priorities… families determine the interventions that are appropriate based on their knowledge of their child and their own circumstances…. Family-centred care gives appropriate emphasis to the parental right to determine what is best for the child, regardless of professional opinions that might differ” (Dormans & Pellegrino, 1998 p.61).

As mentioned before, this family-centred approach is a major change from the ‘medical model’ used in the past. Traditionally, the child was the primary focus of intervention and the professional was central to decision making (Bailey et al, 1992; Dormans & Pellegrino, 1998; Dunst, 1991; King et al, 1998; Leviton et al, 1992; Rosenbaum, 1998; Winton & Bailey, 1997). Services were provided with a child-centred focus in which health professionals set goals to achieve health improvements for the child that were separate to the family, thus making parents passive recipients of therapy services (Hanna & Rodgers, 2002; Rosenbaum, 1998). Viscardis (1998) articulates the change in thinking that is therefore required,

“implementing a family-centred approach…requires a fundamental shift from the belief that service is provided by professionals to a family because the family is unable to solve the problem themselves, to the belief that service is provided by professionals because the family has identified a need and a service that can meet that need. The professional’s role then becomes the provider of a service that exists only to meet the needs identified by families” (Viscardis, 1998, 50-51).

The change in the professional’s role, described by Viscardis (1998), therefore must facilitate change in the parent’s role in the team. The family-centred practice literature describes a philosophy where parents are empowered to reclaim the role of ‘decision maker’ in their child’s health care (Humphrey & Case-Smith, 1996; Rosenbaum et al, 1998). The family-centred model promotes parents’ chose their level of involvement in their child’s health care,

“a truly family-centred approach is one where families are given options about the intensity of their involvement as team member…Parents must be encouraged to define their role in their child’s team for themselves” (Viscardis, 1998, p.44).

This means that parents and therapist would typically collaborate to share decision making responsibilities regarding program planning; service delivery and evaluation in order to devise therapy outcomes that are meaningful to the family (Hanna & Rodgers, 2002). Occupational therapists and
physiotherapists, working in a family-centred framework, place an additional emphasis on building parental caregiving competency as a key aspect of therapy intervention (Washington & Schwartz, 1996) compared to traditional medical approaches which provided child-centred, ‘expert,’ professional care (Hanna & Rodgers, 2002; Thompson, 1998).

“Within this family-centred framework, PT [Physiotherapist] and OT [Occupational Therapist] goals are aimed at enabling the parents and structuring the environment to enhance the child’s development. Assisting parents in building a repertoire of skills to enhance their interaction with their children is another primary goal of physical and occupational therapy intervention” (Washington & Schwartz, 1996, p.34-35).

Parental caregiving competency is defined as,

“the mother’s ability to meet her child’s needs, which may include needs related to safety, health, physical, social and emotional status” (Washington & Schwartz, 1996).

In an Australian context, the very act of ‘parental caregiving’ to children with disabilities assumes parental involvement in ‘specialist services’ to help their child, such as occupational therapy (Thompson, 1998). The Australian interpretation of the family-centred approach has assumed that,

“supporting families in their caregiving role promote[s] the functional development of the child” (Thompson, 1998).

A qualitative study of Australian mothers found that,

“Mothers perceived that the development of their child was unquestionably linked to their efforts as the primary caregivers…[and] the more time they were able to spend repeating and reinforcing therapy sessions at home, the more likely it was that their child would progress and develop” (Thompson, 1998).

Occupational therapy is known to be influential in fostering the caregiving competency of parents (Washington & Schwartz, 1996). Parents of children with disabilities have described, in a qualitative study using semi-structured interviews, an outcome of family-centred therapy services as being an increased perception of competency in managing their caregiving responsibilities for their children (Washington & Schwartz, 1996).

The key elements of family-centred care have been described by the National Centre for Family-Centred Care (1990) in detail. In summary these key elements include:
recognising that the family is the constant in a child’s life, while the service systems and personnel within those systems fluctuate

- facilitating the collaboration between the parent and professional at all levels of health care, from the care of an individual child to policy development
- honouring the racial, ethnic, cultural and socio-economic diversity of families
- recognising family strengths and individuality and respecting different methods of coping
- sharing with parents complete and unbiased information on a continuing basis and in a supportive manner
- encouraging and facilitating family-to-family support and networking
- understanding and incorporating the developmental needs of infants, children, adolescents and their families into health care systems
- implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families
- designing accessible health care systems that are flexible, culturally competent and responsive to family identified needs (National Centre for Family-Centred Care, 1990)

Adopting ‘family-centred thinking’ enables a family to take a “therapeutic pilgrimage” to a more satisfying life (Powell, 1996). Powell (1996) proposes a powerful, positive schema of words, which facilitates professionals to reorientate commonly used language and experiences, to enable families to rewrite their journey. The schema is summarised below:

1. **Joining** or engaging with families builds relationships. This enables families to tell their stories, seek help and develop coping mechanisms.

2. **Discovery** should replace words such as ‘diagnosis’ or ‘assessment’, as discovery implies a collaborative process. Families should begin on a joint venture with professionals as active partners, rather than having something ‘done to them’.

3. **Change** should be valued rather than the word ‘treatment’, as it implies that families are central to the therapy process. It also implies possibility, hope and a future.
Celebrate changes, big or small, as this affirms growth, hope and confidence. It also recognises and appreciates the strengths and potential in families.

Separation or helping families to ‘rewrite’ their stories in a more hopeful context gives the potential for change and new futures.

Reflection on what has happened enables opportunities for growth, research and evaluation (Powell, 1996).

The recognition of the important and central role of the family has not only changed thinking and language but has also changed service provision practice. Today, the family-centred practice approach has been mandated by United States public law (Rosenbaum, 1998). In Australia, disability service policies endorse the family-centred approach as “best practice” (Hanna & Rodgers, 2002; NSW Department of Community Services, 1993). Best-practice is the “continuous, collaborative, and systematic process for measuring and examining internal program’s strengths and weaknesses” (Lewis & Latney, 2002, p.25). So it is natural to think of the best foundation for clinical practice as being a body of well-designed research evidence (Mason, 2002). Along with evidence, professional judgement, proficiency and clinical reasoning are needed to generate ‘best-practice’ decisions that attend to the family’s unique needs (Higgs, Burn & Jones, 2001). Dormans and Pellegrino and others (Ahmann, 1994; Roberts & Magrab, 1991) have for some time recognised family-centred practice, by means of interdisciplinary collaboration, as the ‘gold standard’ in service provision for children with cerebral palsy.

2.6 Occupational Therapy and Family-Centred Practice

In some countries (for example USA and Canada), the occupational therapy profession has assumed the family-centred approach to practice in the area of childhood disability (Baum & Law, 1997; Bazyk, 1989). This widespread shift in thinking is increasing in Australia, but is not yet mandated as an obligation of practice (Hanna & Rodgers, 2002). The adoption of this approach has paralleled the widespread shift in philosophical thinking about the importance of families in health care (Bazyk, 1989). This section will describe the evolution that took place within occupational therapy services, leading to the
implementation of a family-centred practice approach. Also, the important role of collaboration between families and occupational therapists as the mechanism for achieving family-centred practice will be discussed.

2.6.1 Occupational Therapy Service Delivery Models and Family-Centred Practice

A variety of general paediatric occupational therapy service delivery models exist. Dunn and Campbell (1991) have described these broadly:

1. "Direct therapy" where the intervention is individually designed and implemented by the occupational therapist;

2. "Monitoring" is where the occupational therapist assesses the child, plans the intervention, but trains another person to carry out the intervention; and

3. "Consultation" is where a person significant to the child (such as the parent or teacher) identifies problems and desired outcomes and seeks the expertise of the occupational therapist to assist them to address these target areas (Dunn & Campbell, 1991).

As is evident from earlier sections of this literature review, the third model, ‘consultation’, lends itself readily to adopting a family driven approach within home program intervention. The consultation model enables the family to request advice and draw on the ‘technical expertise’ of therapists to broaden the family’s knowledge about their child’s condition and treatments (Rosenbaum et al, 1998). It is of course possible to operate from a family-centred approach using any of these service delivery models but to achieve this it requires the professional to provide intervention within the context of the family, not the child in isolation (Hanna & Rodgers, 2002). The purpose of ‘direct therapy’ or ‘hands on therapy’ provided by an occupational therapist utilising a family-centred approach, should be to extend the skill base of the family and to support the family’s goals. Viscardis (1998) describes this role,

“Service providers and agencies will acknowledge that they are providing a service to meet a need identified by families and that they are in the field to serve families…Families ultimately want to take
control of their situations so they can better provide for their children. A key outcome of family-centred service is that parents become more skilled and empowered to take control” (Viscardis, 1998, p.52).

A review of occupational therapy intervention literature over time for children with cerebral palsy, by the investigator, demonstrated large changes in service delivery styles. Analysis of key home program literature appeared to indicate different ‘schools of thought’ concerning service delivery to children with cerebral palsy. This section of chapter two proposes that these ‘schools of thought’ are thematic. By describing each theme, the following key issues become apparent: (a) changing assumptions about the nature of service have impacted on the delivery of occupational therapy to children with cerebral palsy; and (b) occupational therapy practice as documented in the literature (primarily North American) has evolved to become more family-centred for children with cerebral palsy. Each new theme discussed here has overlapped with the previous one for varying lengths of time. This appears to have occurred until either, the approach achieved a critical mass of professionals who implemented it, or, the approach was mandated by law as ‘best practice’ for children with disabilities. These themes are now described,

(1) Theme One - Institutions: Early in the profession’s involvement with children who have cerebral palsy, ‘expert’, ‘direct occupational therapy’ was provided in an institutional context, which was where the children lived and the overarching view of children’s needs at the time (Bazyk, 1989; Paisley, 1929; Rosenbaum, 1998), which assumed that their complex needs could only be met by professional 24 hours a day carers.

(2) Theme Two - Therapy Centres: As children began to move out of institutions to live at home with their family, families were expected to bring their child to specialist therapy centres and hospitals to receive the regular, ‘expert’ treatment that their child required (Bobath, 1967, Finnie, 1975).

(3) Theme Three – Follow up Home Programs: The recognition of the life long nature of disabilities brought an understanding that desirable outcomes required regular intensive intervention, which a resource limited health system could not fully provide. As professionals began to acknowledge that children are family members, a greater emphasis was placed on the family and home environment as a treatment context (Law & King, 1993). Parents were provided with home programs to follow up and reinforce the effects of the ‘direct occupational therapy’ provided in the hospital or treatment
centre (Bazyk, 1989; Gajdosik, 1991; Gajdosik & Campbell, 1991; Hinojosa, 1988; Hinojosa &
Anderson, 1991; Law & King 1993; Mayo, 1981; Schreiber et al, 1995; Stanton, 1991; Tyler &
Kogan, 1977). These home programs could loosely be described as “between session homework”.

(4) Theme Four – Compliance with Home Programs: Professionals became interested in the effect of
home therapy program ‘compliance’, believing that parents often lacked rigour in carrying out such
programs, to the child’s detriment. Home visits were provided to reinforce the importance of home
programs and boost compliance with the prescribed regimes (Gajdosik, 1991; Gajdosik &
Campbell, 1991; Law & King 1993; Molineux, 1992; Wortis et al, 1954). If from the professional’s
viewpoint, parents failed to follow through with home programs, they were labelled ‘non-compliant’,
reinforcing a passive role for parents and the belief that the therapist knew best (Hanna & Rodgers,
2002).

(5) Theme Five – Home and School Based Therapy: As the practice of inclusive schooling grew,
parallelling the home health movement, expert, ‘direct occupational therapy’ shifted away from
therapy centres and hospitals to be provided in the home and school context. The underpinning
belief was that the practise of functional skills in natural environments would increase
generalisation, the family’s comfort and lead to more realistic activity prescription. (Hinojosa &
Anderson, 1991; Hinojosa et al, 1988; Stephenson & Wiles, 2000; Thompson, 1998; Wortis et al,
1954).

(6) Theme Six – Education and Monitoring: An increased recognition by professionals of the
importance role the family held in a child’s life, revolutionised occupational therapy practice. Not
only could the parent carry out a prescribed follow-up home program but they also could be
instrumental in prioritising and goal setting their child’s intervention needs. In recognising parents
as key team members, therapists began to rely upon parental observations of their child’s progress
to determine critical intervals for providing or changing intervention (Bazyk, 1989; Case-Smith &

(7) Theme Seven – Family-Centred Collaboration: Recognition of parental expertise, enabled parents
to reclaim the role of “director” in their child’s health care. Parents could now direct their child’s
care by requesting professionals to provide clinical services as required, rather than the
professional determining the level and intensity of care received (Bazyk, 1989; Campbell, 1997; King et al, 1998; Hinojosa & Anderson, 1991; Law et al, 1996; Luger, 1996; Stephenson & Wiles, 2000; Thompson, 1998). In this type of family-centred approach, the focus moved from the environment for effective therapy to who is the main provider of daily caregiving, ie. the family. Parental caregiving includes meeting the child’s health and physical needs (Washington & Schwartz, 1996) and occurs naturally in the home environment. Family-centred occupational therapy is influential in fostering the caregiving competency of parents (Washington & Schwartz, 1996). Viscardis writes,

“Because families are the constant in their child’s life, parents know their child best and have much insight to offer about what and how services should be provided…By providing services that meet the needs of the whole family, a greater probability exists that the needs of the child will be met” (Viscardis, 1998, p.42).

In a family-centred collaborative approach the following principles are highly valued:

“(i) the unit of support and intervention is considered to be the family rather than the individual child; (ii) parent and family diversity is celebrated and recognised; (iii) services are provided in ways that are flexible and responsive to family needs, concerns and priorities; (iv) decision-making occurs in a collaborative partnership between parents and professionals, reflecting family rather than therapist goals; and (v) services are expected to incorporate practices that strengthen family systems and encourage use of wider community resources” (Hanna & Rodgers, 2002, p.15).

The following diagram (Figure 1) presents the seven themes in occupational therapy service delivery trends that have occurred over time, as thinking about the role and centrality of the family has evolved.
Figure 1: Summary of Paediatric Occupational Therapy Service Delivery Changes

Theme 1
Direct therapy in institutions carried out by the occupational therapist

Theme 2
Direct therapy in hospitals and centres carried out by the occupational therapist

Theme 3
Direct therapy in hospitals and centres with follow up home programs to be carried out by the parent to reinforce the occupational therapy treatment

Theme 4
Direct therapy in hospitals and centres with follow up home visits carried out by the occupational therapist to increase “compliance” with the home program

Theme 5
Home and school based direct therapy carried out by the occupational therapist

Theme 6
Home and school based intervention, carried out by another person, trained by the occupational therapist, who then monitors the child’s progress

Theme 7
Family-centred collaboration where the occupational therapist is invited to share technical knowledge with the family to build their knowledge base; caregiving skills and to support their goals

The family-centred approach is now widely believed to constitute best practice for working with children who have disabilities (Ahmann, 1994; Roberts & Magrab, 1991), this approach has also been adopted by the discipline of occupational therapy (Hanna & Rodger, 2002; Wallen & Doyle, 1996).

Implementation of this model in occupational therapy clinical practice, for children with cerebral palsy,
has necessitated a shift in traditional service delivery methods (Bailey et al, 1992; Dormans & Pellegrino, 1998; Dunst, 1991; King et al, 1998; Leviton et al, 1992; Rosenbaum, 1998; Winton & Bailey, 1997; Viscardis, 1998). Predominantly the model of service delivery utilised in Australia today is family-centred and collaborative: the seventh theme (Hanna & Rodgers, 2002). Here the parent is recognised as director of their child’s intervention (Dunst et al, 1988). In this model, information is provided to the family on request from the parent (Dunn & Campbell, 1991), and the occupational therapists acts as a resource to families, including informing them in an honest and unbiased manner about the efficacies of various treatment options (Viscardis, 1998). This paradigm therefore requires occupational therapists to understand parent diversity; develop effective parent-therapist relationships; establish shared priorities and goals and develop services that support collaboration (Hanna & Rodger, 2002). In addition to this therapists are required to have a good understanding of the evidence base for practice and any technical skills required – both in the context of clinical reasoning.

The home program, which was once seen as an adjunct or follow-up mechanism for direct ‘hands on’ therapy, is increasingly used as the primary way of delivering occupational therapy services (Law & King, 1993). This delivery preference is driven by financial shortages in health services (Law & King, 1993) but is also influenced by philosophical changes in care towards family-centred practice. Family-centred practice provides a new approach within which home programs can occur. Family-centred home programs recognise the expert role of caregivers and family members and therefore, inherently include them as active participants in therapy provision to a child with cerebral palsy. Schreiber et al (1995) observed that in fact, “Parents may be more likely than physical therapists to identify home program activities that are feasible and that do not increase stress upon the family. Parents serve as natural reinforcing agents for their children and can aid the transfer of learning from program to home, enhancing continuity between home and school” (Schreiber et al, 1995, p.59).

A family-centred occupational therapy home program is ideal for empowering parental control of their child’s health care and recognition of family’s differences and strengths. Adoption of the family-centred framework has also been proposed to achieve better health outcomes for a child with cerebral palsy.
(Rosenbaum, 1998). The latter issue, the quality of outcomes, particularly in occupational therapy family-centred home programs will be taken up later in section 2.7.4.

2.6.2 Collaboration, a Mechanism to Achieve Family-Centred Practice

The pivotal and indeed the starting point of occupational therapy, when utilising a family-centred approach, is to discuss the child’s needs and the family’s goals with the child’s parent. Joint planning is of high importance,

“The family’s contributions to therapy goals and activities determine how well they match the family’s priorities and whether they will result in meaningful outcomes” (Humphrey & Case-Smith, 1996, p.91).

The collaborative parent-therapist partnership means there is agreement on roles and mutual goals are pursued. This cooperation promotes better health outcomes for the child (Dunst, 1991; Humphrey & Case-Smith, 1996). Hinojosa (1990) highlighted the importance of this relationship-building phase through a qualitative study, utilising in depth interviews. Hinojosa investigated mother’s perceptions of what happens when their preschool child with cerebral palsy, has occupational and physiotherapy. Hinojosa (1990) found,

“All the mothers felt their relationship with therapists were personally important. Often, it appeared that the therapist as a person was more important than the therapy itself” (Hinojosa, 1990, p.157).

Law and King (1993) also noted this phenomenon. They observed that a person’s knowledge of the home program and their relationship with the professional related more closely to participation levels in home programs than their amount of knowledge about their child’s disability (Law & King, 1993).

It is important to recognise that when collaborating with parents, that parents of children with disabilities cannot be considered a homogeneous group (Hanna & Rodgers, 2002). In this way each parent-therapist relationship will need to be unique and therefore will seek to meet the individualised needs of the child and the family by appreciating their strengths and diversity.
2.7 Occupational Therapy and Children with Cerebral Palsy

Occupational therapists are trained to evaluate and provide intervention to children who have body function impairments and activity limitations, to enhance their quality of life, experience and participation in their community (Case-Smith, 1996, Law et al, 1998). In the 2001 NSW Occupational Therapy Association annual report, it was noted that was the most commonly identified area of clinical interest was the field of paediatrics. There is a well-established role for occupational therapists in supporting families of children with cerebral palsy to achieve desired health outcomes (Bazyk, 1989; Bobath, 1967; Bleck, 1987; Copley & Kuipers, 1999; Finnie, 1975; Law & King, 1993; Stanton, 1992). When an occupational therapist works with a child who has cerebral palsy, the development of functional independence may be achieved through many specialist intervention techniques and the provision of adaptive equipment (Ketelaar et al, 2001; Stanton, 1992).

The following sections will now describe current occupational therapy practice for children with cerebral palsy. It will begin with the assessment process and treatment planning. Following this will be an explanation of common occupational therapy interventions and the evidence to support these techniques, concluding with a description of instruments to measure outcomes, any of which can be used as part of the evaluation of the occupational therapy family-centred home program.

2.7.1 Occupational Therapy Assessment

The starting point of the family-centred assessment process, as mentioned previously, is establishing a collaborative partnership between the family and the occupational therapist. Once this foundation is achieved, the assessment activities commence. Case-Smith (1996) writes,

“Occupational therapists hold two broad goals for the children they serve. These goals are to improve the child’s functional performance and to enhance the child’s ability to interact with his or her physical and social environment” (Case-Smith, 1996, p.4).
The occupational therapy assessment is uniquely characterised by examination of the child’s ability to perform everyday ‘roles’ and activities, with the child and their family identifying the key focus areas (Copley & Kuipers, 1999; Dunst, 1991; Humphrey & Case-Smith, 1996; Powell 1985). Chapparo and Ranka (1997) suggest children’s everyday ‘roles’ include (1) “productivity” ie. play and school performance, (2) “self-care” eg. dressing, eating, (3) “leisure” eg. play and community sports, (4) “rest” or sleep (Chapparo & Ranka, 1997). In observing the child’s ability to perform everyday ‘roles’, the occupational therapist gathers detailed information about which components of the performance is delayed, deficient or missing (Case-Smith, 1996, Chapparo & Ranka, 1997). The child’s performance of functional tasks and roles is analysed within different environments to highlight individual strengths and limitations, which may benefit from intervention (Case-Smith, 1996).

When assessing a child with cerebral palsy, a comprehensive evaluation is necessary. This includes the use of standardised paediatric assessments, observation instruments and interview protocols to quantify the delayed, deficient or missing components identified (Erhardt & Merrill, 1998). Comprehensive assessment of the child with hemiplegic cerebral palsy is known to routinely include an motor assessment of range of motion, muscle strength, sensation and analysis of the degree of voluntary movement available (Bleck, 1987). However, a plethora of authors have noted, that it is more important to test functional abilities, such as eating, hygiene, toileting and dressing, because motor and sensory impairments do not necessarily translate to functional impairments (Bleck, 1987, Copley & Kuipers, 1999, Harris, 1988, Tardieu, 1984).

Areas of function commonly identified by families and occupational therapists, requiring assessment in children with hemiplegic cerebral palsy, can be grouped broadly into four areas:

(1) Independence in self care activities (Case-Smith, 1996; Christiansen, 1991; Copley & Kuipers, 1999; Dunn Klein 1983; Erhardt & Merrill, 1998; Powell, 1985), specifically:

- Utensil use at mealtimes;
- Hygiene and clothing management with toileting routines;
- Ability to thoroughly wash and dry self in hand washing and bathing routines;
- Fine tuning of grooming activities, such as tooth paste application; and
- Completion of dressing tasks, particularly clothing, which includes fastenings.

(2) **Use of the affected arm** (Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Dormans & Pellegrino, 1998; Exner, 1996; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985), specifically:
  - Control, coordination, speed and dexterity of fine upper limb movement, in particular the functions of reach, grasp, release, carry and in-hand manipulation;
  - Use of controlled or ‘normal’ movement patterns in place of compensatory or synergistic, abnormal movement patterns;
  - Bilateral hand use, ie. the use of two hands;
  - Development of muscle strength; and
  - Sensory awareness and spontaneous use of the affected arm.

(3) **Prevention of deformity** (Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985; Yasukawa, 1990), specifically:
  - Maintenance and development of range of motion;
  - Prevention of fixed contractures caused by; muscle imbalance, abnormal posturing, lack of use and immobilisation;
  - Maintenance of joint integrity and stability;
  - Optimisation of bone growth and density; and
  - Preservation of hand architecture including transverse, longitudinal and oblique hand arches.

(4) **Independence in motor related school tasks** (Case-Smith, 1996; Klemm & DuBois, 2001), specifically:
  - Handwriting; and
  - Management of classroom tools and belongings
From comprehensive assessment findings, occupational therapists then determine which of the identified delayed, deficient, or missing underlying skills interfere with the child’s function and attainment of the family’s goals (Case-Smith, 1996, Christiansen, 1991). This process signifies the end of the assessment phase and the commencement of intervention planning.

### 2.7.2 Occupational Therapy Treatment Planning

The basis of the intervention plan is built around the delayed, deficient, or missing underlying skills. Solutions and strategies are then developed in collaboration with the child and their family (Case-Smith, 1996, Christiansen, 1991, Erhardt & Merrill, 1998).

Three discrete stages typify intervention planning (Christiansen, 1991):

1. Establishment of short and long term goals. The short term goals generally address the delayed, deficient or missing performance components, and the long term goals target independence in functional tasks, such as dressing;
2. selection of the intervention technique; and
3. development of a plan to re-evaluate the child’s progress (Christiansen, 1991).

Clinical reasoning is the process used to plan, direct, perform, and reflect on client intervention (Schell, 1998). It is clinical reasoning that shapes goal setting and the means by which the intervention technique and outcome evaluation is selected. Schell (1998) describes four types of clinical reasoning critical to this process. Firstly, ‘scientific reasoning’ which involves developing an understanding of the condition in order to select the best possible intervention. Secondly, ‘narrative reasoning’ which involves understanding the meaning of the disability to the individual and the ability to see the experience from the family’s perspective. Thirdly, ‘pragmatic reasoning’ which is an awareness of the context in which therapy occurs, including; resources, team members, cost, and practice trends. Finally, ‘ethical reasoning’ which is the overarching reasoning process in clinical decision making, it is the ‘what should be done’ question (Schell, 1998). These four domains of clinical reasoning form an interactive
and integrated process (Schell, 1998), which the clinician utilises to attain individual health outcomes for clients, including children with cerebral palsy.

### 2.7.3 Occupational Therapy Intervention for Children with Hemiplegic Cerebral Palsy

Occupational therapy intervention for children with hemiplegic cerebral palsy predominantly focuses on the development of motor skills, as cerebral palsy is primarily a motor disorder (Erhardt & Merrill, 1998, Law et al, 1998). The ‘delayed, deficient or missing’ motor ‘performance components’ of functional tasks are targeted. For example, if the child’s parent identifies independence in dressing as a goal, the occupational therapist may identify during the assessment, that the child’s major difficulty with dressing tasks is his/her ability to push the affected arm through a sleeve. Further assessment may reveal that this is due to a contracture in the elbow joint, secondary to muscle spasticity, and that weakness in the triceps muscle, makes it difficult for the child to straighten their elbow. The occupational therapy intervention program may then include various motor treatments to improve the child’s ability to straighten the elbow in order to facilitate independence in dressing.

Many varied intervention approaches have been used with children who have cerebral palsy to assist them to reach their goals. The types of motor interventions that have been provided by occupational therapists were summarised and classified by Copley and Kuipers (1999) into the following treatment approaches:

1. **Neurophysiological approaches** which include
   “a variety of approaches which emphasise handling of the person with the aim of inhibiting hypertonicity or abnormal movement patterns and facilitating higher level reactions and normal patterns of movement” (Copley & Kuipers, 1999, p.7).

   Examples include:
   - Neurodevelopmental therapy (NDT) (Bobath & Bobath, 1967, 1996)
- Proprioceptive neuromuscular facilitation (PNF) (Developed by Kabat – In Voss, Ionta & Myers, 1985)
- Inhibitory and facilitative techniques (Rood, 1954)
- Electrical stimulation (Carmick, 1997; King, 1996; Stefanovoska, 1991)

(2) Biomechanical approaches which

“aim to maintain or increase functional movement of the limb by gaining control of specific movements and preventing or addressing the structural changes to joints, muscles and soft issue that occur because of immobilisation and muscular imbalance” (Copley & Kuipers, 1999, p.8).

Examples include:
- Strength training (Damiano et al, 1995, Damiano et al, 1998)
- Stretching (Kottke, 1971)
- Passive ranging of joints (Tookey & Larson, 1968)
- Adjunct techniques, such as; splinting, casting, (medical interventions such as surgery and pharmacology, such as botulinum toxin A)

(3) Learning approaches which

“specifically target the conscious control of active movement” (Copley & Kuipers, 1999, p.9).

Examples include:
- Motor relearning program (MRP), (Carr & Shepherd, 1987)
- Conductive education (Developed by Peto - In Ákos & Ákos, 1997)
  (Copley & Kuipers, 1999).

Evidence for the effectiveness of each of the above treatment approaches varies and many aspects of the approaches require more in depth investigation using sound research methodologies. Most of the treatment approaches hold some value for promoting upper limb function when hypertonicity is present. A combination of techniques is usually required; as the impairments caused by hypertonicity are multifaceted (Copley & Kuipers, 1999, Levitt, 1984, Pedretti, 1996, Trombley, 1995).
It must be recognised that although many treatment approaches have been implemented, with children who have hemiplegic cerebral palsy, not all of these techniques are currently thought to constitute ‘best practice’. The following sections will describe in detail the intervention techniques most commonly used in current occupational therapy clinical practice. These include upper limb retraining, splinting and casting. A description of each technique will be provided along with a critique of the evidence to support the effectiveness of this approach. This provides the basis for the conclusions made about what is, and what is not, ‘best-practice’ interventions, and thus the foundation for the design of the study intervention.

2.7.3.1 Upper Limb Retraining: An Occupational Therapy Intervention Technique

The collective group of treatment approaches used to treat upper limb hypertonicity and maximise upper limb function have been referred to as ‘upper limb function retraining’ (Copley & Kuipers, 1999). Upper limb retraining can be defined as,

“a range of handling and stimulatory techniques that are used to reduce the influence of hypertonicity and/or facilitate the learning or relearning of active movement” (Copley & Kuipers, 1999, p.83).

The terms ‘retraining’ and ‘rehabilitation’ are somewhat confusing when used in the context of life-long disability, as they imply a return to previous level of function. These terms do not fully encompass the range of processes used in family-centred, interdisciplinary care for children with cerebral palsy (Dormans & Pellegrino, 1998). The term ‘participation’, referring to, participation in environments, relationships and activities, appropriate to each stage of life, better captures the overarching objectives of family-centred intervention (Dormans & Pellegrino, 1998). In recognising the subtle difference and implications of various terminologies, the term ‘retraining’ will only be used when referring to the treatment approach ‘upper limb retraining’ to reflect the literature precedent. This precedent established by the authors Copley and Kuipers (1999), named a constellation of specific upper limb therapy approaches as ‘upper limb retraining’.

Upper limb retraining does not include the use of splinting and casting but may be used in combination with these techniques to address a specific goal more effectively. A combination of retraining techniques
should always be used even if the occupational therapist intends to use splinting and casting in conjunction with or following that intervention, as the goals and outcomes are different (Copley & Kuipers, 1999).

Upper limb retraining techniques include facilitation of active control, motor learning and muscle strengthening. These three techniques are now described.

Facilitation of active control and motor learning are therapy techniques used to train or enhance voluntary control of a discrete, desired movement pattern (Copley & Kuipers, 1999). Occupational therapists train voluntary control of movement through the use of therapeutic activities and functional tasks (Case-Smith, 1996). Active control of movement is important for function, as the lack of motor control in the upper extremity seen with cerebral palsy, can significantly impact on a child’s ability to engage in functional skills (Yasukawa, 1992). Therapeutic facilitation of active control specifically targets the lack of active movement and reduced movement control present with hypertonicity (Copley & Kuipers, 1999). Selective, voluntary control of movement is widely recognised to be linked to the attainment of functional skills in children with cerebral palsy (Carmick, 1997, Crocker, et al, 1997, Toner, 1998, VanHeest et al, 1999).

The lack of active control seen with hypertonicity, is believed to be caused by muscular weakness, mechanical stiffness in the primary muscle engaged in contraction (‘agonist’) and inappropriate cocontraction in the opposing muscle providing joint stability (‘antagonist’) (Copley & Kuipers, 1999). Therefore,

“facilitation of active control in both these muscle groups should be a significant focus of intervention” (Copley & Kuipers, 1999, p.106).

Intervention using active motor control techniques train specific, target movements that are deemed to be weak or absent at the time of assessment. Motivation is known to impact on a child’s ability to learn to move and to use new movement patterns (Carmick, 1997). The theory of motor learning emphasises the importance of the learner being actively involved in the treatment process, which is based on the
belief that if the learner is actively involved in practice of a skilled movement, permanent changes will result (Neistadt, 1998).

*Strength training or muscle strengthening* follows the technique, facilitation of active movement control (Copley & Kuipers, 1999). Pinet (1998) noted the importance of muscle strength for function,

“deficits in strength can affect a person’s ability to complete ADLs (activities of daily living), work, and leisure pursuits. Without adequate strength, a person cannot participate in meaningful activities” (Pinet, 1998, p.401).

Strength has been defined by Kisner & Colby as

“the ability of a muscle or muscle group to produce tension and a resulting force in one maximal effort, either dynamically or statically, in relation to the demands placed upon it” (Kisner & Colby, 1990, p.10).

Whenever hypertonicity is present, there is also associated muscular weakness in both the agonist and antagonist muscle groups (Copley & Kuipers, 1999).

It is now understood that people with hypertonicity can benefit from strength training. This practice was previously thought to increase spasticity and was therefore contraindicated with children with cerebral palsy. This belief has since been disproved (Damiano, Kelly & Vaughn, 1995, Fowler et al, 2001). Pinet describes the occupational therapist’s role in developing strengthening programs,

“Once a strength impairment is identified, the occupational therapy practitioner designs a treatment plan to increase strength needed for occupational performance. According to the overload principle, to increase strength, the load or force applied to the muscle must exceed the capacity of that muscle, causing recruitment of more motor units” (Pinet, 1998, p.402).

Strength can be built by practising an active movement within a functional task. The activity can be graded using positioning against gravity and resistance (Copley & Kuipers, 1999). Gravity is one force that places a load on muscles during a contraction. The position of the limb with respect to gravity, changes the amount of work the muscle performs in order to move (Pinet, 1998). Muscle endurance is also important for function and for maximal participation in everyday tasks (Pinet, 1998). Muscle endurance is related to strength because it is
“the ability to contract repeatedly or generate tension and sustain that tension over a prolonged period of time” (Kisner & Colby, 1990, p.12).

Children with cerebral palsy commonly experience muscle fatigue associated with hypertonicity and muscle weakness; therefore strength training seeks to improve endurance (Dormans & Pellegrino, 1998).

2.7.3.2 Splinting and Casting: Occupational Therapy Intervention Techniques

To address both the positive and negative symptoms of hypertonicity, often splinting and casting is used, in addition to upper limb retraining (Copley & Kuipers, 1999). It must be recognised that it is rare for upper limb retraining techniques to be used in isolation or as the sole focus of intervention. Splinting and casting, in conjunction with upper limb retraining is proposed to result in a more successful outcome as these techniques address joint alignment and the balance between muscle groups during active movement (Copley & Kuipers, 1999). Splints are not a replacement for upper limb retraining but rather an adjunct,

“Although hand splints are used to maintain optimal position and balance the forces acting on a joint, they cannot be used in isolation. Splinting must be used as an adjunct to other therapeutic techniques and integrated with an active exercise program” (Naganuma & Billingsley, 1990, p.88).

It is important to define and differentiate between splinting and casting in order to understand their functions and importance in the treatment of hypertonia.

**Splinting** is

“the use of removable orthoses in order to maintain the limb in a specific position for a period of time or to stabilise particular joints and encourage desirable patterns of movement during activity” (Copley & Kuipers, 1999, p.83).

The purpose of splinting is to maintain or promote functional patterns of upper limb use. The functions of splints vary dependent on the symptoms present. When positive symptoms of hypertonicity are present, such as spasticity, and or secondary contracture, the function of the splint is to block or
minimise the effect of the spasticity and or shortened tissues, in order to reposition the limb for optimal function. When negative symptoms are present, such as weakness and incoordination, the function of the splint is to support and stabilise the limb in a position that assists function (Copley & Kuipers, 1999).


- Position the limb for function;
- Maintain muscle balance around a joint;
- Maintain passive and active range of motion;
- Maintain joint integrity;
- Prevent contractures;
- Prevent deformity; and
- Reduce hypertonicity.

Hand splints are classified into different groups according to the splint's function. These classifications are; static splints, dynamic splints, semi-dynamic and prefabricated splints (Copley & Kuipers, 1999, Hill, 1988, Nagumura & Billingsley, 1990). Children with hypertonicity are generally prescribed a combination of static and semidynamic splints. It is these two classifications which will be discussed in more detail.

Static splints as defined by Hill (1988) are,

“Static orthoses have no moving parts and serve to immobilise or rest the intended joints” (Hill, 1988, p.131).

Static splints can be used for positioning the limb at night or to promote function during the day, the design of the splint and the goals of splinting will dictate the function of the splint. For example, ‘resting splints’ are a type of static splint.

“A resting splint is one which immobilises all the joints of the wrist, thumb and hand, positioning them in a neutral, relaxed, ‘at rest’ posture” (Copley & Kuipers, 1999, p.130).
Resting splints provide prolonged static positioning to reduce hypertonicity and maintain joint alignment and available range of motion (Copley & Kuipers, 1999). Such a splint may be worn overnight or for one to two hour blocks during the day to counteract the effects of hypertonicity which can build up from activity (Copley & Kuipers, 1999). The evidence for guidelines on effective wearing schedules is limited (Brennan, 1959, Copley & Kuipers, 1999, Hill, 1988, McPherson, 1981). Exner and Bonder recognised the need for a variety of different types of splints and wearing regimes to be used by children, who have hemiplegic cerebral palsy,

“In considering splinting for cerebral palsied children, it is critical to recognise that children with the same diagnosis ie. spastic hemiplegia, may differ in many characteristics that would affect the type and degree of response to splinting. Thus, some children may respond more positively to one type of splint while other many improve in terms of hand posture and/or function with a different type of splint” (Exner & Bonder, 1983, p.77).

Within this study, children were provided with static splints where indicated, as per the indicators for splinting criteria, outlined by Copley and Kuipers in 1999, and Hill in 1988.

Semidynamic splints are defined by Naganuma and Billingsley (1990) as,

“splints [which] combine properties of both static and dynamic splints. They do not use moving parts, but do position joints in a manner that encourages maximum functional movement of the extremity”


It is the intrinsic, elastic, properties of the materials used to manufacture semidynamic splints that influence limb positioning. Materials such as neoprene, foam and lycra (Copley & Kuipers, 1999). Semidynamic splints are usually circumferential in nature and serve as a support to joints rather than for the purpose of immobilisation (unlike static splints). These types of splints assist the wearer to use or function in a more optimal position, that they can partially already assume (Copley & Kuipers, 1999). Semidynamic splints are considered to be ‘functional’ or ‘working’ splints. That is, they are used during function, to promote active use of the affected limb (Copley & Kuipers, 1999). Consequently, they have little or no value during periods of rest or sleep.
Casting refers to

“the use of serial or inhibitory casts constructed from plaster and or fibreglass. Casts are usually non-removable but are changed regularly throughout the course of the casting program” (Copley & Kuipers, 1999, p.83).


As with splints, casts are classified into different groups according to their function. These classifications include inhibitory, serial, and positioning casts (Copley & Kuipers, 1999).

Inhibitory casting is for the purpose of spasticity reduction. By placing the hypertonic muscle on prolonged stretch, spasticity is proposed to be reduced. Inhibitory casts are indicated when full passive range of motion is available but increased tone or resistance to movement inhibits function (Copley & Kuipers, 1999). The evidence demonstrating the efficacy of upper limb inhibitory casting, where full range of passive movement is present, is growing (Law et al, 1991, Tona & Schneck, 1993, Yasukawa, 1990, Yasukawa and Hill, 1988).

Serial casting is for the purpose of contracture release. Providing prolonged, low-load stretching of the muscle promotes muscle lengthening, by the addition of new sarcomeres. Sarcomeres are the basic units within skeletal muscle that glide and stretch to enable muscle contraction (Copley & Kuipers, 1999). Many authors have demonstrated that casting is a useful technique for reducing upper limb contracture (Copley et al, 1996; Cruickshank & O'Neill, 1990; King, 1982; Smith & Harris, 1985; Steer, 1989; Yasukawa and Hill, 1988).
2.7.3.3 Effectiveness of Occupational Therapy Interventions Techniques for Children with Cerebral Palsy

The body of knowledge about effective treatment options for children with cerebral palsy is growing. Neurodevelopmental therapy was historically the treatment of choice for facilitating motor development (Bobath & Bobath, 1967; Bobath & Bobath 1984). However, researchers are undecided about the short and long term effectiveness of this treatment modality (Fetters & Kluzik, 1996; Palisano, 1991). In the last decade, new evidence has been generated by occupational therapists, physiotherapists and paediatric rehabilitation specialists, which support a more biomechanical treatment approach to developing function in children with cerebral palsy. Effective motor treatments for children with cerebral palsy are:

- **Strengthening** of weak muscles (Damiano et al, 1995; Damiano & Abel, 1998; Darrah et al, 1999; Fowler et al, 2001; Johnson et al, 1998; O’Connell et al, 1992; O’Connell & Barnhart, 1995; Sharp & Brouwer, 1997; VanDen Berg-Emons et al, 1998);
- **Active practice of specific movements** with a motor learning emphasis (Embrey & Hylton, 1996; Giuliani, 1991; Lesensky & Kaplan, 2000); in conjunction with;
- **Splinting** (Duncan, 1989; Exner & Bonder, 1983; Langlois et al, 1991; McPherson, 1982; Wallen & O’Flaherty, 1991); and

Many authors have stated the importance of combining these treatment approaches to achieve better health outcomes for the child with cerebral palsy (Copley & Kuipers, 1999; Yasukawa and Hill, 1988).

The level of empirical evidence to support the effectiveness of common occupational therapy interventions for children with cerebral palsy is still being developed. Evidence is defined as,

“The available facts, circumstances, etc., supporting or otherwise a belief, proposition etc., or indicating whether or not a thing is true or valid” (Thompson, 1995).
The relationship between clinical research and evidence has been described by Bannigan:

“In health care, the evidence of the effectiveness of interventions, or truth about whether an intervention is effective or not, is discovered through clinical research” (Bannigan, 1997, p.480).

The current evidence base for occupational therapy in this area of intervention is small, however, utilising evidence from other disciplines enlarges the evidence base for the effectiveness of a treatment (Lloyd-Smith, 1997). Within this literature review, evidence has been drawn from the occupational therapy, physiotherapy and rehabilitation medicine evidence base.

Each of the treatment techniques employed are now evaluated and graded using Critical Appraisal Skills Programme, hierarchy of evidence (Lloyd-Smith, 1997), shown in Figure 2.

**Figure 2: Critical Appraisal Skills Programme in Lloyd-Smith, 1997, p.476**

<table>
<thead>
<tr>
<th>Stronger</th>
<th>Meta-analysis of randomised controlled trials</th>
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<tbody>
<tr>
<td>Level 1a</td>
<td>One individual randomised controlled trial</td>
</tr>
<tr>
<td>Level 1b</td>
<td>One well designed, non randomised controlled study</td>
</tr>
<tr>
<td>Level 2a</td>
<td>Well designed, quasi experimental study</td>
</tr>
<tr>
<td>Level 2b</td>
<td>Non-experimental descriptive studies - comparative/case studies</td>
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<td>Level 3</td>
<td>Respectable opinion</td>
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<td>Level 4</td>
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**Active Control and Motor Learning:** Two well designed, level 1a evidence, studies, evaluating the effectiveness of motor learning approaches on improving the upper limb function of adults following a cerebral vascular accident, have shown motor learning to be more effective than other standard treatments, such as Bobath's neurodevelopmental therapy (Langhammer & Stanghelle, 2000, Sunderland et al, 1992). The evidence supporting the motor learning approach with children, who have cerebral palsy, is single case study and expert opinion in nature, ie. level 3 & 4 (Embrey & Hylton, 1996,
Giuliani, 1991, Lesensky & Kaplan, 2000). A small, level 2b study of adults with hypertonicity in the upper limb secondary to brain injury, compared rote exercise to activities embedded in function. Subjects acted as their own controls. All subjects demonstrated statistically significant increases in movement of the affected upper limb, during activities embedded within function when compared to rote exercise. The results of this study support the embedding of movement activities into functional tasks (Sietsema et al, 1993).

**Strength Training:** The body of evidence to support the efficacy of strength training in children with cerebral palsy is building. Resistance and strength training are now recognised to be an important part of effective treatment for children with cerebral palsy, as evidenced by seven, level 2b studies utilising pre-post designs, where subjects acted as their own controls (Damiano et al, 1995, Damiano & Abel, 1998, Darrah et al, 1999, Fowler et al, 2001, Johnson et al, 1998, Sharp & Brouwer, 1997, VanDen Berg-Emons et al, 1998). Two small, level 2b, pre-post studies, have demonstrated upper limb strength training in children with cerebral palsy to increase function. In these studies the tasks analysed were wheelchair propulsion speed, distance and endurance, all of which improved in response to strength training (O'Connell et al, 1992, O'Connell & Barnhart, 1995).

**Splinting:** The literature outlining the efficacy of splinting for people with hypertonicity is controversial and expert opinions differ markedly (Copley & Kuipers, 1999, McPherson et al, 1982). The bulk of the literature is of level 3 & 4 in nature, where new splint designs and the theory behind them is proposed and expert opinion is cast. A small number of level 1b, randomised controlled trials exist, supporting the efficacy of splinting (Exner & Bonder, 1983, Langlois et al, 1991, McPherson, 1982).

**Casting:** The role and value of casting as a treatment technique for children with upper limb hypertonicity is receiving increased research attention. A number of small level 1b, randomised controlled trials and level 2b, pre-post experimental studies along with level 3, case studies have demonstrated improved active and passive range of motion, reduction in hypertonicity, reduction in contracture, improved ease of positioning the limb, and improved function in response to upper limb

Many experts, advocate the use of a combined treatment approach, which includes, upper limb retraining, splinting and casting (Copley & Kuipers, 1999, Naganuma & Billingsley, 1990).

2.7.4 Efficacy of Occupational Therapy Programs using the Family-Centred Approach

The combination of these techniques in an individualised program using a family-centred approach could arguably be considered ‘best practice’ as it draws together direct techniques with appropriate approaches to paediatric care. However, there are no published studies evaluating the effectiveness of these combined approaches, that is, family-centred evidence-based home programs.

2.7.5 Evaluation of Occupational Therapy Intervention

To measure the efficacy and effectiveness of intervention, reliable and valid instruments are needed (Campbell, 1996). Quantitative assessments and evaluations provide accountability. In the case of individuals with disabilities, an assessment documents whether or not interventions produce benefits that improve quality of life, foster the development of functional skills and prevents the development of secondary conditions such as contractures and deformities (Campbell, 1996). Since children with cerebral palsy change not only in response to intervention but also with maturation and experience, careful quantitative evaluation is important. It enables differentiation between; therapy gains, the relative effects of differing treatments and allows for comparison between new interventions (Campbell, 1996). Evaluation is also important as it decreases subjective opinions about change and increases the therapist’s ability to obtain reproducible and meaningful results (Bear-Lehman & Abreu, 1989).
A large number of instruments are available to quantify motor function and functional skills in children with cerebral palsy. However, it is important to know the function of the tool and the purpose for measurement in order to select the best available instrument (Ketelaar & Vermeer, 1998). Three classifications of instruments exist, *discriminative*, which distinguishes between individuals with or without a particular characteristic; *predictive*, which classifies people on the basis of what is predicted to happen in the future; and *evaluative*, which measures the magnitude of change in function over time in response to treatment (Ketelaar & Vermeer, 1998). As this study measures the effect of intervention, the measures selected are primarily of the evaluative type.

The following section describes the instruments used to capture assessment and revaluation data within this research study. In doing so, this review provides the evidence that indicates their suitability for use as key outcome measures in this area of cerebral palsy home program practice. Each of the measurement tools used to collect and record clinical change within this research study will now be given explanation, including a description of the tool, its function, classification and usefulness with children who have cerebral palsy.

**Goal Attainment Scale (GAS):** Goal attainment scaling (Kiresuk & Sherman, 1968) is an individualised evaluative measurement tool designed to measure clinical change. King and others (1999) describe this measurement tool,

“One of the most widely used individualised approaches is goal attainment scaling (GAS), which provides an individualised, criterion referenced measure of change. The GAS procedure involves: (a) defining a unique set of goals for each child, (b) specifying a range of possible outcomes for each goal (on a scale recommended to contain five levels, from \(-2\) to \(+2\)), and (c) using the scales to evaluate the child’s functional change after a specified intervention period” (King et al, 1999, p.32).

The two main reasons for using GAS to measure outcomes in the paediatric occupational therapy are,

“(1) to evaluate outcomes for a specific child (to improve services to that child), and (2) to determine the effectiveness of a service or program as a whole. GAS can be used for both purposes, to document
therapeutic change in individual children or to examine change in groups of children” (King et al, 1999, p.32-33).

Goal attainment scaling is recognised as a way of capturing small but significant clinical change, which may otherwise be missed when using global, standardised assessment procedures (King et al, 1999, Ottenbacher & Cusick, 1993, Palisano et al, 1992, Palisano, 1993, Wallen & Doyle, 1996). This tool was therefore selected to measure home program effectiveness because of the instrument’s ability to collect small clinical changes, meaningful to the family (Wallen & Doyle, 1996). This aspect of measurement was considered important because the achievement of goals, meaningful to the family, is considered a critical characteristic of the family-centred approach and an important indicator of ‘process and outcome performance indicators’ (Wallen & Doyle, 1996).

*Paediatric Evaluation of Disability Inventory (PEDI)*: The PEDI is a discriminative and evaluative tool designed to measure functional independence in children with disabilities (Ketelaar & Vermeer, 1998).

The PEDI measures

“the acquisition of skills of individuals with physical disabilities… The PEDI includes the evaluation of self-care, mobility and social function” (Henderson & Pehoski, 1995, p.167).

The function of the tool is

“to identify the child’s functional ability along three scales: (1) typical functional skill level, (2) physical assistance typically required of the caregiver and (3) modifications or adaptive equipment used (ie. braces, motorised wheelchair)” (Ketelaar et al, 1998).

The PEDI has been shown to be responsive to change over a six month period when used with children who have cerebral palsy (Ketelaar & Vermeer, 1998). It is thought to be advantageous over other instruments because of the test item selection, which includes many everyday tasks and its specific attention to the caregiver assistance and modifications the child requires (Ketelaar & Vermeer, 1998). Along with one other motor instrument, the PEDI is the only tool to meet the criteria of good reliability and validity with responsiveness to change. It is thought to be a useful and valuable tool for evaluating the functional motor abilities of children with cerebral palsy (Ketelaar & Vermeer, 1998). This instrument was selected to measure home program effectiveness because (1) it measures functional gains, which
is the focus of intervention for children with cerebral palsy in the family-centred approach (Dormans & Pellegrino, 1998); and (2) the PEDI is considered an important outcome measurement tool for children with cerebral palsy because it shifts the emphasis away from former approaches, which sought to correct impairments (Dormans & Pellegrino, 1998).

*Quality of Upper Extremity Skills Test (QUEST):* The QUEST (DeMatteo et al, 1993) is an evaluative tool designed to measure quality of upper extremity movement in children with cerebral palsy. The QUEST evaluates

“quality of upper extremity function in four domains: dissociated movement, grasp, protective extension, and weight bearing. It is designed to be used with children who have neuromotor dysfunction with spasticity and has been validated with children from 18 months to 8 years of age” (DeMatteo et al, 1993, p.1).

The test’s validity and reliability are reported to be high (Hickey & Ziviani, 1998). Hickey and Ziviani (1998) reviewed the QUEST and concluded,


The QUEST was selected to measure changes in the child’s ability to use their affected arm in response to home program intervention because: (1) the instrument is standardised and was designed to measure clinical change in upper limb movement in children with cerebral palsy (DeMatteo et al, 1993; Hickey & Ziviani, 1998); and (2) ‘use of the affected upper limb’ is an intervention focus area for children with hemiplegic cerebral palsy, commonly identified by parents and occupational therapists (Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Dormans & Pellegrino, 1998; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985). The QUEST has four subtest domains: dissociated movement, grasp, weight bearing and protective extension. In this study, only the first two subtests, the ‘dissociated movement’ and ‘grasp’ domains were administered and aggregated to develop a total test score as per the instrument standard score formula. The test developers indicate that using only some of the subscales to form a total test score is acceptable from a psychometric standpoint (DeMatteo et al, 1993). One, two, three or four domains of the QUEST can be administered...
depending on the clinician’s preference and a total score still reached (DeMatteo et al., 1993). In this 
study, the dissociated movement and grasp domains were aggregated to form the total QUEST score 
as the researcher determined that this combination of test items best reflected the literature described 
parental and therapy intervention focus area - ‘use of the affected arm’. The ‘use of the affected arm’ 
intervention focus area for children with hemiplegia in known to include targeted improvement in: (1) 
control; coordination; speed; and dexterity of fine upper limb movement, in particular the functions of 
reach, grasp and release (Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 
1999; Dormans & Pellegrino, 1998; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985), the very crux 
of the ‘dissociated movement’ and ‘grasp’ QUEST domains; and (2) use of controlled or ‘normal’ 
movement patterns in place of compensatory or synergistic, abnormal movement patterns (Bleck, 1987; 
Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Dormans & Pellegrino, 1998; 
Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985), the precise essence of the QUEST’s ‘dissociated 
movement’ domain. By aggregating the dissociated movement and grasp domains to form the total 
QUEST score the researcher was able to better evaluate the child’s overall upper limb function than if 
the subscales had been reported in isolation. More importantly, this enabled the researcher to 
determine if any meaningful change, that is improvements considered critical for children with 
hemiplegia in the literature, had been made in response to the program.

**Range of Motion (ROM):** Range of motion is each joint’s potential to move in a certain direction and to 
certain limits of motion due to it’s structure and the integrity of surrounding tissues (Trombly & Scott, 
1989). Range of motion is the numeric measurement of a joint’s capability and is measured via a 
‘goniometer’ (Trombly & Scott, 1989). A goniometer quantifies range of motion in degrees using an 
ordinal scale. It can be used as an evaluative measure of clinical change to detect the amount of 
movement available at a given joint. The value of collecting numeric range of motion measurements is 
that, responses to treatment, over time, can be quantified. Goniometry is a frequently used tool and 
recommended aspect of practice for physiotherapist and occupational therapist working with children 
who have physical disabilities (Bear-Lehman & Abreu, 1989, Boone et al, 1978, Campbell, 1996, Copley 
& Kuipers, 1999, Trombly & Scott, 1989). It is widely recognised that children with cerebral palsy are at
risk of deteriorating range of motion secondary to the effects of spasticity (Bleck, 1987, Campbell, 1996, Copley & Kuipers, 1999, Dormans & Pellegrino, 1998). However, debate continues over the reliability of goniometry in the presence of spasticity (Campbell, 1996). There are those who argue that the tool demonstrates adequate reliability and validity (Bear-Lehman & Abreu, 1989, Boone et al, 1978, Copley & Kuipers, 1999, Trombly & Scott, 1989), contrasted by a single case study conducted with a child who had spastic cerebral palsy, where goniometric reliability was shown to be poor (Harris et al, 1985). The reliability for upper limb movements is reported to be higher than for those of the lower limb (Boone et al, 1978, Copley & Kuipers, 1999, Trombly & Scott, 1989). Despite the disparity between researchers, goniometry remains common practice as a choice of measurement for therapists and physicians working with children who have cerebral palsy (Campbell, 1996, Copley & Kuipers, 1999). Goniometry was used in this study as part of a comprehensive assessment to inform the development of home program intervention.

Manual Muscle Strength Testing: Muscle strength is a muscle’s capacity to produce the necessary tension for maintaining a posture, initiating and controlling movement (Trombly & Scott, 1989). Muscle strength can be measured using a variety of tools such as spring scales, tensiometers, dynamometers, weights or manual resistance, with the devices being more exact than manual resistance. However, therapists generally elect to use manual muscle testing for cost and efficiency reasons, which is adequate for most clinical purposes (Trombly & Scott, 1989). The practice of measuring strength in children with cerebral palsy is considered important, as muscle strength directly impacts on functional ability and strength can be improved through exercise training (Damiano et al, 1995). Therefore it is important to measure this variable for the purpose of determining whether or not there is any limitation present that may explain the child’s functional difficulties. Muscle strength assessment was used in this study as part of a comprehensive assessment, to identify clear explanations for the child’s movement and functional difficulties. This information was used to inform the development of home program intervention.
Ashworth Scale: The Ashworth scale measures the resistance offered by the hypertonic limb as it is passively moved through its range of motion. It is used clinically, to determine severity of hypertonicity present, particularly in people with cerebral palsy (Katz & Rymer, 1989). The Ashworth Scale uses a 5 point scale with each grade level descriptively indicating the amount of muscle tone or resistance offered to the movement. The tool’s construction allows it to be used as an outcome measure however; the validity or clinical usefulness of this scale has been criticised. The test authors report good inter-rater reliability of the instrument (Bohannon & Smith, 1987). The Ashworth scale was used in this study as one aspect of a comprehensive assessment for children with cerebral palsy. As the symptom of spasticity is not reduced by therapy but is rather known to be a risk factor for orthopaedic deformity (Russman et al, 1997), the Ashworth scale scores were used to inform the development of home program and prescription of splints and casts.

Home Program Log Calendar: Each family’s voluntary participation in the home program was recorded via a home program log calendar, provided to them by the researcher. The calendar recorded intensity, frequency and duration of home program participation. Logbooks have been widely employed by occupational therapists to record self-reports of frequency and duration of home exercise program completion (Chen et al, 1999; Schreiber et al, 1995; Tooth et al, 1993). To record participation levels in home programs with children who have disabilities, it has been recommended that self report home program log calendars be employed, as they are more accurate than clinician estimates and interviews (Law & King, 1993). As a home program log calendar is recommended in the literature as the most accurate way of capturing home program participation (Law & King, 1993), log calendars were used in this study to capture parental self-selected ‘frequency’, ‘intensity’ and ‘duration’ home program participation.
2.8 Home Program Intervention: Philosophical Frameworks and “Best-Practice”

2.8.1 Home Program Definitions and Frameworks

A search of published articles and well-known occupational therapy texts, sourced within the literature search, revealed that authors wrote ‘about’ home programs and assumed that the reader implicitly knew the meaning of the term rather than defining home programs. Of the articles and texts located that pertained to home program intervention, only one author provided a definition for an occupational therapy home program.

Home programs have been defined by Molineux (1993) as,

“activities / exercises and / or paper and pencil worksheets completed at home by the child with parental supervision, between treatment sessions” (Molineux, 1993, p.23).

From Molineux’s definition it is clear that the role of the parent in the home program is pivotal. The parent assumes responsibility for implementation of the agreed exercises with their child and drives the frequency, intensity and duration of the intervention program.

This definition of the home program is consistent with alternative, but briefer descriptions of occupational therapy home programs,

“home programs [are] for the parents to implement helping the child demonstrate new skills at home” (Humphrey & Case-Smith, 1996, p.89)

and in the cerebral palsy occupational therapy literature,

“therapeutic regimens to be carried out by the parents and children at home” (Law & King, 1993, p.983).

In the paediatric physiotherapy literature, the home program is described as,

“frequent practice of functional skills within a typical daily routine. The frequent practice of functional skills then becomes dependent on the formulation and development of activities that parents and family members can carry out easily in the home. The home program should enhance the functioning of both
the child and the family by improving the ability of the caregiver(s) to care for the child and increasing the
child’s independence” (Schreiber et al, 1995).

It is interesting to note the dual role of the home program within this physiotherapy definition; the home
program addresses the child’s health needs but also the parent’s caregiving skills. The core essence of
home program definitions are the same for all early intervention service providers, ‘therapeutic activities
practised at home with parental input’, with the emphasis on mode of delivery (e.g. exercises versus
paper and pencil etc), varying dependent on the child’s individual needs. Yet the extent of the parent’s
role in the home program appears to differ between health professionals and countries.

When developing a home program, Molineux outlines three issues for consideration prior to prescription
of the program (Molineux, 1993):

1. Consultation with the family about the goals and activities of the home program;
2. Consideration of the readiness of the parent to be involved in a home therapy program. Molineux
   recognised that a parent’s ability or capacity to implement a home program will vary; and
3. Consideration of the potential impact of the home program on the parent-child relationship. This
   cautionary note relates to Tyler and Kogan’s (1977) research into the effect of home programs on
   parent-child interactions, where more negative interactions were observed when parents were
   performing ‘therapy’ activities than ‘parenting’ activities.

The definition and framework described by Molineux, somewhat reflects a former view of occupational
therapy intervention. This historical view is observed when the reader critically examines in Molineux’s
work: (1) ‘who is in charge’ of the home program intervention; and (2) the cautionary notes about
potential undesirable outcomes when ‘parents become therapists’.

The definition that is proposed by Molineux appears to imply that the occupational therapist is the
director of intervention rather than the family. This is seen in the choice of phrase, “between treatment
sessions”, indicating that the primary director of intervention is the therapist and that the ‘pivotal’ aspect
of intervention is the face-to-face contact with the therapist. However, in a family-centred approach, the
home program is likely to be ascribed greater importance, rather than lesser, within the range of intervention options the family is offered. No longer is the home program just utilised “between treatment sessions” but now, in many cases, may be the primary method of service delivery. Further, the therapist is not the primary director. In a family-centred approach, after a process of goal identification by the family, the occupational therapist consults with the family about they may reach their intervention goals, by providing information about how this could be achieved within the family’s routine.

Best-practice is thought of as a continuous, collaborative, and systematic process for measuring and examining strengths and weaknesses of a program (Lewis & Latney, 2002). It is important to differentiate between evidence-based practice and best-practice,

“Best practice requires a level of agreement about evidence to be integrated into practice…Best practice is not a specific practice per se but rather a level of agreement about research-based knowledge [evidence-based practice] and an integrative process of embedding this knowledge into the organisation and delivery of health care” (Driever, 2002).

The rationale behind this investigator developing a ‘best-practice’ home program approach based on current literature, is well summarised in a quote made by Mason (2002):

“You can’t not practice until all the research is in. But you can examine the strongest evidence from current research to determine best practice” (Mason, 2002, p.7).

The literature review presented here will demonstrate that the key ingredients to the definition of best practice: ‘agreement about research-based knowledge’ and ‘embedding of this knowledge into organisations’ has not yet been described. This study will begin to address this gap by examining and synthesising the strongest evidence from current research to formulate a best-practice home program approach.
2.8.2 Historical Perspectives about Home Program Intervention

Early on in the cerebral palsy and early intervention literature, a polarisation was apparent regarding the perceived usefulness of home programs. Moersch (1985) observed:

“for the most part, the situation [parents as therapists] is either casually accepted or upheld as being desirable, beneficial, and expedient...There are those who oppose putting parents in the position of teachers or therapists on the grounds that this practice can diminish their roles as mothers or fathers...They caution about the implicit message to the child: ‘You need to get well – you are unacceptable as you are’” (Moersch, 1985. p135-136).

Yet others argue that home programs are an essential aspect of healthcare for children with cerebral palsy. More recently, explanation for this polarisation is made by Bazyk (1989),

“Our attitudes and beliefs regarding parent participation have evolved through three stages: (a) the medical model, which involved limited parent participation, (b) the education for all handicapped children act, which viewed parents as teachers and therapists; and (c) public law 99-457, which involves family-centred parent participation” (Bazyk, 1989, p.723).

Parental training, which was prevalent in the 1980’s, first expanded the roles of parents in therapy (Bazyk, 1989). Therapists were no longer the sole providers of intervention; parents became responsible for assuming the role of ‘therapist at home’ (Bazyk, 1989). However, “family-centred participation” is different to the “education for all” model, where the goal of parental training was to assist parents to become the one of the child’s “teachers and therapists”. Instead family-centred practice recognises that the parental caregiving role is important in it’s own right and that this role is unquestionably the most influential on the child’s life. Adherence to this belief fundamentally alters the way in which home programs are delivered. It places a new emphasis on development and enhancement of parenting skills rather than metamorphosing parents into health and education specialists. Now the family-centred approach is accepted to be best practice (Ahmann, 1998; Roberts & Magrab, 1991). Theorists and researchers are currently building the evidence base to the support the effectiveness of this approach (Rosenbaum et al, 1998).
Those who have previously opposed home programs, advocate that the parent and therapist role must remain separate because of the potential negative impact on the child’s self esteem (Turnbull & Turnbull, 1978). Many texts cite a 1972 study by Tyler and Kogan, who observed parent-child interactions of children with cerebral palsy. They noted more “negative” behaviour in both the child and mother when the mother was performing therapy activities when compared to performing parenting activities. It is interesting to note that none of the authors who oppose or advocate for home programs argues their case on the basis of evidence of improved therapy outcomes. While there does appear to be a division regarding the use of home programs, little of this controversy appears to be related to outcomes, which might be achieved through home programs. There is instead a focus on the process. This lack of discussion may be related to the paucity of evidence regarding outcomes of home programs.

Despite the conflicting views about home programs, there is a growing trend towards parental involvement in home programs (Hinojosa & Anderson, 1991). Home programs, which have been implemented within various philosophical paradigms, can be designed to fit within a family-centred intervention framework. This is because home based intervention like family-centred intervention can recognise the benefits of the expert caregiving of parents in their children’s lives (Kwok, 1994).

Intervention provided via home programs is now described as having many possible benefits over traditional institutionally based treatment. These benefits impact upon the child and their family and are thought to include (Hinojosa et al, 1988, Humphrey & Case-Smith, 1996, Molineux, 1993, Schreiber et al, 1995):

- empowering parental control of their child’s health care;
- improving the parent’s ability to care for their child;
- children and families feeling at ease in their familiar surroundings thereby creating more favourable conditions for intervention success;
- allowing for intensive practise and motor learning;
- better generalisation of new skills because the intervention occurred in a natural setting;
increasing the child’s independence;
lower cost and disruption to families;
better cost-efficiency for the health system; and
requiring less face to face contact with the occupational therapist, therefore the child will ultimately be less ‘dependent’ on others.

2.8.3 The Family-Centred Approach within Home Program Intervention

Home programs, conducted within a family-centred framework, are characterised by common values and beliefs. It is these values and beliefs that set family-centred home programs apart from former medical approaches to care. Each of these core values and beliefs will now be described. These have been derived from an examination and synthesis of the family-centred literature.


  “Family-centred care supports families in their caregiving roles by building on their unique strengths as families and on the strengths of individual family members. Families differ in the strategies they adopt to realise their dreams of their children and themselves and in the amount of support they will need from the service system. There is no one choice or approach that is right for all families” (National Centre for Family-centred Care, 1990).

- The importance of the inclusion of the significant people in the child’s life. For example siblings, grandparents etc (Bazyk, 1988; Dunst et al, 1988; Kwok, 1994; Powell, 1996; Shilton et al, 1987; Turnbull, 1990).

- Therapy in a natural environment leads to development of more realistic goals, strategies and solutions (Anderson & Schoelkopf, 1996; Moersch, 1985; Shilton et al, 1987).

- Therapeutic activities should be embedded into everyday activities to ease the caregiving strain on families and to ensure that therapy seeks to achieve functional outcomes (Anderson & Schoelkopf, 1996; Moersch, 1985; Stanton, 1992). Stanton, the mother of a child with cerebral palsy advises other parents,
your child will need a therapeutic exercise program but it is important to remember that the
exercises should be slotted into normal everyday life, which will enable your child to lead a full,
happy and active existence” (Stanton, 1992, p. 26).

- An understanding that a child ‘performs’ best in familiar and non-threatening environments
  (Anderson & Schoelkopf, 1996; Clarke & Allen, 1985).

  “At the child’s home the therapist has the opportunity to view the child’s characteristic adaptation in
  its fullest dimension. This is the most significant environment, because it contains those persons
  who can contribute most to the quality of the child’s life” (Clarke & Allen, 1985, p.146).

- Home programs enable flexibility in scheduling and reduce additional costs and inconveniences,
such as travel time, babysitting, for families whose time and financial resources are already
stretched. Home programs in addition to being family-centred are a cost effective service delivery

The family-centred approach gives a new and important emphasis to enhancing the ‘parental
caregiving’ skills as an integral part of intervention. This is a subtle but significant shift away from
training parents to become their child’s ‘teachers and therapists’, as experienced in the ‘education for
all’ model. In a family-centred practice approach,

  “The goal is not for parents to become quasi-professionals” (Humphrey & Case-Smith, 1996, p.86).

Rather the goal, of family-centred intervention is to enhance the daily caregiving capacity of parents, as
one strategy for improving the child’s health and development. Caregiving competency is defined as,

  “the mother’s [family/caregivers] ability to meet her child’s needs, which may include needs related to
  safety, health, physical, social and emotional status” (Washington & Schwartz, 1996).

Thus a family-centred home program fosters the development of the ‘parental caregiving role’. This is a
defining characteristic of family-centred home programs and is what sets them apart from former
intervention approaches. It is a shift away from ‘expert’ professionals teaching parents what to do with
their children (Bazyk, 1989), to placing a new emphasis on enhancing parenting skills for the purpose of
advancing the child’s development; easing parental caregiving strain and promoting positive parent-
child interactions.
“Our aim is to help parents build a repertoire of skills for successful interaction with and greater enjoyment of their child” (Bazyk, 1989, p.725).

It is important to understand that by focussing on parental caregiving competency there is a new attention given to addressing the needs of the whole family not just the child. This is a key element of family-centred intervention, unlike former medical approaches, which were pathology or child-centred (Hanna & Rodger, 2002). Occupational therapists working from a family-centred approach, must value all aspects of the parents role as parents (Bazyk, 1989). One parental responsibility is caring for their child’s health needs but parenting also involves enjoyable interactions with their child, play and rest (Bazyk, 1989). In addition therapists working in the family-centred framework recognise that, parents are likely to engage in other roles such as spouse; homemaker; worker and friend (Bazyk, 1989). Acknowledgement of all of these roles can help occupational therapists to develop more realistic home programs with families (Bazyk, 1989). Thus the practice of fostering the ‘parental caregiving role’, because of a belief in its uniqueness and importance, necessitates a change in the way home programs are delivered within the family-centred approach.

Adopting an approach where services meet the needs of the whole family means that previous criticisms to the ‘education for all’ model are likely to be invalid. Negative parent-child interactions, set up by parents performing ‘therapy’, seen in Tyler and Kogan’s study (1972), are unlikely because the family-centred model promotes aims to positive parent-child interactions (Bazyk, 1989), and some of these interactions may have therapeutic value.

When home programs are embedded within an Australian family-centred practice framework, the daily caregiving of parents is viewed as an opportunity for therapy (Thompson, 1998). Australian policy encourages families to care for their relatives with disabilities at home (Thompson, 1998). When the family member with a disability is a child, the definition of parental caregiving expands to include, providing ‘specialist’ services to help the child (Thompson, 1998). The Australian interpretation of the family-centred approach has assumed that,
“supporting families in their caregiving role promote[s] the functional development of the child” (Thompson, 1998).

In some Australian health settings, parental expertise has been so embraced, that parents, along with professionals, are recognised as vital for achieving desired health outcomes in children with disabilities. A qualitative study showed that Australian mothers of children with disabilities also believe that, “the development of their child was unquestionably linked to their efforts as the primary caregivers… [and] the more time they were able to spend repeating and reinforcing therapy sessions at home, the more likely it was that their child would progress and develop” (Thompson, 1998).

This may mean that home program intervention in an Australian family-centred context may significantly increase the parent’s ‘workload’ within the intervention team. This is because the ‘direct’ therapy services that Australian parents seek, may not be readily available at the parent’s desired intensity level (Thompson, 1998) and therefore a greater reliance may be placed on outcomes that can be achieved by parents at home. Whilst family-centred practice recognises family’s unique needs and thus promotes flexible service delivery options, the range of service options that may be available to families is often limited by the constraints of the health care system (Humphrey & Case-Smith, 1996). This is known to be true in Australia (Thompson, 1998).

The family-centred practice approach assumes a collaborative decision-making approach to intervention planning, individualisation of services and involvement of the whole family (Rosenbaum et al, 1998). When this collaborative approach is taken, many authors describe an increase in parent’s capacity and likelihood to carry out home therapy programs (Bazyk, 1989, Gadjosik & Campbell1991, Hinojosa, 1991, Hinojosa et al, 1988, Law & King, 1993, Majnemer, 1998). Six guidelines have been proposed by Bazyk (1989) for developing family-centred home programs:

1. the parent becomes the decision maker;
2. the parent’s role does not become one of therapist but rather the occupational therapist builds the parent’s repertoire of skills;
3. parent-therapist collaboration exists;
(4) individual difference is recognised;
(5) options are provided that fit into family’s routines and finally; and
(6) the child is viewed as a family member and the family’s acceptance of their child’s disability must be fostered.

2.8.4 Best Practice Approach to Occupational Therapy Home Programs

The shift in thinking about the involvement of parents in health care has been described so far in this chapter, along with the fundamental changes these guiding principles have made to home program intervention. Through a synthesis of the home program and family-centred literature base, this investigator will now propose a best practice approach to occupational therapy home program intervention for children with cerebral palsy. The researcher adopted this program approach as the intervention in the study, since this approach integrated the best available evidence for developing and implementing a home program for children with cerebral palsy. The systematic development of a program based on evidence from literature was therefore considered the most likely to lead to a successful attainment of family goals during the intervention period.

The best practice approach to occupational therapy home program intervention proposed by the investigator includes five phases: (1) establishing a collaborative relationship with the child’s parent; (2) goal setting; (3) constructing the home program; (4) supporting the program’s implementation; and (5) evaluating the outcomes. Each of these phases will now be described, supported by relevant evidence. The level of strength of evidence in cited literature varies, as indicated in previous sections of this chapter. Where the level of evidence is opinion, this is indicated.

2.8.4.1 PHASE ONE: Establishing a Collaborative Relationship with the Child’s Parent

The first phase of a ‘best practice home program’ is establishing an effective relationship with the child’s parent, a partnership that is characterised by collaboration.
The family-centred practice approach is considered to constitute best practice when working with children with disabilities (Ahmann, 1994; Hanna & Rodgers, 2002; Roberts & Magrab, 1991) and is also known to lead to better health outcomes for children with disabilities (Rosenbaum et al., 1998). For this reason, the family-centred practice approach was adopted as the philosophical framework for 'best practice home programs' proposed here. A subtle but important change in focus occurs when the family-centred practice approach is used within home program intervention: that is, the family becomes the focal point of intervention not the child in isolation (Hanna & Rodgers, 2002). This shift in focus enables the family to become active partners in providing health care to their child, because it moves away from former child-centred approaches where professionals told parents how to care for their child (Hanna & Rodgers, 2002). The very goal of the family-centred approach is to support families to control their child’s health care (Bazyk, 1989). This means the starting point for developing a best practice home program is not a conventional assessment of the child’s ‘deficits’ to identify areas for remediation but instead is the establishing of an effective working relationship with the child’s parent to enable joint planning and care provision.

In the family-centred approach, an effective working relationship with the child’s parent is considered to be one that recognises and respects the expertise of parents (National Centre for Family-Centred Care, 1990). A health professional will therefore need to build a collaborative partnership with the child’s parent (Mattingly & Lawlor, 1998) as the starting point to health care provision. The term ‘collaborator’ means:

“associate, colleague, coworker, teammate, copartner and ally” (Crais, 1993, p.29).

It is no coincidence that the term ‘collaborator’ rather than ‘teacher’ is used to describe the health professional within the family-centred approach, because a two-way relationship is sought (Bazyk, 1989). Thus a collaborative relationship between a parent and health professional is characterised by,

“respect for each other’s opinions and contributions, equality in the status of each partner within the relationship, a developing trust, and a generally positive regard for each other as individuals” (Crais, 1993, p.29).
Home program research appears to indicate that the collaborative and personal nature of the parent-therapist interaction is critical to the success and likely uptake of a home program. In a qualitative study that examined the mother’s perceptions about the influence of therapy on their lives, found that, mothers felt their relationships with therapists were personally important, and that the therapist as a person was often more important, than the therapy itself (Hinojosa, 1990). In another qualitative study of mother’s perceptions of the effects of occupational therapy and physiotherapy, mothers viewed therapists as:

“(1) a friend; (2) an advocate; (3) a mentor; (4) a trouble shooter; (5) a source of information; and (6) a primary source of support” (Washington & Schwartz, 1996, p.44).

Thus therapists must place high significance on the influence they have in family’s lives, as the very nature of these relationships appear to assist families to develop intervention for their child (Hinojosa, 1990).

In order to establish successful, collaborative relationships with families, the following inter-personal skills have been identified as essential for health professionals: self-confidence in working with others; the ability to provide mutual support without defensively guarding their own professional role; flexibility and patience; and the ability to balance the role of learner and expert (Laadt-Bruno et al, 1993). A qualitative Australian study demonstrated that therapist’s interpersonal skill; communication skills; and attitudes affected families’ uptake of home programs (Thompson, 1998). When families perceived therapists as ‘friendly’, families were more likely to become involved in their child’s therapy and conversely when therapists are perceived as ‘unfriendly’, families withdraw their involvement (Thompson, 1998). In addition to being ‘friendly’, occupational therapists that display flexible, adaptable, and ingenious attitudes along with possessing a breadth of knowledge and skill are known to positively influence participation in home programs (Robinson, 1987).

As therapist attitudes have been identified as an important aspect of successful home programs, it is also necessary for therapists to consider aligning their attitudes about ‘parental involvement in home programs’ closely with the values of the family-centred approach. Historically, health professionals have prescribed home programs to improve the child’s development, without consideration of parental needs
and concerns (Bazyk, 1989). When parents have been unable to complete these home program
regimes, at the prescribed intensity level, parents have been labelled as ‘non-compliant’ (Bazyk, 1989).
Health professionals have assumed that potential health benefits are lost because ‘non-compliance’
(Molineux, 1993), without considering whether these parents’ actions may have been in the child and
family’s best interest. The term ‘non-compliant’ reflects a former attitude held by many health
professionals, that is, the therapist knows what is best for the child (Bazyk, 1989; Hanna & Rodgers,
2002). When using the family-centred approach, this mind-set about ‘non-compliance’ is replaced by
respect for the parental care-giving role, accompanied by acknowledgment that the parent knows what
is best for their child (Viscardis, 1998). Therefore in the family-centred approach, the parents’ insight
about how health services should be provided is welcomed (Viscardis, 1998).

Along with the necessary interpersonal skills and attitudinal change, another important aspect to
developing collaborative relationships with families is, the defining of team member’s roles. In the
family-centred approach, the role of the therapist shifts to being one of ‘technical expert’ (Rosenbaum,
1998), who supports; encourages; and enhances the care-giving competency of parents (Bazyk, 1989;
Viscardis, 1998), which impacts child’s health. The parent is recognised as the expert caregiver and is
thus given the right to determine and decide what is best for the child (Viscardis, 1998). The parental
decision-making role includes, families having the opportunity to choose their preferred level of
involvement in therapy activities (Bazyk, 1989). Individual families will have different preferences about
the degree of involvement in their child’s intervention, and it is critical that therapists accept and respect
these preferences (Bazyk, 1989). Families will have different capacities at different times in their lives
to carry out home programs (Bazyk, 1989; Kwok, 1993) and so the preferences of parents regarding
their involvement in a home program must be discussed before developing the program (Molineux,
1993).

The first step in instituting a ‘best practice’ home program approach is, establishment of a collaborative
parent-therapist relationship. This relationship is influenced by therapist attitudes; therapist
interpersonal skills; parent-therapist role delineation and parental involvement preferences. The intervention in this study adopted these features.

2.8.4.2 PHASE TWO: Goal Setting

The second phase of a ‘best practice home program’ is goal setting, where the aim of this phase is to establish mutually agreed upon goals.

When a collaborative parent-therapist relationship has been developed, common activities performed by the parent and health professional together are likely to include: assembling resources; creating a product; and working together to achieve a goal (Crais, 1993). In the goal setting phase of home program development, parents and therapists therefore work as a team, to establish the program goals. This involves,

“explore[ing] with the parents their needs and priorities regarding interaction with and the care of their child. Do they have any concerns about their child’s feeding, dressing, hygiene, play and interaction with the environment?” (Bazyk, 1989, p. 726).

The goals that families typically generate relate to: family relationships; child management; and daily routines, with the emphasis being on managing the disability and its effect on everyday life (Coles, 2001).

Historically, therapists have generated home program goals from a ‘deficit’ model, where they identify what aspects of the child’s performance is delayed, deficient or missing’ (Case-Smith, 1996, Chapparo & Ranka, 1997) following a strengths and limitations analysis in various environments, in order to pinpoint focus areas for intervention (Case-Smith, 1996). Specific problem identification using this technique still forms an important part of a comprehensive assessment for a child with cerebral palsy (Bleck, 1987; Erhardt & Merrill, 1998) but is not the starting point of collaborative goal setting in the family-centred approach. Family-centred collaborative goal setting individualises the home program to suit the family’s unique strengths and routines and then progresses to meeting the child’s needs (Bazyk, 1989). The ‘solution focused’ approach (Berg, 1994) offers an alternative goal setting strategy, which
includes the whole family and the child (Coles, 2001). The ‘solution focused’ model focuses on: the family’s resourcefulness; competence; strengths; and their ability to change, which assists families to clearly articulate their goals in a way that is akin to family-centred practice (Coles, 2001). Goal setting using the solution-focused approach is elicited by ‘the miracle question’ technique (Berg & DeJong, 1998). The miracle question is posed by the health professional to the family like this,

“Let’s suppose, tonight when you are asleep a miracle occurs, and a problem or problems that we have been talking about were solved. But when you woke up, you didn’t know this miracle has happened. What would tell you in the morning that this had occurred? What would you look for that would tell you that this miracle had happened?” (Coles, 2001, p.101).

The miracle question evokes a variety of responses, creating opportunities for the therapist to ask the family about and highlight times when, desired changes were happening or had happened (Coles, 2001). This type of goal setting exchange enables the family to identify their own solutions that leads them towards their individual aspirations (Coles, 2001) and therefore this approach builds on the parent’s caregiving capacity.

Once goals have been identified, the ultimate decision about the focus for intervention belongs to the family; parents should be the primary decision makers in intervention for their child (Humphrey & Case-Smith, 1996). The basic premise of the family-centred approach is that,

“Parents know their children best and want what is best for their children” (Rosenbaum et al, 1998).

Thus it is the therapist’s responsibility to encourage

“parental decision-making based upon appropriately presented information, in the context of clearly defined child and family needs, and built upon child and family strengths” (Rosenbaum et al, 1998, p. 5).

When these responsibilities are met, the therapist provides services that meet the needs identified by families, because they recognise their role is to empower families (Viscardis, 1998).

When planning intervention, including home programs, a comprehensive occupational therapy assessment for a child with cerebral palsy is recommended (Bleck, 1987; Erhardt & Merrill, 1998). This process has been detailed earlier in chapter two, in “Section 2.7.1: Occupational Therapy Assessment”
and therefore will not be discussed here in detail. With the family-centred framework, the comprehensive assessment should only inform the goal setting process, rather than driving it as it did historically. The occupational therapy assessment should focus on goal areas identified by the parent and seek to identify ‘why’ attainment of these goals is difficult for the child. Assessment findings used in this way can inform the development of the home program by identifying subcomponents or ‘impairments’ pertaining to the goal areas that are difficult for the child. As the therapist communicates with the family ‘how’ each of the sub-goal areas could potentially be addressed, this process is likely to identify possible home program strategies.

It is widely accepted that therapy provided in natural environments leads to the development of more realistic goals, strategies and solutions (Anderson & Schoelkopf, 1996; Moersch, 1985; Shilton et al, 1987). Therefore once the parent has identified goals, the therapist is required to explore with the family their daily routines and the best times for implementing a home program (Bazyk, 1989).

The goal-setting phase of the best practice home program approach involves parental decision-making about mutually agreed intervention goals. The goal setting process is informed by a comprehensive occupational therapy assessment and an exploration of the family’s typical daily routine. To provide clarity about the family’s goals, the ‘miracle question’ technique can be used as a framework for eliciting information about the family’s strengths and preferred solutions.

2.8.4.3 PHASE THREE: Construction of the Home Program

The third phase of a ‘best practice home program’ is construction of the home the program, where the primary task of this phase is to select the therapeutic activities to be employed within the program.

Therapeutic activities selected for the home program should be embedded into everyday tasks, to ease the caregiving strain on families and to ensure that intervention seeks to increase the child’s function (Anderson & Schoelkopf, 1996; Moersch, 1985; Stanton, 1992). This approach to therapy provision has been described as the ‘family-centred functional approach to therapy’ (Law et al, 1998). The ‘family-
centred functional approach to therapy’ is underpinned by the following principles: (1) promotion of functional performance is more important than remediation of impairments; (2) the optimal time to intervene with therapy is when the child is trying to do something new; (3) solutions are found by identifying and changing the primary constraints of the task that prevent achievement; these may include the child’s skill level or environmental factors; and (4) practice of new skills is necessary (Law et al, 1998).

As part of a ‘best practice home program’, based on family-centred principles, there is likely to be a radical shift in understanding about ‘who’ determines the most appropriate therapeutic interventions. Historically, this role has been solely assumed by the health professional. In former child-centred approaches, professionals told parents how to care for their child, based on a belief that they knew what was best for the child (Hanna & Rodgers, 2002). More recently, health professionals have embraced the belief that, the expert caregiving of parents will positively influence a child’s health. Mothers of children with cerebral palsy are known to integrate their experiences of therapy and to adapt treatment techniques into a mothering style that meets the unique needs of their child (Hinojosa, 1990). In valuing parental caregiving competence parent-therapist roles may shift. It may mean that it is the parent who devises the ‘therapeutic’ activities for the home program, not the therapist as per convention. This is because parents are best positioned to know the family’s unique preferences and routines and because parents seem to enhance the therapeutic value of intervention activities. Parents have unique creativity and inventiveness for adapting play, furniture, toys and activities to make them therapeutic (Hinojosa, 1990).

“Therapists must recognise that mothers themselves may offer innovative interventions…mother’s [have] creative skills in their ability to adapt home activities and routines to address their children’s therapeutic goals. Most of these adaptations suggest that these mothers comprehend basic treatment principles. More importantly, we found that the therapeutic value of the activity can be enhanced by the mother who is adapting it into her daily routine” (Hinojosa & Anderson, 1991, p.277).

Hinojosa and Anderson’s (1991) qualitative review of mother’s perceptions of home therapy programs identified three important characteristics of successful home program activities:
“(a) they were pleasing for the mother to do, (b) they were not stressful for the child, and (c) they were not stressful for the mother or the rest of the family” (Hinojosa & Anderson, 1991, p.276).

Hinojosa and Anderson’s (1991) study seemed to suggest that if parents select the intervention activities to reach mutually agreed goals, rather than activities being prescribed by the therapist, it is more likely that the activities will suit the family’s routine; the child’s preferences and that the quality of the selected activities may be enhanced. Therefore the therapist must enable the parent, or give permission for, the parent to devise or exchange the selected therapeutic activities with new activities that the parent develops in the home context. As it seems that parent generated activities are more likely to be therapeutic; functional; successful; fit the family routine and be enjoyed by the child. If the therapist fails to release the role of therapeutic activity selection to the family, it seems that families may be unlikely to carry out a therapist-directed home program. Eight mothers of children with cerebral palsy, interviewed and observed in a qualitative study by Hinojosa (1990), all reported choosing not to carry out their therapist-prescribed home program. The mothers explained that this was because of competing responsibilities that demanded their time, not because of perceived lack of importance of the activities (Hinojosa, 1990). Instead, seven of the eight mothers were observed to develop their own intervention program by incorporating therapeutic activities into their mothering style (Hinojosa, 1990).

Once the goals have been set and the therapeutic activities for the home program have been selected, the therapist should consider how this information will be conveyed to the family. In the majority of cases, it is important to describe the goals and activity suggestions in written and pictorial format, as this is preferred by parents (Case-Smith & Nastro, 1993). Therapists and physicians also report that home programs are more likely to be completed if the therapeutic activities are explained and written down for families (Molineux, 1993; Rappoff & Christophersen, 1982; Simon 1988). Families of children with physical disabilities, demonstrated home program participation rates of 77.5%-80.3%, when the home program was given in written format, supported by Polaroid photographs of the activities (Schreiber et al, 1995). It is also important to supply families with a home program recording system as it may serve as a daily reminder to participate in the home program (Schreiber et al, 1995).
When the occupational therapist and family select the therapeutic activities to include with the home program, the intervention approaches chosen ought also to be based upon judicious use of the ‘best available’ evidence (Sackett et al, 1996). That is, intervention activities that have been proven to be effective (where this evidence is available) are the ones that ought to be recommended by the occupational therapist. The purpose of blending the best available evidence with clinical expertise is to develop home programs that are: accurate; effective; and safe (Sackett et al, 1996). When the occupational therapist uses this approach, they promote the likelihood of effective intervention (Sackett et al, 1996) and act as a resource or ‘technical expert’ to the family so as to extend the family’s skills (Rosenbaum et al, 1998; Viscardis, 1998).

Before recording the selected home program activities for the family, it is important to describe how and why the activity will help the child achieve a certain goal (Bazyk, 1989). This process of explanation is likely to require demonstration and training, so that the parents understand how to perform the activities in a therapeutic way (Molineux, 1993; Rappoff & Christophersen, 1982; Simon 1988). Successful training is characterised by the parent feeling capable of using the therapy technique, without feeling overwhelmed. Mothers of children with cerebral palsy suggest that demonstration of one therapy technique at a time is helpful, as it is difficult to remember details about several techniques if they are taught simultaneously (Hinojosa & Anderson, 1991). This point is important to remember when training, as parents of children with disabilities are more likely to implement treatment recommendations when they feel competent and comfortable to do so (Gajdosik & Campbell, 1991). Some families have a higher preference for verbal explanations; others, written explanations; while others prefer modelling or a combination of learning strategies (Bazyk, 1989). So, when the home program activities are developed, they should be prepared into a format to distribute to the family that reflects the family’s preferred learning style (Bazyk, 1989), which is likely to include text; pictures and demonstration.

The home program construction phase of the ‘best practice home program approach’ involves selection of individual therapeutic activities deigned to address the family’s goals. The chosen therapeutic activities should be embedded into functional tasks and parents need to be given permission to devise
or exchange the selected activities in order to reach their goals. The home program then should be disseminated to the family in a way that reflects their learning style, but is likely to include writing up the program goals and activities supported by pictures and ‘hands on’ demonstration. These features were adopted in the development of the study home program.

2.8.4.4 PHASE FOUR: Supporting the Home Program Implementation

The fourth phase of a ‘best practice home program’ is identifying ways to support the implementation of the home program, to ensure that the program is meeting the family’s needs and can be feasibly carried out. Home programs are not complete once they are provided to the family: implementation support and evaluation are required. The literature summarised below, seems to indicate that home programs, which are supported in an ongoing way by the therapist, are more likely to be implemented by families.

Families report that they learn about caregiving by watching therapists interact with their child (Hinojosa & Anderson, 1991), and by seeking reassurance and feedback from therapists (Thompson, 1998). Thus these facets of support should be built into a best practice home program. Even though a family-centred home program is parent directed (Bazyk, 1989), the parent can still seek support as required, if the occupational therapist makes themself available as a consultant or resource to the family (Dunst, 1991).

“We serve as consultants to the parents to help them acquire the knowledge and skills they need to care for their children with special needs…We work together with parents to identify treatment choices, and allow them to decide what fits best for their family” (Bazyk, 1989, p.725).

The active and ongoing seeking of support from occupational therapists by families, and mothers in particular is likely,

Mothers of children with disabilities describe constantly seeking reassurance and feedback from therapists about their child (Thompson, 1998). Mothers use therapist’s feedback as a strategy for ensuring they do everything within their power to help their child and to assess whether services are worthwhile (Thompson, 1998).

In addition to building a therapist-parent relationship where support-seeking is viewed positively, the following support strategies of therapists, have been identified in Gajdosik’s (1991) literature review, as leading to a greater likelihood of the home program being implemented:

- frequent contact with the parent to review the program;
- instruction to the family on how to identify improvements in their child;
- watching the parent perform the therapeutic activities and providing feedback;
- identifying and relaying the child’s improvements to the parent;
- positive reinforcement of the parent, to build their confidence; and
- communication of interest and concern for the family.

The home program implementation phase of the ‘best practice home program approach’ involves regularly reviewing the home program to support the parents to engage in the selected therapeutic activities. This assistance includes building a parent-therapist relationship where support seeking is valued and encouraged. It also involves the therapist relaying the child’s improvements to the parent; providing feedback and reinforcement; as well as providing the family with information about how to identify improvements in their child’s development. These mechanisms of support were built into this study.

2.8.4.5 PHASE FIVE: Evaluating the Home Program Outcomes

The fifth and final phase of a ‘best practice home program’ is evaluating the outcomes of the home program, to ensure that the program met the family’s goals agreed upon in phase two.
Health programs outcome evaluation of any kind typically focuses on the impact of the program by conducting three types of evaluation: (1) consumer satisfaction evaluation; (2) clinical outcomes evaluation; and (3) cost-effectiveness evaluation (Naar-King et al, 2000). Consumer satisfaction of health programs is a critical aspect of evaluation because: consumer satisfaction is linked to health outcomes; there are behavioural consequences of consumer dissatisfaction including lower participation rates; and it provides useful information about the structure, process and outcomes of care (Naar-King et al, 2000). The evaluation of clinical outcomes is typically achieved through the use of robust standardised outcome measures (described in section 2.7.5 - Evaluation of Occupational Therapy Intervention) and when evaluating the clinical impact of home program intervention, this should also be the strategy of choice. In addition to the evaluation of clinical outcomes, the achievement of the goals set by families, should also be evaluated (Wallen & Doyle, 1996). This type of evaluation provides important information about outcomes meaningful to the family and child (Wallen & Doyle, 1996). The evaluation of the achievement of goals set by families can be measured using the use of the Goal Attainment Scale, described in “Section 2.7.5 - Evaluation of Occupational Therapy Intervention” (Wallen & Doyle, 1996). Use of the Goal Attainment Scale is therefore recommended within the ‘best practice home program approach’ as one way of evaluating and quantifying the family perspective health outcomes.

The fifth and final phase of the ‘best practice home program approach' thus involves evaluating the home program outcomes. This includes eliciting family perspectives on: goal attainment and reviewing clinical progress using robust instruments.

The ‘best practice home program’ described in this study was developed on the basis of literature presented throughout chapter two, and synthesised in the above section2.8. The ‘best practice home program’ is now summarised in Figure 3.
2.9 Effectiveness of Home Programs: A Gap in our Knowledge Base

Despite the overwhelming support and recognition of the importance of home programs with children who have cerebral palsy there is a paucity of literature pertaining to their effectiveness in helping families achieve desired health outcomes (Schreiber et al 1995). To date, the literature pertaining to

The notion of parental ‘compliance’ is outdated when using the family-centred approach (Bazyk, 1989). It implies that the parent should adhere to a program that is prescribed, developed and determined by the professional in charge. This former viewpoint is described by Hanna & Rodgers (2002),

“ If parents failed to follow through with prescribed activities at home, they were often described by professionals as being non-compliant, reflecting the belief that the therapist knew what was best for the child” (Hanna & Rodgers, 2002, p.17).

The family-centred approach instead advocates for the parent to drive and determine what is important for their child in the provision of health care services. There has been a shift to valuing parent participation in the development and implementation of home programs (Bazyk, 1989).

A more recent effectiveness study, conducted since the inception of the family-centred approach, has given new insight into the important and perhaps pivotal role of parents in home programs. In 1993, Law and King compared the effect of two different occupational therapy interventions for children with cerebral palsy in a randomised controlled trial. As a secondary finding, they uncovered a positive relationship between parental participation in a home program and the child’s individual outcome:

“Children whose parents rated their own compliance as high had better outcomes…When parents indicated a higher degree of compliance, their children showed greater improvement in hand function” (Law & King, 1993, p.987).

In Law and King’s study (1993), parental compliance was the only significant predictor of clinical change, not the type of intervention approach selected. Many factors could have been at work here.
This finding highlights the need for more research, designed to specifically evaluate the effectiveness of home programs, in reaching desired health outcomes of children with cerebral palsy.

For children with cerebral palsy, where their arms are affected, it is generally accepted that improving the quality of upper limb use is an important therapy goal and is typically a long, sustained process. Copley and Kuipers identify that

“any intervention used to address upper limb hypertonicity involves regular and/or ongoing commitment, these factors also play a major role in whether the outcomes of the intervention are sustained over time”

(Copley & Kuipers 1998, p.79).

It is then expected that many therapists would seek to use home programs, for children with life long disabilities such as, cerebral palsy. Providing therapy within a home program context address two important aspects of providing sustained treatment: firstly, it recognises that the parent is a constant in the child’s life and is therefore a factor in the success of the intervention. Secondly, upper limb training is both time and resource intensive, and it is not realistic to expect a family or a health system to maintain a lifelong commitment to the ‘hands on’ approach alone. Copley and Kuipers (1998) write regarding treatment intensity,

“Hands on techniques often require a large investment of time and effort” (Copley & Kuipers, 1998, p.95).

Several authors working with children with cerebral palsy have recommended the need for follow up or maintenance of intervention effects to occur in a home context (Hinojosa et al, 1988; Hinojosa & Anderson, 1991; Law & King, 1993; Mayo, 1981; Schreiber et al, 1995). Despite this, the literature does not provide evidence of the effectiveness of home program interventions with this client population.

If occupational therapists acknowledge that home programs have become central to paediatric health care for children with cerebral palsy, because of changes in approaches to children with disability and economic shortages in the health system (Law & King, 1993) then occupational therapists must also recognise that there is a pressing need for a good quality study to evaluate the effectiveness this

2.10 Statement of the Problem

The family-centred approach is accepted to be best practice when working with children who have disabilities (Ahmann, 1994; Roberts & Magrab, 1991). Adopting a family-centred approach, in paediatric occupational therapy practice, has necessitated a shift in service delivery methods (Bailey et al, 1992, Dormans & Pellegrino, 1998, Dunst, 1991, King et al, 1998, Leviton et al, 1992, Rosenbaum, 1998, Winton & Bailey, 1997, Viscardis, 1998). By developing an understanding of the importance and centrality of families, fundamental changes have occurred in key aspects of occupational therapy, for children with cerebral palsy. One such change is the role of home programs. Home programs were historically seen as an adjunct or follow up mechanism for direct therapy. With the embracing of family-centred practice, there has been a transformation to valuing parental participation in the development and implementation of home programs (Bazyk, 1989). Home programs have now become a key strategy in delivering occupational therapy services (Law & King, 1993).

There is, however, a paucity of literature pertaining to the way in which a family-centred home program for children with cerebral palsy should be structured, and further the effectiveness of occupational therapy, delivered via the family-centred home program to children with cerebral palsy. No single study has addressed the pertinent issue of what a family-centred home program for children with cerebral palsy should look like or whether or not occupational therapy home programs are effective in helping families achieve desired health outcomes.

In the era of evidence-based practice, there is timely and critical need, for a study to evaluate the effectiveness of family-centred home programs. The need for more home program research was identified by Hinojosa and Anderson (1991), Rodgers (1986) and most recently by Schreiber et al (1995). This study aims to address the knowledge gap identified in the literature.
2.11 Synopsis

This chapter has provided the literature background on which this study is based. This has been achieved through an in depth review of the literature pertaining to; the impact of cerebral palsy on children’s development, the heightening role of home programs in a family-centred framework, current clinical practice for developing function in children with cerebral palsy and a best practice approach to home programs. This review has identified that there is a need for a study, to investigate the effectiveness of occupational therapy home programs that use a family-centred approach for children with cerebral palsy. The next chapter will outline the method used in the study to conduct this investigation.
CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter will outline the methodology adopted in this study, discuss issues relating to the methodology and provide a rationale for its selection. The following topic areas are discussed within this chapter: research design; description of the participants; variables within the study; instrumentation used to collect data; procedures followed to collect data; and statistical analysis used to generate the study findings.

3.2 Design

The design used within this study was a single group pre-post intervention evaluation, which was non-experimental, i.e.; the independent variable (frequency, intensity and duration of participation in a home program) was not controlled or manipulated by the researcher (Domholdt, 2000; Thorne & Slane, 1997). The study design is pictorially represented using Campbell and Stanley’s, 1966, standard notations, presented in figure 4.

Figure 4: Study Design

![Diagram of Study Design]

Group A: $O_1 - X - O_2$

$X$ = Treatment

$O$ = Observation

$O_1$ = Baseline

$O_2$ = 6 months after baseline

3.2.1 Rationale for Design Selection

The rationale and justification for selecting a level three evidence (Lloyd-Smith, 1997), non-experimental research design, where the independent variable was not manipulated, is as follows:
1. This design allowed the participant or family to self-select their preferred level of participation in a home program. Central to family-centred care, is the belief that therapy should be driven by the family, not the professional, or in this case, the researcher (Winton & Bailey, 1997). In order to truly evaluate the effect of home programs delivered in a family-centred context, the researcher needed to allow participants to direct or control their own care, i.e. self-select their preferred level of participation in a home program. If the amount of time to be spent on the home program was prescribed by the researcher this would (a) remove the critical family-centred component and (b) make this study the same as previous research where ‘compliance’ with therapist prescribed programs was measured.

2. In this design, evaluating the effectiveness of home programs, pre and post implementation, was considered to be important for laying the groundwork for future randomised controlled trials regarding home programs, which are of higher evidence levels. As there is currently no research literature pertaining to description of a ‘best practice’ home program for children with cerebral palsy, or effectiveness of occupational therapy family-centred home programs, with children who have cerebral palsy, it was not possible to design a randomised controlled trial, with precision. This is because there is not yet enough understanding about ‘gold standard’ treatment commonly preferred for intervention protocols, or about efficacy of the intervention model so that elements like expected treatment effect sizes could be calculated. This study will build a foundation for understanding efficacy: as it presents a program based on literature; a representative sample is used; and the impact of the home program is measured using robust instrumentation. Through this research study, it will then be possible to identify the factors worthy of in-depth examination in a randomised controlled trial using estimates of effect size that are empirically based. It is important that this initial study is conducted, to develop an understanding of the level of efficacy to be expected from family-centred home programs. Independent of the study’s contribution to future studies, it will provide an important information base at level 3 evidence (Lloyd-Smith, 1997) for practice in an area currently characterised by even lower levels of evidence.
3.2.2 Prospective Non-Experimental Design

There are many types of non-experimental research (Domholdt, 2000). The principle differences between these research types are the (a) the purpose of the research, which can be to; describe, analyse relationships or analyse difference, and (b) the timing of the research, which can be either; retrospective or prospective (Domholdt, 2000). This study meets three of Domholdt's types; ‘prospective descriptive research’, ‘prospective analysis of relationships’ and ‘prospective analysis of difference’ (Domholdt, 2000). Each of these types of non-experimental research will be described in relation to the purpose of this study. The purpose of this study is to a) describe a program framework based on literature and identify measurable components of such a home program; b) identify outcomes typical of home programs for children with hemiplegic cerebral palsy; and c) explore relationships between specified program components and program outcomes: in particular the relationship between the intensity, duration and frequency of home program participation.

In this study, the impact of occupational therapy home programs was demonstrated by the change in scores on selected measures. Using the ‘prospective descriptive research’ framework, data was systematically collected about: the child's demographic and clinical attributes; level of participation in home programs; participant’s upper limb function; and independence in self care tasks. Collecting the data in a prospective method strengthened the design of the study, as the choice of measurement tools could be selected by the researcher and were administered in a standardised manner at routine intervals (Domholdt, 2000). The literature review in chapter two identified that these were commonly accepted outcomes for children with cerebral palsy when receiving treatment. In this study these were developed into measurable components of home programs and typical outcomes of home programs for children with hemiplegic cerebral palsy (see instrumentation – section 3.5).

Data was collected prospectively; pre and post, commencing a home program (independent variable), using a range of standardised instruments. The aim was to determine whether or not the participants
reached desired occupational therapy treatment outcomes levels (dependent variable), such as improvements in the use of the affected upper limb and increased independence in self care activities.

3.3.3 Controlling Threats to Validity through the Design

Threats to internal, construct and external validity of the study were reduced by:

- **Control of the independent variable**: In this non experimental research, no control data was collected as it was not practical or possible given the service provider organisation requirements and brief: to have a no-treatment control and to withdraw occupational therapy services from children, as they have previously been proven to be effective treatment in this age group, in a randomised controlled trial (Case-Smith et al, 1998) and in a before and after design (Stewart & Neyerlin-Beale, 2000). An alternative control group of ‘standard’ care could also not be used as the time required to recruit the larger sample size would have exceeded the candidature time available for the study, based on estimated recruitment rates from the service provider organisation.

Domholdt notes that, “Differences between groups or within a group can also be analysed in the absence of a controlled manipulation” (Domholdt, 2000, p.145).

Whist an experimental design, with random assignment to groups, would produce stronger empirical evidence, this present study design still produces clinically significant information and answers the research question, because of the intervention program development, prospective data analysis and standardised measurement tools used, producing uniformity of data (Domholdt, 2000).

Partial control of the independent variable was achieved by providing evidence-based standardised uniform home programs which were typed on a standard template, and included: the agreed goals; the intervention activities; the rationale for the activities; and standard information about how to reward and encourage the child. A standard log calendar was also provided to the participant’s parent, for him or her to record their level of participation in the home program.
Control of the participant selection: A sample of ‘convenience’ or a non-probability sample of volunteers was constructed from participants that were readily available (Cozby, 1997; Domholdt, 2000). This was necessary as no ‘sampling frame’ or cerebral palsy register, listing the population of potential participants living in New South Wales, currently exists. Volunteers were engaged using a comprehensive recruitment strategy, described in section 3.3.2. All volunteers were screened using inclusion criteria, presented in Table 1. This criteria was used to determine whether occupational therapy intervention was required and whether there were any current or impending confounding indications to participating in the research, such as scheduled surgery etc. Those who met the criteria were enrolled in the study (following informed consent), until the study sample was filled. This process generated a homogeneous sample group. Given that participants were recruited via voluntary participation, it is recognised that the sample cannot be automatically assumed to be representative of the population of all families who have children with hemiplegic cerebral palsy. Even though the children were representative of those with spastic hemiplegic cerebral palsy who typically utilise occupational therapy services by virtue of their inclusion criteria characteristics. The likeness of the children in the sample to the target population was confirmed by comparison of the sample’s intervention needs and goals to commonly identified areas for occupational therapy intervention identified in the literature review, in chapter two. This comparison between the sample’s intervention goals and the literature is outlined in chapter four. The parental participant’s were from a diverse range of environmental, educational, ethnic and socio-economic family backgrounds and therefore appear to be representative of the population of families with children who have hemiplegic cerebral palsy. Participants also demonstrated a diverse history of exposure to occupational therapy services; with this it is likely that they also held diverse understandings of the potential benefits of occupational therapy treatment and home programs.
Table 1: Screening Criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
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<tbody>
<tr>
<td>Diagnosis of hemiplegic cerebral palsy</td>
<td>Diagnosis other than hemiplegic cerebral palsy</td>
</tr>
<tr>
<td>Aged between two to eight years of age</td>
<td>Mild motor signs evident on “unaffected” upper limb, during fine motor tasks</td>
</tr>
<tr>
<td>Associated upper limb spasticity of at least grade 2 measured by the Ashworth Scale</td>
<td>Scheduled for a medical procedure to treat upper limb function, during study duration, eg. surgery, botulinum toxin A</td>
</tr>
<tr>
<td>Active use of the affected upper limb observed by the investigator during a functional task</td>
<td>Child was accessing an alternative therapy intervention, which focussed on developing their upper limb use, eg. conductive education</td>
</tr>
<tr>
<td>Response to light touch and pain sensation intact, with vision occluded</td>
<td>Parent stated that they did not want to carry out any form of home program intervention</td>
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- **Controlling of the setting or environmental factors:** For each participant in the study, pre and post measures were taken in the same environment, at the same time of the day, using the same equipment set up (table and chair) and same test material (a select range of toys).

- **Control of measurement:** A range of reliable and valid instruments was selected and administered pre and post intervention with each participant. The validity and reliability of the instruments was considered to be of critical importance for drawing conclusions from the results of the study (Domholdt, 2000; Law, 1987). The instruments selected were based on a review of the literature, pertaining to measurement tools recommended for use with the target population, ie. children with hemiplegic cerebral palsy. Pilot testing of the instruments was conducted, as recommended by Domholdt in 2000, with three participants prior to commencement of the study to ensure that the measures were reproducible and sensitive to change (Domholdt, 2000), refer to Appendix B for a description of the pilot study.

- **Control of information given to researchers and participants:** Single blinding of the results of the study was built into the design, to reduce bias, ie. each participant’s QUEST scores were calculated, from video footage, by a blinded rater who was a second occupational therapist (ie. not the researcher), experienced in working with children with cerebral palsy, and who was unaware of...
whether it was the participant’s pre or post video. This reduced the possibility of the reported pre and post scores being biased by the researcher.

3.3 Sample

3.3.1 Sample Type

The method of sampling selected should logically fit the research question (Punch, 1998). Convenience sampling was necessitated, as at the time of the study there was no ‘sampling frame’ currently in existence New South Wales. All participants, who met the inclusion criteria at an investigator’s screening assessment, were enrolled in the study (following informed consent), until the study was filled. This process generated a homogeneous sample group.

3.3.2 Recruitment

It was essential to develop a recruitment strategy, which targeted children with spastic hemiplegic cerebral palsy and their family. In NSW there is no central register of children with this condition that could be used as a sampling frame. Consequently a strategy where potential participants were self-identified volunteers was required. Within clinical research it is difficult and requires an intense effort to generate a homogeneous sample, meeting sample size calculations, within a reasonable time frame (Schoenfeld et al, 2000; Sorkness et al, 2001). This is true of occupational therapy research with people with cerebral palsy,

“Sample size calculations, in our experience, often lead the investigator in OT [Occupational Therapy] trials to conclude that either a protracted and unfeasible period of entering subjects is required, or more feasibly several treatment centres must participate in any proposed RCT” (Cadman et al, 1989, p.244).

In addition, cerebral palsy research is also confounded by differences in disability severity; hand function; age etc. (Law et al, 1989). It was therefore critical that this study implemented a vigorous multi-method recruitment strategy to assemble a homogenous and representative sample. To increase
the likelihood that the convenience sample selected was representative of the target population of children with hemiplegic cerebral palsy, the following recruitment strategies were adopted:

- Recruitment advertisements, study information sheets and consent forms were sent to all managers and therapists within the Spastic Centre of NSW who provided therapy services to children with cerebral palsy, in both rural and metropolitan NSW. 79 packages including the aforementioned print material forms were sent out.

- Recruitment advertisements, study information sheets and consent forms were sent to all Paediatricians within metropolitan and rural NSW. 400 recruitment packages were mailed out.

- A recruitment advertisement was placed in the Spastic Centre NS W newsletter “I Am”, which is distributed to all client consumers of The Spastic Centre of NSW and to service providers such as Department of Aging, Disability and Home Care, Early Intervention Centres, and Department of Health. The distribution mailing list for this magazine includes approximately 4000 addresses. In follow up to all inquiries generated from this advertisement, 89 telephone consultations were provided and information sheets with consent forms were mailed out to all interested parties. 57 potential participants who met the inclusion criteria were also offered a screening assessment.

- Information seminars were provided to all occupational therapy staff at The Spastic Centre of NSW and Sydney Children’s Hospital about how to make a referral, the outline of the study and commitment for participants. An additional information seminar was provided to all occupational therapy staff working with children in the Riverina area of rural NSW about how to make a referral, the outline of the study and commitment for participants. In total 4 seminars were conducted.

- Information about the study and contact details for inquiries was provided to the parent support group entitled, ‘Hemi Club’. This support group is an informal network of parents who have children with hemiplegia.

The sample was drawn from all of the above recruitment sources. See Table 2 for participant recruitment strategy results.
Table 2: Recruitment Strategy Profile

<table>
<thead>
<tr>
<th>Recruitment Strategy</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spastic Centre recruitment advertisements</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>Paediatrician recruitment advertisements</td>
<td>5 (25%)</td>
</tr>
<tr>
<td>I Am newsletter</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Information seminars</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Hemi club</td>
<td>1 (5%)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>N = 20</strong></td>
</tr>
</tbody>
</table>

3.3.3 Inclusion Criteria

Voluntary participants were enlisted, following recruitment advertisements and screening evaluations. Children enrolled in the study met the following inclusion criteria:

- Diagnosis of hemiplegic cerebral palsy
- Aged between two to eight years of age
- Associated upper limb spasticity of at least grade 2 measured by the Ashworth Scale in one or more muscle groups in the affected upper limb
- Some active use of the affected upper limb observed by the investigator during a functional task such as carrying or stabilising a toy
- Some response to light touch and pain sensory stimulus on the affected upper limb, when vision was occluded

3.3.4 Volunteer Screening

All potential volunteer participants were screened at a face-to-face assessment, accompanied by their parent. These assessments were conducted by the investigator, at The Spastic Centre, in a children’s therapy assessment room, which included children’s toys and furniture. Each screening assessment was approximately 45 minutes in length. At the assessment, an interview was conducted with the parent about the child’s medical history and planned interventions. In addition, the investigator observed the child in an unstructured play session. Toys were given to the child that required bilateral hand use, to enable the investigator to observe the child’s preferred movement patterns; ability level and approach to the tasks. When the child felt comfortable, the Quality of Upper Extremity Skills Test
(QUEST) was conducted to enable the investigator to observe and quantify the child’s ability level and movement potential compared to their self-selected abilities demonstrated in the unstructured play session. The combination of these data sources was used to establish whether the child met the study inclusion criteria or whether there was any need to exclude the child because of contraindicated variables as defined in the exclusion criteria. Table 1 presented the screening criteria. Those who met the criteria were enrolled in the study (following informed consent), until the study sample was filled (N=20).

3.3.5 Sample size

The sample size in a clinical intervention study is important for concluding whether or not a treatment should continue to be offered based on its effectiveness (Cadman et al, 1989). A priori power calculations were not a suitable strategy for determining an appropriate sample size within this study because of the pre-post single group design adopted. To determine an appropriate sample size the investigator reviewed the sample sizes of precedent studies in: (1) the home program literature; (2) validity/reliability studies of the ‘gold standard’ PEDI instrument; and (3) cerebral palsy intervention effectiveness studies that used PEDI as an outcome measure. The studies identified through a literature search of Medline databases are summarised in Table 3. The precedent literature revealed generally smaller sample sizes. Sample sizes for quantitative home program studies ranged from 8 participants per group through to 18 participants per group - group numbers in the study examining home program recording methods varied (Law & King, 1993). Sample sizes for PEDI validity/reliability studies ranged from 17 participants per group through to 41 participants per group with the exception of the McCarthy et al (2002) study where the sample size was significantly larger with 115 participants. Sample sizes for cerebral palsy intervention effectiveness studies ranged from 1 participant per group through to 29 participants per group.
<table>
<thead>
<tr>
<th>Study &amp; Citation</th>
<th>Sample Size Used</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home Program Quantitative Research Studies</strong></td>
<td></td>
</tr>
<tr>
<td>Mayo (1981). The effect of a home visit on parental compliance with a home program.</td>
<td>N = 18 (9 in experimental group; 9 in control group)</td>
</tr>
<tr>
<td>Law &amp; King (1993). Parent compliance with therapeutic interventions for children with cerebral palsy.</td>
<td>N = 72 (Block randomisation scheme divided sample into 4 different intervention groups)</td>
</tr>
<tr>
<td><strong>PEDI Validity/Reliability Studies</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Effectiveness Studies using PEDI as an Outcome Measure</strong></td>
<td></td>
</tr>
</tbody>
</table>
From this literature the investigator determined that a cohort of 20 participants for this study was appropriate as: (1) the sample would be larger than any previous home program study; (2) a study consisting of 20 participants was similar in size to the majority of validity and reliability studies for the PEDI instrument, an outcome measure used in this study; and (3) recent intervention effectiveness studies for children with cerebral palsy had a mean group size of 13-14 participants.

3.4 Variables

3.4.1 Dependent Variables

Dependent variables in this study were the ‘expected outcomes’ (Nachmias, 1981; Creswell, 1994). In this study these were the level of attainment of collaboratively developed program goals, such as improvements in the use of the affected upper limb and increased independence in self-care activities. General outcome measure prototypes described by Rosenthal and Rosnow (1991) were applied to this study. Specifically, this research study used selected variables that would be expected to indicate change in factors related to the program goals. These were:

1. **Measures which quantify the ‘direction of the observed change’ in independence in self care, quality of upper limb movement, passive and active joint range of movement, and muscle strength.** Desired occupational therapy treatment outcomes for children with hemiplegia routinely include seeking to affect a positive increase in all of these domains. The ‘direction of observed change’ (Rosenthal & Rosnow, 1991) was measured using Goal Attainment Scales (GAS); Pediatric Evaluation of Disability Inventory (PEDI); Quality of Upper Extremity Skills Test (QUEST); Range of Motion (ROM); and Manual Muscle Test instruments.

2. **Measures which detected the ‘amount of change’ in independence in self care, quality of upper limb movement, passive and active joint range of movement, and muscle strength.** Desired occupational therapy treatment outcomes for children with hemiplegia include, seeking an increase in all of these domains, where more is perceived as better. The ‘amount of change’ was measured using GAS, PEDI, QUEST, ROM, and Manual Muscle Test instruments.
Specific instruments for each of the above variables are presented in section 3.5.

In addition to using the Rosenthal and Rosnow (1991) outcome measure prototypes, measurement instruments selected for detecting clinical change in response to the home program also had to meet the ‘Instrument Evaluation Process Algorithm’ criteria developed by Law (1987). That is, in order for an instrument to be considered to have sufficient ‘scientific rigor’ and ‘utility’ to measure clinical change in response to the home program it had to: (1) be an instrument which was an outcome measure i.e. designed to measure change over time; (2) be clinically useful; (3) have adequate test construction; (4) be standardised; (5) be reliable; (6) be valid; and (7) be responsive enough to measure small changes in an individual over time (Law, 1987). Each instrument was assessed against each of the above rigor and utility criteria and is presented in section 3.5.

3.4.2 Independent Variable

The independent variable, ‘treatment conditions’ or ‘presumed cause’ (Nachmias, 1981, Creswell, 1994) of reaching desired family and occupational therapy outcomes (dependent variable), within this study is the home program. The independent variable, the home program is conceptually defined as follows,

“home programs are often a part of physical and occupational therapy regimes for children with developmental delays. Parents are asked to participate in home activities…these activities give the child more opportunities to practice the procedures and assist him or her in transferring learned skills from the clinic to the home” (Gajdosik, 1991, p.73).

Many dimensions of the home program could be explored. In previous research, analysis of compliance with the prescribed program has been evaluated, along with the effect of home programs on parent-child interactions. It is the purpose of this study; to evaluate the effectiveness of a family-centred home program, as the primary method of intervention, in reaching desired family and occupational therapy outcomes. Outcomes such as, independence in self-care tasks and increased upper limb use were evaluated. Therefore in this study, the investigator operationally defined home programs as, ‘therapeutic activities, designed by the family and therapist to reach mutually agreed goals, to be
Home program participation was further specified according to the following operational definitions. Frequency was defined as how often the family chose to engage in the home program. Intensity was defined as how long the family spent on the selected therapeutic activities per session. From this data, home program duration was defined as the home program frequency multiplied by the intensity.

### 3.5 Instrumentation and Materials

To determine which intervention approaches should to be used within the home program and to measure the direction and amount of change in the dependent variable, ie. reaching desired family and occupational therapy outcomes, a number of instruments were used. Each of these instruments will be described in detail, exploring the usefulness of the instrument and it’s validity and reliability. The instrument’s relationship to the dependent variable is summarised in a table 2.

<table>
<thead>
<tr>
<th>DEPENDENT VARIABLE DOMAIN</th>
<th>INSTRUMENT USED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individualised child or family-centred goals</td>
<td>GAS</td>
</tr>
<tr>
<td>Independence in self care activities</td>
<td>PEDI, GAS</td>
</tr>
<tr>
<td>Quality of upper extremity movement</td>
<td>QUEST</td>
</tr>
<tr>
<td>Quantity of upper extremity movement</td>
<td>QUEST, Range of motion via a goniometer</td>
</tr>
<tr>
<td>Muscle strength</td>
<td>PEDI, Manual Muscle Test</td>
</tr>
<tr>
<td>Muscle resistance/spasticity</td>
<td>Ashworth Scale</td>
</tr>
<tr>
<td>Home program participation level</td>
<td>Self report log calendar</td>
</tr>
<tr>
<td>Participant characteristics and home program history</td>
<td>Investigator designed self report open-ended question survey (completed in interview format)</td>
</tr>
</tbody>
</table>

The instruments used to measure clinical outcomes were also scrutinised from a hierarchical perspective based on the literature review presented in chapter two, this is presented in Figure 5.
Instruments that evaluated whether or not the parent’s goals were met during the intervention period were considered to be the most important (Wallen & Doyle, 1996). Instruments that evaluated whether or not the child made functional gains in response to the program (Bleck, 1987, Copley & Kuipers, 1999, Harris, 1988, Tardieu, 1984) were considered second most important after goal evaluation. Instruments that identified and quantified the degree impairment present were considered least important, as therapy for children with cerebral palsy should focus on improving function not remediation of impairments (Law et al, 1998). For this reason, coupled with in depth appraisal of instruments’ rigour and utility, instruments were assigned either a ‘diagnostic’ or ‘evaluative’ purpose by the researcher.

**Figure 5:** Instrument Use in this Study

### 3.5.1 Goal Attainment Scaling (GAS) of Home Program Goals:

Goal attainment scaling is an individualised measure of clinical change, using quantifiable goals (Kiresuk & Sherman, 1968). King et al, describe this measurement tool, "One of the most widely used individualised approaches is goal attainment scaling (GAS), which provides an individualised, criterion referenced measure of change. The GAS procedure involves: (a) defining a unique set of goals for each child, (b) specifying a range of possible outcomes for each goal (on a scale recommended to contain five levels, from −2 to +2), and (c) using the scales to evaluate the child’s functional change after a specified intervention period" (King et al, 1999, p.32).
Each goal is assigned weighting according to its importance. A range of possible outcomes is defined for each goal, where the expected outcome is given the median score, i.e. 0. Outcomes above and below the expected outcome are assigned positive and negative values respectively. At the re-evaluation period, an overall goal attainment score is calculated, which reflects any change since baseline (Kiresuk & Sherman, 1968).

Goal attainment scaling (GAS) can be used to measure both individual and program outcomes, “There are two main reasons for measuring outcomes in the field of pediatric therapy: (1) to evaluate outcomes for a specific child (to improve services to that child), and (2) to determine the effectiveness of a service or program as a whole. GAS can be used for both purposes, to document therapeutic change in individual children or to examine change in groups of children” (King et al, 1999, P.32-33).

Goal attainment scaling is recognised as a way of capturing small but significant clinical change, which may otherwise be missed when using global, standardised assessment procedures (King et al, 1999, Ottenbacher & Cusick, 1993, Palisano et al, 1992, Palisano, 1993, Wallen & Doyle, 1996). Goal attainment also has the added benefit of adopting a collaborative family-centred approach (King et al, 1999). This is a central theme in this study, which supports the adoption of this instrument.

The validity and reliability of the instrument have been criticised, as unintentional bias can occur in the goal setting process (King et al, 1999). In particular, goals can be too easy to attain (Palisano, 1993). Reliability and validity of the instrument is improved by: training raters; clear delineation of outcome levels; and the use of multiple raters (Ottenbacher & Cusick, 1990). Within this study, multiple trained raters were used to establish the goal attainment scales. These raters were familiar with the child’s assessment findings but were not the child’s treating clinician, i.e. they were independent raters. This was done in accordance with literature recommendations to reduce potential bias in setting the goal attainment level too low (Cytrynbaum et al, 1979; King et al, 1999). To evaluate change in the child’s performance, if any, on the goals following the home program intervention, the child’s performance of the tasks in the goal attainment scale was videotaped at the six-month reassessment appointment. The team of raters (which excluded the child’s treating therapist) then graded the child’s performance
against the child’s attainment scale from the videotape footage. Each rater was blinded to the child’s initial status and the order of the evaluations data they were reviewing, as per literature recommendations for reducing potential bias (Ottenbacher & Cusick, 1990). Where dressing was set as a home program goal, videotaping was deemed inappropriate by the investigator for privacy and child protection reasons. In these cases, the child was observed performing the task in a private assessment room by the investigator, with their parents present. The grading of the task was then done by having the parent/s select the goal attainment scale level that best represented their child’s performance that they had just observed.

Within this study, GAS was used to evaluate the impairments, disabilities and handicaps, identified collaboratively by the parent and researcher, for the purpose of quantifying mutually agreed upon focus areas within the home program intervention. The GAS instrument is recommended as an occupational therapy evaluation tool for measuring goals that are meaningful and important to families (Wallen & Doyle, 1996). The goal areas developed on the GAS scales within this study were designed to measure important dimensions of occupational therapy intervention which were either not captured by the other standardised measures or were not measured sensitively enough by other instruments. Standardised paediatric measures are known to have considerable disadvantages, including: lacking an Australian context for interpretation; having questionable validity as outcome measures; having inconclusive relevance to the presenting functional problems; and lacking sensitivity to central occupational therapy domains (Wallen & Doyle, 1996). The use of GAS is thus recommended as a method for achieving meaningful outcome measurement, since this tool addresses a critical gap created by other typical standardised occupational therapy measures (Wallen & Doyle, 1996). Therefore the GAS was adopted within this study to ensure that the child’s progress, if any, on the family’s priority areas of the home program, could be rigorously and comprehensively evaluated in a meaningful way.

### 3.5.2 Pediatric Evaluation of Disability Inventory (PEDI):

The PEDI is a standardised measurement tool, designed to measure
“the acquisition of skills of individuals with physical disabilities… The PEDI includes the evaluation of self-care, mobility and social function” (Henderson & Pehoski, 1995, p.167).

“The inventory is designed to identify the child’s functional ability along three scales: (1) typical functional skill level, (2) physical assistance typically required of the caregiver, and (3) modifications or adaptive equipment used (ie. braces, motorised wheelchair). Each scale is divided in to three domains: self-care, mobility and social function” (Ketelaar et al, 1998).

The test authors propose that the PEDI has three functions: (1) to detect functional deficits; (2) to monitor progress in paediatric therapy programs; and (3) to evaluate program outcomes (Hayley et al, 1992). Many authors have described the usefulness of the PEDI in evaluating the functional skills of children with physical disabilities (Nichols & Case-Smith, 1996, Ziviani & Wright, 1995, Reid et al, 1993), including children with cerebral palsy (Ketelaar & Vermeer, 1998; Russman et al, 1997). The PEDI has been shown to be sensitive to clinical change in the population being examined within this study, that is, children with hemiplegic cerebral palsy (Nordmark et al, 2000, Ketelaar & Vermeer, 1998). Ketelaar and Vermeer (1998), systematically reviewed literature pertaining to measurement tools for children with cerebral palsy. Their findings were that the PEDI was the only self-care instrument to demonstrate sensitivity to detecting clinical change over a six month period of time. Their review included analysis of other commonly used tools such as, Functional Independence Measure for Children (WeeFIM) (Msall et al, 1994); Barthel Index (Mahoney & Barthel, 1965); and Kenny Self Care Evaluation (Schoening et al, 1965).

“The PEDI has been developed for discriminative as well as evaluative purposes. A number of studies support the PEDI as a reliable and valid assessment of functional performance in children with disabilities. In addition, the responsiveness of the PEDI to change over a six month time period when used with children with cerebral palsy has been confirmed” (Ketelaar & Vermeer, 1998).

The choice of this instrument as an outcome measure was thus supported on utility grounds.

The choice of instrument was also supported on psychometric grounds. Nichols and Case-Smith (1996) examined the validity and reliability of the PEDI. Reliability of the instrument for intra-rater reliability was high for functional skills summary scores (ICC 0.98) and ranged from 0.68-0.90 for the self-care
caregiver assistance scale (Nichols & Case-Smith, 1996). The PEDI can be administered as a parental self-report; a semi structured interview or be solely administered by therapists to assess the functional abilities of children (Feldman et al, 1990). When PEDI assessment data is collected from both parents and therapists the instrument is still considered reliable and consistent, supported by a ICC for intra-rater reliability of 0.84-1.00 (Nichols & Case-Smith, 1996). The implications of this finding was applied within this study, ie. both the parent and therapist contributed to completing the PEDI evaluation simultaneously, as this was perceived by the investigator to be a family-centred approach to program evaluation and it increased the probability of more accurate data collection as the parents were more likely than the researcher to observe their child’s self-care skills (Nichols & Case-Smith, 1996). Concurrent validity with the Peabody Developmental Motor Scales were moderate to high (r= 0.64-0.95) (Nichols & Case-Smith, 1996). Feldman et al, also showed concurrent validity to be moderately high (r= 0.70-0.80), when the PEDI was compared to the Battelle Developmental Inventory Screening Test (BDIST) (Newborg et al, 1984). Construct validity was supported by a) significant difference between peer scores of children with and without disability on PEDI scores, and b) discriminant analysis, which showed the PEDI to discriminate better children with and without disabilities than the BDIST (Feldman et al, 1990).

3.5.3 Quality of Upper Extremity Skills Test (QUEST)

The QUEST is a standardised, criterion referenced, paediatric measurement tool which,

“evaluates quality of upper extremity function in four domains: dissociated movement, grasp, protective extension, and weight bearing. It is designed to be used with children who have neuromotor dysfunction with spasticity and has been validated with children from 18 months to 8 years of age” (DeMatteo et al 1993, p.1).

Further to this, the test authors note,

“The Quality of Upper Extremity Skills Test (QUEST) was developed to capture patterns of movement that are part of normal development and are the basis for functional upper extremity performance” (DeMatteo et al 1993, p.3).
This test was selected to measure change in functional upper limb use caused by the home program, as the QUEST captures patterns of movement that are foundational to functional arm use.

The QUEST was developed by a team of Canadian paediatric researchers, as a clinical trial outcome measure, to evaluate the effect of upper limb casting in children with cerebral palsy (DeMatteo et al, 1993). DeMatteo et al’s literature synthesis demonstrated that at the time of test development, there were no other measurement tools that adequately evaluated quality of upper extremity movement in children with cerebral palsy, existing instruments focussed on quantity of movement not quality. This review included evaluation of widely recognised paediatric measurement tools, such as, the Peabody Developmental Motor Scales (Folio et al, 1983), The Miller Assessment of Preschoolers (Miller, 1982) and the Erhardt assessment (Erhardt, 1982).

Of the four possible QUEST test item domains: dissociated movement, grasp, weight bearing and protective extension, only the first two were measured during this study. The test developers indicate subscale use is acceptable: one, two, three or four domains of the QUEST can be administered depending on the clinician’s preference and a total score still reached. For the purpose of this study, only the first two domains (dissociated movement and grasp), were administered as they pertained solely to upper limb function. In the third and fourth domains, upper limb function is measured whilst simultaneously performing gross motor activities. Whilst there is no literature precedent for using the tool this way in a research study, the test manual and test reviewers write that the test scoring was constructed in such a way to allow for this to occur (DeMatteo, 1993, Hickey & Ziviani, 1998). This same methodology was adopted in 1997 by Hickey, (who published the review of the QUEST instrument), in an unpublished clinical trial which used the QUEST as the primary outcome measure. Hickey’s trial investigated the effectiveness of semi-dynamic upper limb splints for children with cerebral palsy, but had to be discontinued due to poor splint durability, which introduced extraneous variables into the study which could not be controlled for by the investigator. It should be noted that the two QUEST domains administered in this research study, grasp and dissociated movement, are reported to have the highest concurrent criterion validity. The dissociated movement domain also has the highest test retest
reliability and inter-rater reliability (Hickey & Ziviani, 1998). Measurement of any potential change in score in the latter two sub-tests within this study was deemed by the researcher to be confounded by other variables. Principally, the majority of participants within this study were also simultaneously receiving physiotherapy treatment to improve their gross motor skills. Many of the core skills, evaluated in the latter two domains of the QUEST, are standard paediatric physiotherapy goals for children with hemiplegia (Bobath, 1984, & Bly, 1991). For this reason, these skill areas were not assessed or targeted in the home program. If an improvement occurred, in either of these two domains, it would be difficult to ascertain, whether this was caused by the home program or by the physiotherapy treatment. This same issue has been recognised by other authors conducting occupational therapy research while children are concurrently receiving physiotherapy treatment (Stewart & Neyerlin-Beale, 2000).

The validity of the QUEST is reported to be high. The QUEST review by Hickey and Ziviani states, “Item selection is well grounded in theoretical and clinical context and high to moderate construct validity measures support the notion that inferences about quality of movement can be made from QUEST scores. Concurrent criterion validity findings strengthen the construct validity…. Preliminary work on its [QUEST] responsivity is an advance on most other tools used for evaluation in this population” (Hickey & Ziviani, 1998, p.133).

Test reliability is also reported to be high, “the instrument (QUEST) has shown excellent inter-observer reliability (0.96) and test-retest reliability (0.95) for total scores (Hickey & Ziviani, 1998, p.133).


It is for this reason, along with the above mentioned psychometric properties, that the QUEST was selected as an outcome measure for evaluating the impact of this occupational therapy home program.
3.5.4 Passive and Active Range of Motion (PROM & AROM)

Range of motion is defined by Trombly and Scott as,

“Each joint is potentially able to move in certain directions and to certain limits of motion due to its structure and the integrity of surrounding tissues” (Trombly & Scott, 1989, p.184).

Range of motion is the numeric measurement of a joint’s capability. Passive Range of Motion (PROM) is defined as

“The amount of movement available at a joint when it is moved by an assistant” (Copley & Kuipers, 1998, p.298).

Compared to Active Range of Motion (AROM) which is

“The amount of movement available at a joint when the limb is moved voluntarily by the person” (Copley & Kuipers, 1998, p.297).

Range of motion is measured via a ‘goniometer’. Trombly and Scott (1989) describe the goniometer;

“The most widely used method of measuring joint motion is the system of using the universal goniometer. Every goniometer has a protractor, an axis, and two arms. The stationary arm extends from the protractor on which degrees are marked. The other arm is termed the moveable arm and has a centre line or pointer to indicate the degrees of the angle measured. The axis is the point where these two arms are riveted together” (Trombly & Scott, 1989, p.184).

The measurement of range of motion, via a goniometer, has long been common practice by occupational therapists and physiotherapists and is still used widely today, despite technological advances in computerised measurement systems (Armstrong, 1998, Bierma-Zeinstra et al, 1998, Boone et al, 1978, Copley & Kuipers, 1999, MacDermid et al, 1999, Stratford et al, 1984, Trombly & Scott, 1989). The measurement of range of motion is routinely taken when hypertonicity is present, as the risks of discomfort and contracture are elevated in this client population through restricted range of motion, which can lead to a secondary loss of functional skills (Copley & Kuipers, 1999). The value of collecting numeric range of motion measurements is that responses to treatment over time can be quantified and therapy intervention adjusted accordingly.
The reliability of goniometric measurement has been examined for both the tool and the procedure (Bear-Lehman & Abreu, 1989, Boone et al, 1978, Copley & Kuipers, 1999, Trombly & Scott, 1989). In the upper limb, inter-rater reliability is reported to be 0.85-0.86, and intra-rater reliability 0.88-0.93 (Boone et al, 1978, MacDermid et al, 1999). A technical measurement error of 5 degrees is reported for the upper limb (Boone et al, 1978, Copley & Kuipers, 1999, Trombly & Scott, 1989). In this study, an improvement or deterioration in range of motion was thus defined as, a change in goniometric measurement greater than 5 degrees, to accommodate the possibility of technical error. In a recent study by Armstrong et al (1998), comparing standard goniometric measurements to computerised goniometry in the upper limb, it was concluded that reliable measurements are obtainable using either device when a standardised administration method is used. They also noted like Trombly and Scott that measurement error for repeated measurements was less when taken by the same tester (Armstrong et al, 1998). To ensure the best possible measurement reliability, the recommended procedure by Armstrong et al, of using standardised administration and only one tester, was therefore used in this study. In addition detailed measurement guidelines outlined by Trombly in diagrams and text were followed. These included; measurement by the same assessor, using the same testing instrument and measurement technique, measured at same time period of the day in a familiar setting (Trombly & Scott, 1989).

3.5.5 Manual Muscle Strength Testing:

Muscle strength is

“the ability of a muscle or muscle group to produce tension and a resulting force in one maximal effort, either dynamically or statically, in relation to the demands placed upon it” (Kisner & Colby, 1990, p.10).

It is necessary to produce sufficient tension for maintaining a posture, initiating and controlling movement (Trombly & Scott, 1989). Copley and Kuipers recognised that

“Muscle weakness limits performance by reducing the person’s ability to maintain posture, initiate movement, and control movement against resistance” (Copley & Kuipers, 1999).
Muscle weakness is present in people who exhibit hypertonicity, including those with muscle spasticity, hemiplegia and cerebral palsy (Copley & Kuipers, 1999). Participants in this study had all three symptoms present.

Muscle strength can be measured using a variety of tools, Trombly and Scott write,

“Strength of muscle contraction can be measured by means of spring scales, tensiometers, dynamometers, weights or manual resistance. Although the measurement of strength taken using apparatus is more exact, it is difficult and time-consuming to set up the apparatus as precisely as it must be in order to get accurate measurements of each muscle group. Therefore clinicians use manual muscle testing, which they have found to be adequate for most clinical purposes” (Trombly & Scott, 1989).

Dynamometers are recognised to be more sensitive than manual muscle testing and their use is preferable, when clinically possible (Bohannon, 1997). In this research study however, manual muscle testing was conducted in preference to strength apparatus testing, for the following reasons:

- Strength measurement apparatus are constructed to suit adult proportioned limbs and are often too large for children to use. Additionally, the results of strength testing when using apparatus' are based on normative data for the adult population (Trombly & Scott, 1989). Manual muscle testing can be used with all age groups.

- The use of foreign or unfamiliar “medical” instrumentation can elevate the stress level of children, which can affect motivation in performance. Motivation is recognised as a key element in the reliability of muscle strength testing results (Trombly & Scott, 1989).

- A strength measurement apparatus generally measures only one to two movement patterns; it was desirable in this study to select a measurement tool, which could be utilised for all upper limb movements. Manual muscle testing achieved this goal.

The reported reliability of manual muscle strength testing varies. The reliability of manual muscle strength testing with children, who have physical disabilities, has been reported to range from 0.65 to 0.93 (Florence et al, 1992). Florence et al (1962) concluded that manual muscle testing is sufficiently
reliable for assessing muscle strength when consecutive evaluations are taken by the same assessor. Copley and Kuipers (1999) have suggested that assessing muscle strength in children with childhood disabilities may be better conducted by or in conjunction with functional evaluations, such as the PEDI, as these children have no previous experience of normal movement unlike a person with an acute injury (Copley & Kuipers, 1999, Pedretti, 1996). In this study, manual muscle strength testing was therefore conducted in conjunction with a functional evaluation, namely the PEDI.

In this study the standard manual muscle testing prescribed method was used: the child’s upper limb was positioned in such a way that the required test movement was against gravity. Based on performance, a numeric grading was assigned to each muscle group (Trombly & Scott, 1989). To increase the reliability of the manual muscle testing results, the protocol outlined by Trombly and Scott was followed in this study. Trombly and Scott advocate a uniform approach to manual muscle testing, “There are established procedures for muscle testing to make this evaluation as reliable as possible….Of greatest importance to the reliability of the scores of repeated tests is the strict adherence to the exact procedures of muscle testing” (Trombly & Scott, 1989, p.232).

In the Trombly and Scott text, “Occupational Therapy for Physical Dysfunction” (1989), photographs demonstrate the measurement positions and techniques clearly to the assessor: these were adhered to in this study.

Due to the uncertain reliability of Manual Muscle Testing, this instrument was not used as an outcome measure within this study. Instead it was used as a ‘diagnostic’ tool, within a comprehensive group of assessments, to identify underlying impairments causing functional difficulties. Manual Muscle Testing was used only to confirm or refute the presence of muscle weakness, a common symptom of children with cerebral palsy (Copley & Kuipers, 1999), and therefore informed the rationale for selection of treatment approaches within the home program.
3.5.6 Ashworth Scale:

The Ashworth Scale (Ashworth, 1968) measures the resistance offered by the hypertonic limb as it is passively moved through its range of motion. It is used clinically, to determine severity of hypertonicity present (Katz & Rymer, 1989). The Ashworth Scale uses a subjective 5 point ordinal scale, each level is a “grade” of spasticity, descriptively indicating the amount of muscle tone or resistance offered to the movement. Zero is a normal score, a score of five would indicate a rigid limb.

Quantifying the degree and distribution of spasticity present is important for determining the impact of spasticity on movement impairments as opposed to other hypertonicity symptoms such as, weakness or loss of range of motion (Copley & Kuipers, 1999). Pandyan et al (1999) recognised that whilst there is a large focus on treatment of spasticity, clinicians rarely measure it.

The validity or clinical usefulness of the Ashworth scale has been criticised. Pandyan et al (1999) conducted a systematic review of the literature pertaining to the validity and reliability of the Ashworth Scale and Modified Ashworth Scale (MAS), which included a review of 40 papers. They concluded the following; the Ashworth Scale was more reliable than the MAS was; the reliability of the Ashworth Scale is better in the upper limb than the lower limb but that the validity of the instrument was questionable. This is because the Ashworth Scale measures resistance to passive movement, which can be influenced by many factors, only one of these being spasticity. The Ashworth Scale should be therefore be viewed as a measure of resistance to passive movement but not spasticity (Pandyan et al, 1999). Despite the enormous validity weakness created by what the tool claims to measure, the Ashworth Scale is known to be sensitive to detecting treatment effects from pharmacological adjunct interventions in spastic cerebral palsy (Campbell, 1996). Good inter-rater reliability of the Ashworth Scale is reported at a Kendall’s tau correlation of 0.847, when the instrument is used to measure elbow flexor spasticity (Bohannon & Smith, 1987).
Within the present study the Ashworth Scale was used to confirm the presence of resistance to passive movement, one aspect of hypertonicity. The researcher determined the relative contribution of spasticity to the upper limb movement difficulties that the child presented with using the information gained from the Ashworth Scale. This critical assessment information directed which treatment modalities were indicated for each child within their home therapy program. For example, it highlighted which muscle groups required ‘inhibitory’ upper limb casting intervention and conversely which movement patterns required alternate treatment approaches such as strength training and active movement practice. It was therefore not used as an outcome measure to detect clinical change associated with the home program because of its inherent validity flaws. Rather the Ashworth Scale was utilised in this study as one tool, within a comprehensive group of assessments, to diagnose underlying impairments at baseline, which may inform the selection of necessary intervention approaches and priorities.

3.5.7 Home Program Log Calendar:

The family’s voluntary participation in the home program was recorded via a self-report home program log calendar, provided to them by the researcher. Each day families were asked to record, how often they chose to engage in the home program (frequency), and how long they spent on the home program activities per session (intensity). This enabled the home program duration measures to be calculated, which was the home program frequency multiplied by the intensity. The precedent for self reporting participation or ‘compliance’ as it was formerly referred to, via diaries and calendars is well reported in the mental health and medical literature, with respect to medication usage; symptom manifestation; pain levels; and drug taking behaviour (Jamison et al, 2001, Schandry et al, 1996, Rosner et al, 1992, O’Hare et al, 1991). Logbooks have also been employed by therapists to record self-reports of frequency and duration of home exercise program completion (Chen et al, 1999; Schreiber et al, 1995; Tooth et al, 1993). Several authors, working with children and families have advocated the use of self-report diaries or calendars (Gajdosik, 1991; Law & King, 1993; Schreiber et al, 1995). Law and King (1993) compared five measures of parent participation in home programs: parent rating of participation
level, therapist rating of participation level, therapy attendances, mean hours of cast wear and daily log books. They demonstrated that self report measures of parental participation in home programs were more reliable than any other measure of participation level and were the only measure predictive of clinical outcome (Law & King, 1993).

Parental participation in home programs for children with disabilities has been shown to be high (Law & King, 1993, Schreiber et al, 1995). Schreiber, Effgen and Palisano (1995) measured parent participation in home programs using a randomised controlled trial, evaluating the effect of parental collaboration in developing home programs. Schreiber et al (1995) reported compliance levels of 77.5-80.3% in parents carrying out home programs. They suggested this high level of compliance might be attributable to families' interest in doing a home program as well as the method used to report compliance (Schreiber et al, 1995). To collect compliance data, Schreiber et al (1995) provided each family with a daily data collection form to complete, this logbook recorded the number of activities attempted and whether the activity was successfully completed. Compliance was calculated by dividing the number of activities attempted by the number of opportunities to carry out the activities during the study duration. Therefore this study followed a similar logbook protocol. In this study a daily logbook was provided to families but instead of asking families to record whether the daily activities were successfully completed, the study logbook recorded the amount of time the family spent practising the activities. The minor modification to Schreiber et al (1995) logbook protocol made by this researcher was necessary to enable this study to capture self-selected parental participation intensity levels rather than ‘compliance’ levels with a prescribed regime.

3.5.8 Parental Self Report Survey

Parental self-report surveys were conducted by the investigator to collect baseline information regarding participant's attributes; their history of participation in home programs and the child's history of wearing functional hand splints. The surveys were carried out using open-ended questions in an interview format. The researcher would orally ask the parents a series of questions that were designed to capture
a home program history about their child. This methodology was adopted because interviews are considered an appropriate way to obtain basic, factual information from participants (Domholdt, 2000). Also, the interview easily allowed the researcher to adjust the level of language so as to maximise the participation of families from a range of educational backgrounds and/or culturally and linguistically diverse backgrounds; ensuring that all families provided information in sufficient depth. Although an interview technique could be used to elicit information on the participant’s beliefs, experiences and preferences concerning home programs, these survey questions were not designed to generate this kind of data. The study as a whole uses a quantitative paradigm and the parental self-report surveys reflected this orientation.

### 3.5.9 Instrument Utilisation Rationale

From the description provided of each instrument it is clear that not all of the instruments utilised within this study had sufficient rigour and utility to warrant their use as measurement tools for evaluating the effectiveness of the home program. Therefore the researcher used only the rigorous instruments to evaluate the effectiveness of the home program. The remaining instruments, were used only as part of the baseline assessment as diagnostic tools, for identifying ‘impairments’ that explained ‘why’ a child was having difficulty performing a functional task, which helped inform the development of the home program. Therefore their usage was to inform the construction of the home program, not to measure its effectiveness. The rigour and utility of each study instrument was discussed in sections 3.5.1 to 3.5.8, and is now summarised in table 3. The decision by the researcher to allocate the instrument to either an evaluative or diagnostic purpose based on the instrument’s rigour and utility, along with consideration of the domain area the instrument was designed to measure, is summarised in table 4.
### Table 3: Instruments’ Rigour & Utility Summary

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Evaluative Purpose</th>
<th>Clinically Useful</th>
<th>Adequate Construction</th>
<th>Standardised</th>
<th>Reliable</th>
<th>Valid</th>
<th>Responsive</th>
</tr>
</thead>
<tbody>
<tr>
<td>GAS</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>GAS</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>PEDI</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>QUEST</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>Likely, more research needed</td>
</tr>
<tr>
<td>ROM</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Manual Muscle Test</td>
<td>✓</td>
<td>X</td>
<td>Ordinal scale only</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Ashworth Scale</td>
<td>✓</td>
<td>✓</td>
<td>Ordinal scale only</td>
<td>?</td>
<td>?</td>
<td>X</td>
<td>Unlikely for this type of intervention</td>
</tr>
<tr>
<td>Log Calender</td>
<td>Researcher generated instrument *</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental Survey</td>
<td>Researcher generated instrument *</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Based on pilot data reported in Appendix B
## Table 4: Researcher Assigned Instrument Utilisation

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Outcome Measure</th>
<th>Diagnostic Measure</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>GAS</td>
<td>✓</td>
<td></td>
<td>Good rigour and utility as an outcome measure - refer to table 2. Recommended for this use (King et al, 1999; Wallen &amp; Doyle, 1996).</td>
</tr>
<tr>
<td>PEDI</td>
<td>✓</td>
<td></td>
<td>Good rigour and utility as an outcome measure for children with cerebral palsy - refer to table 2. Recommended for this use (Ketelaar &amp; Vermeer, 1998; Ziviani &amp; Wright, 1995).</td>
</tr>
<tr>
<td>QUEST</td>
<td>✓</td>
<td></td>
<td>Good rigour and utility as an outcome measure for children with cerebral palsy - refer to table 2. Recommended for this use (Hickey &amp; Ziviani, 1998). This instrument does not strictly measure function but rather movement skills that contribute to functional arm use, such as grasp (DeMatteo et al, 1993). It was included as an outcome measure within this study, as it is considered the best available measure of movement quality (Hickey &amp; Ziviani, 1998), the primary presenting problem in children with cerebral palsy (Erhardt &amp; Merrill, 1998) leading to therapy referral.</td>
</tr>
<tr>
<td>ROM</td>
<td>✓</td>
<td></td>
<td>The ROM instrument has adequate rigour given the test’s construction and intended application (Bear-Lehman &amp; Abreu, 1989, Boone et al, 1978, Copley &amp; Kuipers, 1999, Trombly &amp; Scott, 1989). This instrument was only used for diagnostic purposes within this study, despite its adequate rigour, because it only evaluates the child’s movement impairment not any dimension of function.</td>
</tr>
<tr>
<td>Manual Muscle Test</td>
<td>✓</td>
<td></td>
<td>Poor rigour and utility (Florence et al, 1992) therefore unsuitable as an outcome measure. This instrument measures impairment only.</td>
</tr>
<tr>
<td>Ashworth Scale</td>
<td>✓</td>
<td></td>
<td>Poor rigour, particularly validity (Pandyan et al, 1999), therefore unsuitable as an outcome measure. This instrument measures impairment only.</td>
</tr>
<tr>
<td>Log Calender</td>
<td>✓</td>
<td></td>
<td>Recommended for this use (Law &amp; King, 1993, Schreiber, Effgen &amp; Palisano, 1995)</td>
</tr>
<tr>
<td>Parental Survey</td>
<td>✓</td>
<td></td>
<td>To determine factors which may influence the programs outcome.</td>
</tr>
</tbody>
</table>

The researcher’s rationale in table 3 is represented diagrammatically in figure 6, to demonstrate the relationship between the instrument’s utilisation within this study, and the literature about intervention measurement domains for children with cerebral palsy, summarised in chapter two.
In summary, a large battery of instruments was used, but with two different purposes: (1) diagnosis (Stewart, 2001; Richardson, 2001) and (2) outcome measurement (Law, 1987; Ottenbacher & Cusick, 1990). The ‘diagnostic measures’ were used in the child’s baseline assessment, to inform the home program construction, by identifying impairments that were causing the presenting functional difficulties (Stewart, 2001). The ‘outcome measures’ were used to quantify whether or not children with hemiplegic cerebral palsy, reached desired family and occupational therapist outcomes, in response to a home program. Collectively, the ‘outcome measures’ enabled the researcher to evaluate if change occurred, the direction of the change and the amount of change.

### 3.6 Procedure

The following steps were used in the procedure for this pre-test, post-test, non-experimental design:

1. All volunteer potential participants underwent a 45-minute face-to-face screening assessment, at The Spastic Centre. Screenings included: a parental interview about the child’s medical history and planned interventions; an observation of the child’s unstructured play and administration of the Quality of Upper Extremity Skills Test (QUEST). The combined results were used to determine whether the volunteer met the inclusion criterion, presented in table 1.
Those who met the criteria were enrolled in the study (following informed consent), until the study sample was filled (N=20). Those who did not (N=37) were thanked for their interest.

2. For each participant, administer the battery of instruments, selected to pre-test the dependent variable (reaching desired occupational therapy treatment outcomes), i.e. participant’s baseline; quality and quantity of upper limb movement, muscle strength and spasticity and independence in self care activities were administered.

3. Expose the whole group to the non-experimental treatment (home program).

4. Re-administer the same battery of instruments, to post-test the dependent variable (reaching desired occupational therapy treatment outcomes), to determine the direction and amount of change in score, since baseline.

5. Have the pre and post-test data scored by the blinded assessor.

### 3.7 Statistical Analysis

All data collected for this study was stored in individual hard copy files, which were coded by the investigator and entered into a Statistical Package for the Social Sciences (SPSS) electronic database (SPSS, Chicago, IL, USA). Quantitative analyses of this electronic data were performed to generate the results from this study.

#### 3.7.1 Descriptive Statistics

Descriptive statistics were used to describe single variables. Within the study this procedure involved, calculating descriptive statistics about the participant’s demographics and the range and distribution of study instruments scores. An analysis of the sample attributes was carried out to determine whether the characteristics of the sample were homogeneous. A homogeneous sample was desired to enhance the strength of the study’s internal validity. This was also done to demonstrate that the sample represented the typical population of children with hemiplegic cerebral palsy, for the purpose of enhancing the study’s external validity.
3.7.2 Inferential Statistics

Inferential statistics were used: (1) to compare whether there was any difference in outcomes on selected variables before and after intervention; and (2) to investigate relationships between variables. The purpose of these inferential statistics were to reach conclusions from the study results and to support these conclusions with probability statements (Kuzma, 1992) about the likelihood of these inferences being correct (Rowntree, 1981).

‘Prospective analysis of difference’ testing was the technique used to compare whether or not a statistically significant difference existed between scores on varying instruments in response to the intervention provided (Domholdt, 2000). This statistical methodology enabled the researcher to determine the effectiveness of the home program, by determining whether a significant difference existed between child’s pre and post scores on the specified instruments. The ‘analysis of difference’ statistical tests used in this study were the ‘paired t-test’ and ‘Wilcoxon Ranked Sum Test’. The paired t-test is the analysis of difference parametric test for comparing data sets from a ‘dependent sample’ (Domholdt, 2000). The data collected in this study was dependent, because it was obtained from the same data source but at two different times (Kuzma, 1991). Not all of the data collected met the assumptions for conducting a parametric test and therefore the Wilcoxon Ranked Sum Test was also employed. The Wilcoxon Ranked Sum Test is the non-parametric version of the paired t-test (Domholdt, 2000).

Prospective ‘analysis of relationships’ testing was conducted to determine the interrelationships between the variables (Domholdt, 2000). This enabled the researcher to explore whether or not there was an optimal level of parental home program participation in order to gain a therapeutic impact; how long participation in the home program was required to achieve any therapeutic impact; how intense the participation needed to be; and in what combination to achieve any impact. ‘Analysis of relationships’ was statistically tested, using the Pearson Product Moment correlation analysis technique. The
Pearson Product Moment correlation coefficient is the measure of the strength of the linear relationship between two variables (Kuzma, 1991). This test was employed to determine whether parental participation levels were related to achieving desired home program outcomes, and by what extent.

3.8 Synopsis

This chapter outlined the research design used within this study. Included was a description of the participants, the variables within the study, the instrumentation used to collect the data, the research design of the study, the procedure employed to collect the data and the statistical analysis taken to generate the study findings. The next chapter will present the research findings.
CHAPTER 4: RESULTS

4.1 Introduction

Chapter three detailed the specific methods executed in this intervention study to determine the effectiveness of occupational therapy services delivered via family-centred home programs. It described the research design; the subjects and the variables within the study; the instrumentation used to collect data; the process of data collection; and the statistical procedures for analysing the findings.

The study has so far designed a “best practice” home program for children with cerebral palsy who have upper limb dysfunction, identifying and describing the measurable components and outcomes of these programs (objective one) and this program has been implemented (objective two). Chapter four will now address the three remaining study objectives presented in chapter one:

- **Objective three**: Measure and describe outcomes of the “best practice” home program implemented in the study;

- **Objective four**: Explore the impact of program components on program outcomes: specifically, changes in independence in: activities of daily living; and quality of upper limb movement.

- **Objective five**: Explore parental participation in the home program as a factor possibly related to clinical outcome; specifically the level of parental participation in terms of intensity, frequency and duration.

To achieve objectives three through to five, two stages of data analysis were conducted. Firstly, descriptive statistics were calculated to summarise the data set. It is important to take note that, parental participant attributes were not collected or analysed in this study, as these variables are known not to be good predictors of parental participation in home programs (Gajdosik & Campbell, 1991). Secondly, inferential statistical methods were used to investigate each of the above research objectives. The participant’s change in scores, on the study instruments, from baseline to completion of the study were calculated and compared to their level of participation in a home program. This was done to determine whether any relationship existed between specified program components and program outcomes.
4.2 Descriptive Statistics

Descriptive statistics were used to describe the characteristics of each of the variables within the study and describe the nature of the participants self-selected level of participation in family-centred home programs. The following section will outline the descriptive statistics pertaining to: the sample attributes; their home program goal profiles; their scores on the study instruments; and their level of participation in the home program.

4.2.1 Sample

A total of 20 children with hemiplegic cerebral palsy and their parents from metropolitan and rural New South Wales were recruited to the study. These families came to self-select entry into the study, after learning about the research from a wide range of recruitment ascertainment sources. All 20 participant pairs completed their involvement in the study (100%), there were no drop outs. A description of the participant's attributes will now follow.

4.2.1.1 Age and Sex

Child participants’ ages ranged from 2 years to 7 years, with the mean age being 3.8 years. Seventy percent of child participants were aged two to four years (70%) with the majority being 2 years of age (30%). Sixteen child participants were male (80%) while four were female (20%). Participant’s age data is summarised in Table 4 and Figure 7.
Table 4: Frequency Distribution of Participants by Age

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>6</td>
<td>30.0</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>15.0</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>25.0</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>15.0</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>5.0</td>
</tr>
<tr>
<td>7</td>
<td>2</td>
<td>10.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>20</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Figure 7: Distribution of Children’s Age - Bar Graph

4.2.1.2 Diagnosis and Movement Impairment Severity

*Diagnosis:* All of the child participants enrolled in the study had been diagnosed with cerebral palsy and associated hemiplegia prior to commencement in the study (100%). Eleven had right-sided hemiplegia (55%), while nine had left-sided hemiplegia (45%).
**Co-Morbid Conditions:** In this study, twelve of the child participants had associated diseases or disorders along with their primary diagnosis of cerebral palsy (60%), with conditions such as, epilepsy and asthma being prevalent.

**Joint Movement:** At baseline, all of the child participants presented with normal, full, passive, joint range of movement in their affected elbow; wrist; fingers; and thumb (100%). However, passive range of motion in the forearm was reduced in three (15%) of the participants. Three child participants had a forearm supination contracture (15%), while the other seventeen child participants had full passive joint range of movement in supination (85%). This data is summarised in Table 5.

**Table 5: Child Participant’s Range of Motion (ROM) Status by Upper Limb Joint**

<table>
<thead>
<tr>
<th>ROM Status</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Elbow flexion ROM</strong></td>
<td>Normal ROM 20</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>Contracture 0</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Supination Forearm ROM</strong></td>
<td>Normal ROM 17</td>
<td>75.0</td>
</tr>
<tr>
<td></td>
<td>Contracture 3</td>
<td>15.0</td>
</tr>
<tr>
<td><strong>Wrist flexion ROM</strong></td>
<td>Normal ROM 20</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>Contracture 0</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Finger flexion ROM</strong></td>
<td>Normal ROM 20</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>Contracture 0</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Thumb flexion ROM</strong></td>
<td>Normal ROM 20</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>Contracture 0</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Thumb opponens ROM</strong></td>
<td>Normal ROM 20</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>Contracture 0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

**Muscle Resistance to Movement:** At baseline, all child participants had symptoms of resistance to movement present in two or more of the major muscle groups of their affected arm (100%), which is to be expected given their diagnosis was ‘spastic hemiplegic cerebral palsy’. The specific breakdown of resistance to movement by muscle groups is summarised in Table 6.
The resistance to movement in the affected upper limb muscle groups of the child participants was assessed by the researcher to be of grade two or three, as scored by the Ashworth Scale (100%). These Ashworth scores indicate that all child participants had a mild to moderate degree of resistance to movement (100%), in their affected upper limb. This information was used to inform the selection of treatment approaches and therapeutic activities for the home program.

4.2.1.3 Participant’s Functional Abilities

All twenty of the child participants ambulated independently (100%), with walking being their main form of mobility. Verbal speech was used by all twenty participants as their primary form of communication (100%). All children could effectively communicate their basic physical needs to their parents, including pain responses (100%). Further to this, all twenty child participants could sit without assistance and all of the children were able to independently transfer in and out of a child-size table and chair, to participate in fine motor table-top activities during occupational therapy assessment (100%).
4.2.1.4 History of Participation in Occupational Therapy and Home Programs

In the six months immediately prior to commencement of the study, ten child participants had access to occupational therapy (50%), ten did not have any access to occupational therapy (50%). Sixteen child-parent participant pairs had used a home program in the six-months prior to the study (80%) and ten child participants had worn an upper limb splint for their affected arm (50%). Of the sixteen child-parent participant pairs who had used a home program in the six months prior to commencing the study, the mean number of hours of participation in a home program was estimated by parents to be 2.3 hours per week. Of ten child participants who had worn an upper limb splint for their affected arm in the six months prior to commencing the study, the mean number of hours of splint wearing was estimated by their parents to be 21.3 hours per week.

4.2.1.5 Participant’s Major Life Occupations and Activities

As the ages of child participants ranged within the study, so did their daily life occupations and activities. Six of the study child participants were enrolled at school (30%), while the other fourteen participants were too young to attend (70%). Of the six child participants who were enrolled in school, all six of them attended mainstream school (100%). Of the fourteen child participants too young to attend school, all fourteen of them attended a day-care or pre-school facility at some time during the week (100%). Families identified that these educational facilities provided additional opportunities for practising individualised exercise programs for their children. All twenty parents reported that they provided teachers and teaching assistants with copies of their child’s ‘home program’, which had been designed by the researcher in collaboration with the family at the commencement of the study (100%).

4.2.1.6 Social Context

All child participants lived at home with one or more birth parent (100%). Sixteen child participants lived at home with both birth parents (80%); four child participants lived at home in a single parent family (20%). All child participants attended occupational therapy appointments with one or more parents, and
on some occasions by a grandparent who provided regular part-time care (100%). This enabled capture of parent self-report data from a direct caregiver source during appointments.

4.2.2 Participant's Score Profiles on Study Instruments

The dependent variables for examination in this study were the reaching of desired family and occupational therapy outcomes, such as increased independence in self care activities and improvements in the child’s ability to use their affected upper limb. As discussed in chapter three, these variables were measured using a range of rigorous outcome measure instruments that measured home program goal attainment and functional skills. These instruments included: Goal Attainment Scale (GAS); Pediatric Evaluation of Disability Inventory (PEDI); and Quality of Upper Extremity Skills Test (QUEST). The characteristics of participant's scores on each of these study outcome measure instruments will now be described.

4.2.2.1 Goal Attainment Scaling Participant's Scores

The researcher set up individualised goal attainment scales for each participant, based upon collaborative goal setting with the child’s parent. Each of the mutually agreed upon home program goal areas were built into measurable tasks by the researcher, using the Goal Attainment Scale (GAS) format, discussed in chapter three, section 3.5.1. These goals were designed to quantify the expected progress of each participant in response to six months of home program intervention. A total of 47 goals were developed to reflect the parent’s desired focus areas for home program intervention. Goals were grouped into categories for descriptive analysis, according to the four intervention focus areas identified in chapter two. The chapter two literature review described four intervention focus areas commonly identified by parents and therapist for children with hemiplegic cerebral palsy. These were:

(1) independence in self care activities (N=27; 57.4%) (Case-Smith, 1996; Christiansen, 1991; Copley & Kuipers, 1999; Dunn Klein 1983; Erhardt & Merrill, 1998; Powell, 1985); (2) use of the affected arm (N=20; 42.6%) (Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Dormans & Pellegrino, 1998; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985); (3) prevention of
deformity (N=0)(Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985; Yasukawa, 1990); and (4) independence in motor related school tasks (N=0)(Case-Smith, 1996; Klemm & DuBois, 2001).

Families thus had the highest preference for developing home program goals that worked to bring about improvement in the child’s self care skills, followed by goals that encouraged their child to actively use their affected arm. There was no preference by parents to develop and prioritise goals that addressed improving the child’s motor abilities within school tasks. Home program goals that sought to prevent the development of deformity were intentionally not developed by the researcher as this aspect of intervention was precisely measured using standard range of motion goniometry.

At the completion of six months of home program intervention, participants’ mean level of attainment for goals was calculated for each goal individually. For goal one the mean goal attainment score was +0.10 (SD = 1.83) indicating an average score slightly above the expected outcome. For the second goal the mean goal attainment score was +0.28 (SD = 1.71) also indicating an average score slightly above the expected outcome. For the third goal the mean goal attainment score was –0.37 (SD = 1.69), which was slightly below the expected outcome. A frequency graph of participants’ six-month ‘GAS total weighted t-scores’ is shown in Figure 8. The GAS total weighted t-scores ranged from a lowest score of 30.0, through to a highest score of 69.9. Given that nine participants (45%) scored below the mean and eleven participants (55%) scored above the mean, the mean weighted total t-score for this sample was 50.12 (SD = 12.87). The total t-score mean of this sample 50.12 (SD = 12.87) accurately mirrored the expected t-score of 50.0 (SD = 10) specified by the test developers (Kiresuk & Sherman, 1973).
4.2.2.2 Pediatric Evaluation of Disability Inventory Participant’s Scores

The Pediatric Evaluation of Disability Inventory (PEDI) was administered at baseline with all twenty participants. The PEDI has two domains of measurement for each skill area being assessed. These are (1) the child's ability level, which is referred to as ‘functional skills’; and (2) the amount of assistance given by the parent to complete each task, which is named the ‘care-giver assistance score’. Each of the participant's self-care skills in these two domain areas will now be discussed.

The baseline PEDI self-care ‘functional skills' mean score was 44.15 (SD = 14.15), and increased to a mean of 52.1 (SD = 11.69) after six months of home program intervention. This was a mean change of 7.95 points out of a maximum possible score 73 points for the PEDI self-care ‘functional skills' scale. At baseline the lowest score was 18 ranging through to a highest score of 69. At the six-month post-intervention evaluation, the lowest score was 26 extending through to an uppermost score of 71. The distribution of the participant's functional skills scores at completion of the study is shown in Figure 9.
The median baseline PEDI 'functional skills' score was 48.50 indicating that more than half of the child participants PEDI scores were higher than the mean. The median score at six-months increased to 52.50. The baseline and follow-up PEDI 'functional skills' scores which occurred most frequently were bimodal, meaning two scores occurred with equal frequency. The lowest of the two baseline and follow-up scores was both 34.00. The participant's PEDI 'functional skills' scores, showed large variation about the mean, with the baseline standard deviation being calculated to be 14.15, and slightly narrowing to a standard deviation of 11.69 at the follow-up assessment. The baseline and follow-up PEDI self-care 'functional skills' data were normally distributed about the mean, with the skewness being negative -0.31 and -0.626 respectively.

Figure 9: Distribution of Participant’s Six-Month PEDI 'Functional Skills' Scores

On the second domain of the PEDI instrument, 'care-giver assistance', the mean baseline score was 22.30 (SD = 12.16) increasing to 27.40 (SD = 9.08) at the six-month follow-up assessment. This was a mean change of 5.1 points out of a maximum possible 40 points for the PEDI 'care-giver assistance' scale. The caregiver assistance scale has been constructed in such a way that, an increasing score equates to the child requiring less assistance from their parent to complete functional tasks. At baseline the lowest participant score was 4 ranging through to the maximum possible score of 40. At the six-month post-intervention evaluation, the lowest participant score increased to 13 extending through to a
peak score of 38, which was slightly lower than the maximum score reported at baseline. The participant whose PEDI caregiver assistance score regressed from 40 to 38 over six-months of intervention lived in multiple family homes and thus had multiple primary caregivers who accompanied the child to appointments. This small variation in scores does not categorically equate to deterioration in independence within this subject, but may possibly be explained by different self-ratings of the grandparent caregiver attending the follow-up appointment to the parental caregiver who attended the baseline assessment. Therefore the different scores may reflect different raters self-report opinions or differing performances by the child in differing family home environments.

The distribution of the participant’s ‘care-giver assistance’ scores at completion of the home program is shown in Figure 10. The baseline median PEDI ‘care-giver assistance’ score was 21.50, indicating that more than half of the participants PEDI ‘care-giver assistance’ scores were lower than the mean. This increased to a score of 30.00 at the six-month follow-up assessment. The most frequently occurring baseline PEDI ‘care-giver assistance’ score was a modal score of 7.00, which increased to 30.00 at the follow-up evaluation. The sample’s PEDI ‘care-giver assistance’ score showed large variation about the mean, with the baseline standard deviation being calculated to be 12.16 and lowering to 9.08 at the six-month measurement. The PEDI ‘care-giver assistance’ baseline data was normally distributed about the mean, with the skewness being in the positive direction at a value of 0.15. At the review evaluation the data remained normally distributed, with the skewness reversing to become a value of -.466.
4.2.2.3 Quality of Upper Extremity Skills Test Participant’s Scores

At baseline, a Quality of Upper Extremity Skills Test (QUEST) was administered on all twenty child participants. The QUEST has four domains of measurement, where the domain standard scores are summed and averaged to develop a total score. Within this study, only the first two domain areas, dissociated movement and grasp were assessed, which the test developers describe as psychometrically acceptable. Domain one, ‘dissociated movement’ and domain two, ‘grasp’ standard scores were then converted into a total QUEST score as per instrument guidelines. Participant’s performances on the total QUEST score will now be discussed.

The mean baseline total QUEST score for child participants was 33.83 (SD = 12.20) increasing by 5.98 points over six months to a mean score of 39.81 (SD = 13.29). The maximum possible total QUEST score is 100 points, which indicates normal arm movement. At baseline the lowest total QUEST score was 16.25 ranging through to a highest score of 53.44. At the six-month evaluation, the lowest score was 16.25 extending through to an uppermost score of 64.59. The distribution of the participant’s total QUEST scores at the post-intervention evaluation is shown in Figure 11. The baseline median QUEST
score was 31.99, indicating that more than half of the child participants’ total QUEST scores were lower than the mean. The median QUEST score increased to 43.91 at six-months, which was above the mean. The most frequently occurring baseline and follow-up total QUEST score was a modal score of 16.25. The sample’s total QUEST score showed large variation about the mean; with the standard deviation being calculated to be 12.20 and increasing to 13.29 at the six-month follow up evaluation. Despite the large variation in QUEST scores demonstrated by the standard deviations, all the QUEST data, including the domain data, was distributed normally about the mean, with the skewness being 0.12 at baseline and –0.31 at six-months.

**Figure 11: Distribution of Participant’s Six-Month QUEST Total Scores**

![Distribution of Participant’s Six-Month QUEST Total Scores](image)

4.2.3 Level of Participation in the Home Program

The independent variables or presumed cause of reaching the desired family and occupational therapy outcomes, within this study are home programs. This variable was measured through the use of a self-report log calendar. For each day of the study, families were asked to record, how often they chose to
engage in the home program (frequency), and how long they spent practising therapeutic activities per session (intensity). This enabled home program duration measures to be calculated, that is, the home program frequency multiplied by the intensity. The characteristics of participant's participation level in a home program will now be described by their self-selected frequency, intensity and duration measures.

4.2.4.1 Home Program Participation Frequency

Frequency was the measure of how often families chose to engage in the home program. The mean frequency of home program participation over the duration of the study was 0.90 times per day (SD = 0.11), in other words, less than once a day but approximately 27 times per month. The lowest frequency was 0.63 times per day ranging through to 1.00 (once per day), which was the most commonly self-selected home program frequency or mode. Participant’s home program frequency data is summarised in Figure 12.

Figure 12: Frequency of Home Program Participation per Day

4.2.4.2 Home Program Participation Intensity

Intensity was a measure of how long families spent on the selected therapeutic activities per session. The mean intensity of home program participation over the duration of the study was 14.22 minutes per
session (SD = 8.53), which demonstrates wide variation about the mean. The lowest intensity was 5.00 minutes per session ranging through to an uppermost intensity of 43.33 minutes per session. The most commonly self-selected home program intensity was a modal time of 6.67 minutes. This data was not normally distributed about the mean (skew 2.19), due to high participation rate of one family whose intensity of 43.33 minutes per session was more than three standard deviations above the mean. The distribution of self-selected home program intensity rates per session (in minutes) is summarised in Figure 13.

Figure 13: Intensity of Home Program Participation - Minutes Per Session

4.2.4.3 Home Program Participation Duration

Duration was calculated by multiplying the family’s home program frequency by their self-selected intensity. The mean duration of home program participation over the six-months of the study was 12.95 (SD = 8.03) minutes per day, which like the intensity data also demonstrates wide variation about the mean. The lowest duration was 4.18 minutes ranging through to an uppermost intensity of 40.24 minutes. The mode duration was 4.18 minutes with the median being 12.95 minutes per day. This data was not normally distributed about the mean (skew 2.12), which is not surprising given the skewed intensity data reported above in the intensity results - section 4.2.4.2. The high intensity rate of one
family at 43.33 minutes per session was more than three standard deviations above the mean, which naturally skewed the distribution of the duration time. The distribution of home program duration time is summarised in Figure 14.

Figure 14: Home Program Duration in Minutes Per Day

4.3 Inferential Statistics

Inferential statistics were used in this study for two purposes. Firstly, to determine whether a significant difference existed between child’s pre and post scores on the specified instruments, and secondly, to determine to what extent study variables were related to each other (Dumholdt, 2000). These analyses will now be described.

4.3.1 Analysis of Difference Statistics

‘Analysis of difference’ testing was used to determine the effectiveness of the home program, by determining whether a significant difference existed between child’s pre and post scores on the specified instruments. A significant difference existed between child’s pre and post scores was
interpreted to mean the child made a significant improvement in the variable measured by the instrument, over the study’s duration.

**4.3.1.1 Change in Participants Goal Attainment Scale Scores**

To determine whether a significant difference existed between the Goal Attainment Scale (GAS) scores before and after the home program was implemented, the Wilcoxon Signed Rank Test was used (Domholdt, 2000; Fethney, 2002). The Wilcoxon Signed Rank Test compared the difference between the ‘before and after’ GAS total weighted score means, to detect whether or not equal variance existed (Fethney, 2002). This test was selected because the data being tested was from a dependent sample, i.e. before and after measurements on the same sample (Domholdt, 2000). In addition, the GAS baseline data did not meet all three assumptions for a parametric paired t-test to be conducted. These assumptions being: (1) the subjects were randomly selected from a normally distributed population, which was violated because the sample’s baseline total t-scores were not-normally distributed as demonstrated by a skew value greater than one (1.073); (2) population variance was homogeneous; and (3) the GAS scores were ‘ratio’ data. As the baseline GAS total weighted scores data were not-normally distributed, a requirement of a parametric test, the non-parametric equivalent test, the Wilcoxon Signed Rank Test was therefore used.

Within this study, a difference between means was considered significant, when p < 0.05. That is, the researcher considered a significant difference between a pre and post scores to exist, when p < 0.05, knowing that there was a 5% chance of result being caused by chance rather than the variable being examined.

The mean total GAS weighted t-score before intervention was 29.86 (SD = 8.21) and six months after the home program was implemented increased to 50.12 (SD = 12.87), an average change of 20.26 points. Analysis of difference, using the non-parametric Wilcoxon Signed Rank Test, indicted that the 20.26-point change in mean scores over the six-month period of home program intervention was statistically significant (p < 0.000). This data is summarised in Figure 15.
4.3.1.2 Change in Participants Pediatric Evaluation of Disability Inventory Scores

The PEDI has two domains of measurement, the child's ability level, which is referred to as 'functional skills'; and the amount of assistance given by the parent to complete each task, which is called the 'care-giver assistance score'. The analysis of each of these domains will now be described.

To determine whether a significant difference existed between the Pediatric Evaluation of Disability Inventory (PEDI) scores before and after the home program was implemented, the paired t-test was used (Domholdt, 2000; Fethney, 2002). The parametric paired t-test was the test of choice for analysing the PEDI data, because the data being tested was from a dependent sample and data met all three assumptions for a t-test (Domholdt, 2000). These assumptions being: (1) All the PEDI data was normally distributed as demonstrated by skew values less than one, baseline functional skills skew (-0.311), six-month functional skills skew (-0.626), baseline caregiver assistance skew (.145), six-month caregiver assistance skew (-.466), indicating that all the PEDI data was randomly selected from a normally distributed population; (2) the PEDI population variance was homogeneous because of the
pre-post methodology adopted; (3) the PEDI data was a 'ratio' level of measurement, that is the PEDI functional skills and caregiver assistance data exhibited all three components of a real-number system: the data was ‘ordered’, the higher the number, the greater the characteristic being measured; the data had ‘distance’, the magnitude of the difference between successive numbers was equal; and the data had ‘origin’ that is zero represented an absence of the measured quality (Domholdt, 2000). Within this study, a difference between PEDI before and after functional skills and caregiver assistance means was considered significant, when p<0.05. That is, the researcher accepted that there was a 5 in 100 chance of the result being caused by chance rather than the variable being examined.

At baseline, the mean PEDI functional skills score was 44.15 (SD = 14.15) and six months after the home program was implemented increased to 52.05 (SD = 11.69). Analysis of difference, using the paired t-test, indicted that the change of 7.95 points in mean scores over the six-month intervention period was statistically significant (p < 0.002). Figure 16 summarises the change in mean functional skills scores. This change seen in these scores, over the period of home program intervention, indicates a significant increase in the participant’s self-care functional abilities.

**Figure 16: Change in PEDI Functional Skills Score Means**
For this sample, the mean PEDI caregiver assistance score at baseline was 22.30 (SD = 12.16) and increased to a mean score of 27.40 (SD = 9.08), following six-months of home program implementation. The paired t-test was used to analyse the difference between these two means, as per the statistical justification given above. This analysis indicted that the change in PEDI caregiver assistance scores mean scores over the six month period of home program intervention, was also statistically significant (p < 0.003). The difference in mean scores over the six-month period is summarised in Figure 17. This result indicates that over time, child participant's required less assistance form their parents to complete self-care tasks.

**Figure 17: Change in PEDI Caregiver Assistance Score Means**

The paired t-test was used to determine whether a significant difference existed between the participant’s pre and post Quality of Upper Extremity Skills Test (QUEST) total scores (Domholdt, 2000; Fethney, 2002). The paired t-test was applied because dependent sample data was being tested and the t-test assumptions were met (Domholdt, 2000). QUEST total score data met the t-test assumptions.
because: (1) it was normally distributed, as demonstrated by the baseline 0.12 skew value and follow-up skew value of −0.310 indicating the data was randomly selected from a normally distributed population; (2) the variance was homogeneous; and (3) QUEST total scores were ‘ratio’ data, that is data that resembled a real-number system (Domholdt, 2000). Within this study, a difference between QUEST total score before and after means was considered significant, when \( p < 0.05 \). That is, the researcher accepted that there was a 5% chance of result being caused by chance rather than the variable being examined.

At baseline, the mean QUEST total score was 33.82 (SD = 12.19) and six months after the home program was implemented increased to 39.81 (SD = 13.29). Analysis of difference, using the paired t-test, indicted that the change of 5.98 points in mean scores over the six-month intervention period was statistically significant (\( p < 0.004 \)). Figure 18 summarises the change in mean QUEST total scores and also shows the change in QUEST domain score, which are the basis of the total score. The change seen in total QUEST scores, over the period of home program intervention indicates a significant improvement in the participant's quality of upper limb movement.

Figure 18: Change in QUEST Total Score Means
4.3.2 Analysis of Relationship Statistics

‘Analysis of relationships’ testing was used to determine whether parental participation levels in home programs were related to, and to what extent the achievement of desired home program outcomes. In order to compare home program participation levels with other variables, the home program duration data was used. As the duration data was calculated from the home program frequency and intensity data it therefore provided an aggregate of home program participation. Within this study the strength of the relationship was described according to Munro’s (1997) strength of correlation coefficients, shown in Table 7.

Table 7: Munro’s Strength of Correlation Coefficients

<table>
<thead>
<tr>
<th>Correlation Coefficient</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>.00 - .25</td>
<td>Little, if any correlation</td>
</tr>
<tr>
<td>.26 - .49</td>
<td>Low correlation</td>
</tr>
<tr>
<td>.50 - .69</td>
<td>Moderate correlation</td>
</tr>
<tr>
<td>.70 - .89</td>
<td>High correlation</td>
</tr>
<tr>
<td>.90 - 1.00</td>
<td>Very high correlation</td>
</tr>
</tbody>
</table>

4.3.2.1 Relationship between Home Program Participation Level and Study Instruments Scores

To determine whether a relationship existed between the parental home program participation level (duration) and the outcome measures, a series of correlation calculations was performed. The correlation calculation enabled the researcher to describe the strength of the linear relationship between the variables (Ott & Longnecker, 2001) but not determine the cause (Domholdt, 2000). The home program duration participation data did not meet all the assumptions for a parametric correlation analysis. That is, the relationships if any between the variables would be linear; the data was collected in pairs; the data was interval or ratio; but the home program duration data was normally distributed as outlined in sections 4.2.1.3 (Domholdt, 2000; Fethney, 2002). Non-parametric correlation analyses were therefore conducted using the Spearman’s Rank Order Correlation Coefficient.
Coefficients are mathematical expressions that describe the magnitude and direction of the relationship between two variables, a Spearman’s Rank Order Correlation Coefficient is expressed as ‘rho’ notated by ρ (Domholdt, 2000).

There was little if any linear correlation between the participant’s home program participation level (duration) and the child’s final Goal Attainment Scale (GAS) scores (ρ = -0.07 little or no correlation); Pediatric Evaluation of Disability Inventory (PEDI) functional skills scores (ρ = -0.22 little or no correlation); Pediatric Evaluation of Disability Inventory (PEDI) caregiver assistance scores (ρ = -0.14 little or no correlation); and Quality Of Upper Extremity Skills Test (QUEST) score (ρ = -0.36 low correlation).

Outlier data is known to have a marked effect on the accuracy of correlation coefficients (Kuzma, 1992) and therefore should be removed prior to correlation calculations (Fethney, 2002). In this data set the home program participation data of one participant was considered to be an outlier, as this participant’s home program participation rate was more than 3 standard deviations above the mean, as shown previously in figure 14. This participant’s data was therefore removed from the data set to enable more accurate recalculation of the correlation between parental home program duration and the child’s final Goal Attainment Scale (GAS) scores; Pediatric Evaluation of Disability Inventory (PEDI) scores; and Quality Of Upper Extremity Skills Test (QUEST) scores (N=19). When this participant’s data was removed from the home program duration data, the duration data become normally distributed (skew = 0.21), with a narrowed mean (11.51) and standard deviation (SD=4.95) see Figure 19.
As the duration data was now normally distributed, the correlations between the home program duration and the child’s final Goal Attainment Scale (GAS) scores; Pediatric Evaluation of Disability Inventory (PEDI) scores; and Quality Of Upper Extremity Skills Test (QUEST) scores could be calculated using the preferred parametric test, the Pearson Product Moment (Domholdt, 2000). The Pearson Product Moment is notated by a correlation coefficient of $r$ (Domholdt, 2000).

With the outlying data removed, reducing the sample size to 19 participants, there remained little if any linear correlation between the participant’s home program participation level (duration) and the child’s final Goal Attainment Scale (GAS) scores ($r = 0.00$ little or no correlation); Pediatric Evaluation of Disability Inventory (PEDI) functional skills domain scores ($r = -0.10$ little or no correlation); Pediatric Evaluation of Disability Inventory (PEDI) caregiver assistance domain scores ($r = 0.01$ little or no correlation); and Quality Of Upper Extremity Skills Test (QUEST) total score ($r = -0.38$ low correlation). These results indicate that there was no relationship between the amount of time the participants spent on home program intervention and the child’s outcome.
4.3.2.2 Relationship between Participant’s Age and Study Instrument Scores

To determine whether a relationship existed between the participant’s age and the child’s final Goal Attainment Scale (GAS) scores; Pediatric Evaluation of Disability Inventory (PEDI) scores; and Quality of Upper Extremity Skills Test (QUEST) score, an additional series of correlation calculations was performed. The correlation coefficients calculated were used to describe the strength of the linear relationship between the variables (Kuzmar, 1992) but not determine the cause (Domholdt, 2000). The participant’s age and the child’s final Goal Attainment Scale (GAS) scores; Pediatric Evaluation of Disability Inventory (PEDI) scores; and Quality of Upper Extremity Skills Test (QUEST) score data met all the assumptions for a parametric correlation analysis. That is, the relationships if any between the two variables would be linear; the data was collected in pairs; the data was interval or ratio; and the data was normally distributed (Domholdt, 2000; Fethney, 2002). The Pearson Product Moment parametric test was therefore calculated with the results notated by a correlation coefficient of $r$ (Domholdt, 2000). The strength of any relationship reported, was described according to Munro’s (1997) strength of correlation coefficients, as shown previously in Table 7.

A moderate linear relationship existed between the child’s age and function as measured by the Pediatric Evaluation of Disability Inventory (PEDI) functional skills scores ($r = 0.67$), which was significant at the 0.01 level and the Pediatric Evaluation of Disability Inventory (PEDI) caregiver scores ($r = 0.67$), which was also significant at the 0.01 level. This correlation indicated that (1) as the child’s age increased so did their functional ability and (2) that as the child’s age increased their need for parental assistance decreased, indicated by increasing PEDI caregiver assistance scores.

Little if any linear correlation existed between the child’s age and their final Goal Attainment Scale (GAS) scores ($r = -0.12$) and Quality of Upper Extremity Skills Test (QUEST) scores ($r = 0.05$). This lack of relationship between these variables was to be expected, as both of these instruments are not based on normative values. The QUEST is a criterion-referenced measure (DeMatteo et al, 1993) and GAS is an individualised measure of change (Kiresuk & Sherman, 1968).
4.4 Synopsis

This chapter outlined the research findings from this study. Included was a description of the sample’s attributes; the participant’s score profiles on the study instruments; the types of home program goals developed; the significant change in predicant’s scores in response to the home program intervention; and the lack of relationship between home program participation duration and the child’s outcome. The next chapter will discuss the results presented within this chapter and make recommendations for education, policy, practice and research.
CHAPTER FIVE: DISCUSSION

5.1 Introduction
Occupational therapy home programs are considered essential and ‘best practice’ for children with cerebral palsy in order for them to attain desired health outcomes. Yet little is known about the effectiveness of this intervention approach. It is therefore necessary that the effectiveness of such a standard intervention is established, along with identification of program characteristics, which lead to successful outcomes. The aims and objectives of the study, presented in chapter one, were therefore designed to address this significant issue for clinical practice. This rigorous evaluation of home program effectiveness was supported in chapter two by the gap identified in the literature. Chapter three outlined the methods used to investigate the issue of home program effectiveness. Chapter four detailed the results of the enquiry by describing the sample attributes and participant participation and inferential analysis of participant change. This final chapter will explore the findings by discussing the relationships amongst study outcomes, research objectives and the literature. A practical outcome of this discussion is to describe a new evidence base to better inform families and clinicians about the potential usefulness of home programs. The chapter will also outline recommendations for education, policy, practice, and research arising from the findings of this study.

5.2 Summary of Key Findings
This study identified key findings. The statistically significant difference between the participant’s pre and post scores on all three outcome measure instruments: Goal Attainment Scale (GAS) total t-scores ($p < 0.000$); Pediatric Evaluation of Disability Inventory (PEDI) functional skills scores ($p<0.002$); PEDI caregiver assistance scores ($p<0.003$); and Quality of Upper Extremity Skills Test (QUEST) total scores ($p<0.004$), suggests that the ‘best practice’ home program carried out within this study was highly effective.
In summary, these key findings indicate that home program intervention for children with hemiplegic cerebral palsy, significantly advances the achievement of meaningful family & therapy goals; improvement in functional ability; reduction in care requirements and improvement in quality of upper limb movement.

The key findings of the study are that:

a) Inappropriate, inadequate and incomplete occupational therapy clinical services had been provided to children with cerebral palsy prior to their enrolment in the study even though they had received services from paediatric therapists.

b) Families of children with hemiplegic cerebral palsy in this study generated home program goals that focussed on (i) developing their child’s self-care skills and (ii) the use of their affected arm.

c) Families do carry out home programs when clinicians adopt a protocol based ‘best practice’ home program approach as presented in this study.

d) With six months of home program intervention, children with hemiplegic cerebral palsy not only achieve their family’s goals, but also demonstrate clinical change in self-care skills and the ability to use their affected arm. These outcomes all can be detected with standardised instruments: Goal Attainment Scale (GAS); Pediatric Evaluation of Disability Inventory (PEDI); and Quality of Upper Extremity Skills Test (QUEST).

e) No relationship exists between the intensity of home program participation and the rate of the achievement of health outcomes. Any level of participation greater than five minutes per day is worthwhile and leads to measurable change and improvement in function and upper limb use.

f) These findings quantify the impact of family’s input into intervention outcomes and the effectiveness of the ‘best practice’ home program approach.

These key research findings and the implications of this study for the utilisation of home programs will now be discussed in detail.
5.3 Findings in Detail

This section will explore the findings from descriptive and inferential data analysis in the context relevant literature.

5.3.1 Sample

In clinical research that focuses on children with cerebral palsy, it is accepted that sample variation is important to control, as results are meaningless unless children have comparable motor abilities (Miller & Bachrach, 1995). In this study careful attention was therefore paid to recruiting a ‘like’ sample. The researcher attentively controlled the potential sample variation by ensuring through screening that participant’s had similar personal attributes and motor abilities.

For instance, ‘age’ is naturally a significant variable when evaluating clinical change over time with children due to the contribution of developmental maturation. This study developed strict inclusion criteria that defined an acceptable alike age range for potential participants. Child participants ranged from 2 years to 7 years old, as per the inclusion criteria, with the mean age being 3.8 years. The age of participants was unequally spread across the target age group, with 30% of participants being 2 years old. A limitation arising from this is that the results of this study are less specifically focussed on older aged children. Another potential limitation is that study results are skewed towards more accelerated changes as younger children tend to make more substantial improvements.

The sex of participants could also potentially affect the outcome of any study and therefore equal distribution of sexes is generally desired. Males, however, more commonly than females have cerebral palsy (Stanley, Blair & Alberman, 2000). In this study, sixteen of this sample’s participants were male (80%) while four were female (20%), which reflects the naturally occurring distribution of sexes in the cerebral palsy population. The study findings are thus population relevant.
In addition to age and sex, the specific nature of diagnosis of cerebral palsy is also important. The motor and functional abilities of children with hemiplegia are distinctively different to children with other types of cerebral palsy, where functional mobility and independence are more affected (Stanton, 1992). All of the children in the sample had the diagnosis of ‘spastic hemiplegic cerebral palsy’, which was achieved through narrow inclusion and exclusion criteria. The stringent adherence to homogeneity of cerebral palsy type was considered important as spastic hemiplegia is the form of the condition, where normal academic, employment, and independent living potential is anticipated (Bleck, 1987; Molnar & Gordon, 1976; Stanton, 1992). Hemiplegic cerebral palsy has two types: right sided and left sided, with the right-sided presentation being more common (Stanley, Blair & Alberman, 2000). In this sample, eleven children had right-sided hemiplegia (55%), while nine had left-sided hemiplegia (45%) which is the standard left/right distribution amongst the hemiplegic cerebral palsy population (Stanley, Blair & Alberman, 2000). This study’s sample was therefore precisely homogeneous with respect to motor ability.

The prevalence of co-morbid conditions with cerebral palsy is also important to consider as the presence of these common conditions is known to impact on movement ability. The presence of epilepsy, which is commonly associated with cerebral palsy (Erhardt & Merrill, 1998; Stanley, Blair & Alberman, 2000), was considered as a variable. In this study, twelve participants had associated conditions including epilepsy (60%) making the sample alike and therefore representative of the typical hemiplegic cerebral palsy population.

A common therapy aim for children with cerebral palsy is maintain range of motion in order to sustain a child’s movement and functional ability (Bleck, 1987; Boehme, 1988; Copley & Kuipers, 1999). Children with the spastic type of cerebral palsy are known to be at risk of developing joint contractures, which affects movement ability and motor potential (Copley & Kuipers, 1999). It is therefore important when studying children with spastic cerebral palsy to consider the presence of contracture as a variable affecting outcome. Three participants had a forearm supination contracture (15%) secondary to spasticity, at the commencement of the study. The presence of ‘pronator’ muscles shortening, leading
to supination contracture seen in these three participants, is consistent with the known pattern of
contracture development in hemiplegia. The pronator muscles have been identified as the most likely to
shorten first, causing upper limb supination contracture (Boyd & Graham, 1997). The presence of
contracture in three participants is thus representative of the typical paediatric hemiplegic cerebral palsy
population.

Untreated muscle spasticity in cerebral palsy leads to contracture, resulting in functional deficits (Boyd &
Graham, 1997). The measurement of spasticity as a result is thus fundamental to the identification of
risk factors for contracture (Copley & Kuipers, 1999). At baseline assessment, resistance to movement,
a feature of muscle spasticity, was assessed as “present or not”, in each of the child’s upper limb
muscle groups. The presence and severity of resistance to movement was identified using the Ashworth
Scale. The validity flaws of the Ashworth instrument have been discussed earlier in chapter three, and
are a limitation to the interpretation of the following findings. All child participants had symptoms of
resistance to movement present in two or more of the major muscle groups of their affected arm
(100%). These were assessed by the researcher to be of Ashworth grade two or three, indicating a mild
to moderate degree of resistance to movement (100%). This finding was expected, as all participants
had the diagnosis of ‘spastic hemiplegic cerebral palsy’. The pattern of resistance to movement seen in
the children’s elbow flexors; pronators; wrist and finger flexors; and thumb muscles is consistent with
the known pattern of upper limb posturing in hemiplegic cerebral palsy (Bleck, 1987; Copley & Kuipers,
1999). Therefore the sample group’s upper limb posture and relative risk of contracture development
was representative of the typical hemiplegic cerebral palsy population.

Cerebral palsy has many types, even within one type the resultant level of disability can vary greatly
(Bleck, 1987). It was therefore important to control for disability severity within the sample to ensure
that participants were of like ability. Children with spastic hemiplegia usually independently ambulate
and communicate using verbal speech (Bleck, 1987). In this study, all twenty participants could
independently ambulate (100%) and use verbal speech as their primary form of communication (100%).
All participants could also sit independently and transfer in and out of a regular chair and table (100%).
The high degree of physical functioning of the sample group was therefore consistent with the known independence levels of the hemiplegic cerebral palsy population.

In summary, although the sample was assembled through volunteers, the sample was representative of children with 'spastic hemiplegic cerebral palsy', particularly with respect to their motor ability level when sample attributes are considered in the context of the literature. It is therefore likely that the sample represents children who typically access occupational therapy services and use home programs. These sample attributes in the context of literature, contribute positively to the external validity of study findings.

5.3.2 Parental Participation in Home Programs

Parental participation in the home program was measured through the use of a self-report log calendar. The log calendar raw data permitted calculation of three participation variables: frequency; intensity; and duration. *Frequency* was the measure of how often families chose to engage in the home program. The mean frequency of home program participation over the duration of the study was 0.90 times per day (SD = 0.11). *Intensity* was a measure of how long families spent on the selected therapeutic activities per session. The average intensity of home program participation was 14.22 minutes per session (SD = 8.53), with high variability from one family to the next. *Duration* was calculated by multiplying the family’s home program *frequency* by their self-selected *intensity*. The average duration of home program participation over the six-months of the study was 12.95 minutes per day (SD = 8.03). The sample’s mean *duration* thus demonstrated diligent home program follow-through by the parents involved in this study.

Parental participation rates in home therapy programs are of interest to occupational therapists because there is a belief that low follow-through will lead to less desirable health outcomes (Molineux, 1993). Previous home program ‘compliance’ research indicated high variability in the self-selected rate of home program participation, from 67-73% compliance (Gajdosik & Campbell, 1991) to 77.5%-80.3%
compliance (Schreiber et al, 1995). In contrast, two qualitative studies interestingly reported that mothers choose not to implement home programs at all because they were too difficult and too time-consuming to perform (Hinojosa & Anderson, 1991; Hinojosa, 1990). Parents also perceived they lacked the necessary confidence to carry-out programs (Hinojosa & Anderson, 1991; Hinojosa, 1990). As noted in chapter two the literature describes a spectrum of observations about likely home program participation by families. The lack of synergy between quantitative and qualitative research findings does not provide treating therapists with any clear expectations of anticipated or desirable parental participation. The parental participation findings of this study can therefore be considered ‘high’. This makes an important new contribution to the home program literature, because the protocol based program used in this study reflects current thinking about family involvement and family preferences and the likely impact on levels of parental program participation.

In this study the average participation rate was 12.95 minutes per day (SD = 8.03). It may be that the intensity of participation is attributable to the way in which the home programs were constructed, i.e. the ‘best-practice approach’. The ‘best-practice approach’, developed in chapter two by the researcher, is based on factors identified in the literature known to positively influence parental home program participation levels. Examples of key factors identified in the literature included (Gajdosik & Campbell, 1991; Hinojosa & Anderson, 1991; Molineux, 1993; Schreiber et al, 1995):

- frequent overseeing of the home program by the therapist;
- provision of parental training on how to identify developmental changes in their child;
- structuring opportunities for the parent to observe the therapist ‘treating’ the child;
- choosing ‘functional’ and practical home program activities which fitted into the family’s routine;
- providing positive support and feedback about parent generated solutions and actions;
- demonstrating a genuine interest in the child and the parent.

The ‘best practice’ home program approach described in chapter two is based on family-centred principles and thus encourages parental input and participation. Not only does describing this approach make a new important contribution it also the first time a family-centred, evidence-based practice,
protocol based home program has been presented. It is pleasing to note that the assumption of family-centred practice in increasing parental participation was verified.

This research therefore indicates that when the factors identified in the literature for positively influencing parental follow-through with home programs are implemented, high home program participation rates are elicited. This is an important new finding and extends the home program evidence base. Much of the previous occupational therapy literature cites low pharmacology type ‘compliance’ behaviour as ‘proof’ that parents do not participate in home programs (Law & King, 1993; Mayo 1981; Molineux, 1993). The findings of this home program study indicate that pharmacology type compliance is not an accurate predictor of home program participation. This study has found that when an ‘optimal’ therapeutic context for home program participation is established, (i.e. use of the ‘best practice’ home program approach presented in this study), parents of children with cerebral palsy carryout home programs by choice and with high frequency, intensity and duration. The previous gap existing in literature about likely home program participation rates has been filled by this study. This means that occupational therapists using home programs for children with cerebral palsy can now discontinue using pharmacology type compliance literature as a basis for program adherence and calculate predictive estimates of home program participation based on occupational therapy home program participation findings.

5.3.3 Inadequacies of Occupational Therapy Services

A factor known to influence home program participation is the family's perception of the perceived importance and efficacy of the home program treatment (Molineux, 1993; Robinson, 1987). Hence this study sought to measure the effectiveness of home programs, when standard, effective, ‘evidenced-based’ occupational therapy interventions were carried out at home. To gain an understanding of the family's perception of the perceived importance of the occupational therapy interventions to be offered in this study an intervention history was taken at baseline. This history included: (a) parental self-report on their home program participation rate over the six-months prior to commencing the study; and (b)
their uptake of known effective occupational therapy interventions. The findings of this history in relation to such interventions as splints and casts were somewhat alarming as is now described in the context of literature.

The history taking exercise indicated that for the most part children with hemiplegic cerebral palsy in this study did not have access to standard efficacious treatments prior to study intervention, such as splints and casts. It appears that inappropriate, inadequate and incomplete therapy services may have been provided, even though children with cerebral palsy were receiving services from paediatric occupational therapists and physiotherapists. While there are many examples that could be given for the study participants this claim of inadequate, inappropriate and incomplete therapy will now be verified by an in-depth exploration of one example of a known efficacious treatment not being provided to the study cohort by their regular treating therapists (both occupational therapists and physiotherapists).

All of the children in this study had muscle resistance present in the pronator muscle group (100%), which is to be expected in children with hemiplegic cerebral palsy (Boyd & Graham, 1997). Further to this, all of the children had some ability to actively supinate their forearm but could not achieve not full active range of motion (100%), due to the presence of pronator muscle spasticity; supinator muscle weakness; and motor control impairments. It is recommended that treatment of this cluster of symptoms in a child with cerebral palsy includes the prescription of the ‘TASS splint’ (Casey & Kratz, 1988; Reid, 1992) (also known as a ‘supination splint’). All of the children in the study met the clinical indicators for prescription of the ‘TASS splint’ (100%), despite this only one of the children had ever been prescribed a supination splint by their therapist (5%). This prescription rate is extremely low given presenting clinical indicators in the study sample. This finding is however not surprising as this type of clinician prescribing practice has also been reported in a national Canadian study (Reid, 1992). Splint prescription was infrequent (Reid, 1992), with 84% of Canadian respondents never having used the “TASS” splint, with the major reason cited as being a lack of familiarity with the splint. Other less
common reasons given were: lack of child/parent compliance; difficulty fitting the splint; and poor cosmetic appeal (Reid, 1992).

In this study, when families were offered the prescription of an appropriate splint at the commencement of the study; the entire group of parents elected for their children to receive the treatment (100%). This suggests the probable reason for the lack of splint wearing in this cohort was not parents declining splinting intervention or discomfort experienced by the child but more unfavourably was due to a lack of access to the splint from their therapist. This was confirmed by the investigator asking parents if they had ever been offered such a splint by their therapist.

In addition to the supination splint example which applied to all but one participants, another stark example confirms the inadequate, inappropriate or incomplete service. Three of the cohort of children had a supination contracture present (15%), for which the recommended treatment is casting (Copley & Kuipers, 1999). The efficacy of casting intervention to reduce contracture is well supported by research evidence (Copley et al, 1996; Cruickshank & O’Neill, 1990; King, 1982; Kitson, 1998; Law & King, 1993; Smith & Harris, 1985; Tona & Schneck, 1993; Yasukawa, 1990; Yasukawa & Hill, 1988). None of these three children however, had been previously offered casting intervention by their therapist (100%). In addition the children’s parents were not only unaware of the potential benefits of casting intervention, they were also unaware their child even had a contracture present. When these families were offered casting treatment at the commencement of the study, all elected for their children to receive the treatment. The lack of previous uptake of casting was thus not due to refusal of casting intervention but due to lack of access to the intervention. The possible explanations for the lack of appropriate intervention being provided are numerous, all of which should be of great concern to paediatric therapists, service providers, families and educators. Possible explanations include:

(1) The child’s range of motion (ROM) had not been regularly assessed by their occupational or physiotherapist and therefore the treating therapist was unaware of the presence of a contracture. Even so, regular ROM assessment is recommended as part of a comprehensive evaluation for children with cerebral palsy (Bleck, 1987); or
(2) The presence of a contracture was not of concern or an intervention priority to the child’s occupational or physiotherapist. Yet maintenance of ROM and prevention of contractures are frequently cited as an intervention priority for this group of children (Bleck, 1987; Boheme, 1988; Chapparo & Ranka, 1997; Copley & Kuipers, 1999; Feldman 1990; Erhardt & Merrill, 1998; Powell, 1985; Yasukawa, 1990); or

(3) The occupational or physiotherapist was unaware of efficacious treatment options for the reduction of contracture. Nevertheless, this area of clinical practice has been the focus of much therapy research, which has proven the benefits of casting treatment (Copley et al, 1996; Cruickshank & O’Neill, 1990; King, 1982; Kitson, 1998; Law & King, 1993; Smith & Harris, 1985; Tona & Schneck, 1993; Yasukawa, 1990; Yasukawa & Hill, 1988); or

(4) The occupational or physiotherapist was unable to provide casting treatment for the reduction of contracture, due to a lack of skill, resources, time, cost etc. It is possible that the explanation for low usage of upper limb casting intervention is similar to the low prescription rates for upper limb splints. The poor uptake of splinting interventions, amongst Canadian occupational therapists for children with cerebral palsy, is attributed to a lack of familiarity with the splints; lack of available resources (time and materials); and a lack of clinical experience (Reid, 1992); or

(5) The ROM assessment results had not been conveyed to the parents, nor had the potential adverse implications of this contracture been explained. Such a professional stance would be in direct conflict with a family-centred approach, where parents are viewed as ‘knowing and wanting what is best for their child’ (Rosenbaum et al, 1998). When service providers respect this premise, parental decision-making about the child’s care is encouraged and is supported by appropriate provision of information to enlighten decision making (Rosenbaum et al, 1998).

As the sample was assembled from a variety of sources and thus a variety of health providers, it was not possible within the scope of this study for the researcher to determine which of these explanations may have been at work. Literature strongly supports the ‘lack of skill’ mechanism outlined in point number four as a possibility but this type of data was not collected for analysis.
5.3.4 Priority Goal Areas for Home Programs

Parent participants in this study developed home program goals and therapeutic activities analogous to the intervention ‘focus areas’ for children with hemiplegic cerebral palsy described in literature. These focus areas being,

1. *Independence in self care activities* (N=27; 57.4%) (Case-Smith, 1996; Christiansen, 1991; Copley & Kuipers, 1999; Dunn Klein 1983; Erhardt & Merrill, 1998; Powell, 1985);

2. *Use of the affected arm* (N=20; 42.6%) (Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Dormans & Pellegrino, 1998; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985);

Interestingly, two other areas described in literature were not selected by any participants as home program focus areas, these are:

3. *Prevention of deformity* (N=0) (Bleck, 1987; Boehme, 1988; Chapparo & Ranka 1997; Copley & Kuipers; 1999; Feldman, 1990; Erhardt & Merrill, 1998; Powell, 1985; Yasukawa, 1990); and


This finding demonstrates that families had the highest preference for developing home program goals that worked on enhancing their child’s self-care skills and the use of their affected arm. The lack of preference for developing motor related school task goals is not surprising, given that 70% of the sample were only pre-school aged. Families commonly discussed with the researcher ‘concerns’ about their child developing a deformity in their upper limb. The standard efficacious occupational therapy intervention for this goal is the prescription of upper limb splints, which were made available to all child study participants where clinically indicated. This intervention was provided or discussed prior to the collaborative goal setting. The low parental preference in identifying explicit ‘deformity prevention’ as a priority goal area was therefore not surprising. It is likely that parents believed that deformity prevention would be adequately addressed by the prescription of upper limb splints – the standard intervention approach. The commonly held parental assumption that active use of the affected arm will help to prevent the development of deformity may also have influenced goal selection and lack of deformity.
prevention as a goal focus. If this assumption was present, it may explain why families showed a higher preference for identifying and prioritising goals that sought to increase the child’s active use of their affected arm.

5.3.5 Home Program Effectiveness

The ‘best practice’ home program implemented in this study proved to be effective in the following areas:

(1) achieving goals meaningful to the family (Goal Attainment Scale (GAS) \( p<0.000 \));

(2) improving self-care skills (Pediatric Evaluation of Disability Inventory (PEDI) functional skills \( p<0.002 \));

(3) reducing the amount of parental assistance required to carry out self-care tasks (PEDI caregiver assistance \( p<0.003 \)); and

(4) improving the quality of upper limb movement (Quality of Upper Extremity Skills Test (QUEST) \( p<0.004 \)).

Improvements in all of these three domains is not only statistically significant but also meaningful and important, because these ‘focus areas’ have been identified by parents and therapists as critical for children with hemiplegic cerebral palsy (Bleck, 1987; Boehme, 1988; Case-Smith, 1996; Chapparo & Ranka 1997; Christiansen, 1991; Copley & Kuipers, 1999; Dormans & Pellegrino, 1998; Dunn Klein 1983; Erhardt & Merrill, 1998; Powell, 1985; Feldman, 1990; Klemm & DuBois, 2001; Yasukawa, 1990).

The results of this study therefore indicate that families and therapists can use home programs as an effective intervention strategy for making improvements in key areas for children with hemiplegic cerebral palsy.

The results of Goal Attainment Scale (GAS) demonstrated that home program intervention was effective for achieving meaningful health outcomes, as identified by families and the occupational therapist \( p<0.000 \). Not only did participants make significant gains over a six-month period, the results show that regular home program input leads to achievement of desired health outcomes at or in advance of
the estimated rate of accomplishment. This is demonstrated by the sample’s six-month GAS weighted T scores mean of 50.12 (SD=12.87), which mirrors the expected score of 50.00 (SD=10.00) described by the test authors (Kiresuk & Sherman, 1973). These results mean that on average, each participant reached the expected ‘zero score’ on each individual GAS goal scale by the end of six months. The participant’s mean level of attainment for goal one was +0.10 (SD=1.83), which was slightly above the expected zero score. For the second individual goal the mean achievement was a score of +0.28 (SD=1.71), which was also slightly above the expected zero score. For the participant’s third goal the mean score was –0.37 (SD=1.69), slightly below the expected achievement rate. When these individual goal scores are tallied and the GAS weightings applied, the whole sample performed as expected in response to intervention (mean 50.12; SD=12.87). This finding indicates that not only do families participate in home programs with high frequency, intensity and duration; they also achieve the type of results their occupational therapist would expect from six months of intervention. This finding therefore supports the use of home program intervention with this client population as an effective way of achieving desired health outcomes. The findings presented here, must however be weighed against the criticisms of GAS. That is that goal scales can be set too low and therefore achievement of goals is too easy (King et al, 1999; Palisano, 1993). This measurement flaw is unlikely however to have occurred in this study because of the instrument development strategies built into the study design by the researcher (Cytrynbaum et al, 1979; King et al, 1999; Ottenbacher & Cusick, 1990). That is, two raters developed all goal scales, and goal attainment was measured from video footage by a blinded rater, except where goals measured aspects of personal care deemed inappropriate for videoing (as noted in chapter three).

Home programs have traditionally been viewed as a secondary intervention strategy, prescribed to support the ‘expert’ direct services provided by an occupational therapist. The findings of this study require the questioning of this belief and a reconsideration of the use and value placed on home programs within intervention practice. In this study six-months of home program intervention achieved goals meaningful to the family (GAS p<0.000) – thus it can be concluded that the ‘expert’ caregiving of parents is highly effective, when supported by ‘best practice’. Within this study, home program
intervention in the absence of direct ‘hands-on’ therapy achieved desired health outcomes. The uptake and implementation of the ‘best practice’ home program intervention model presented in this study is therefore proposed for clinical intervention with this population.

5.3.6 Relationship between Parental Participation Duration and the Child’s Outcomes

This study did not find any noteworthy relationship between the time spent on a home program and the child’s outcome on the study instruments (GAS $r=0.00$; PEDI functional skills $r=-0.10$; PEDI caregiver assistance $r=0.01$; and QUEST $r=-0.38$). This is in spite of study’s findings, that the ‘expert’ caregiving of parents is highly effective. Taken together, these findings thus suggest that any home program intervention (of 12.9 minutes per day average) has a positive change effect. This finding is important as it refutes current clinician beliefs about low parental participation causing harm with low participation being defined as no follow-up or less than the therapist prescribed regimen (Molineux, 1993). To fully understand the implications of this finding it is necessary to explore what is already known about the relationship between input intensity and the corresponding size of the desired outcome. It is also necessary to explore whether the design of the study influenced the outcome. These issues will now be explored.

The issue of ‘optimal’ home program participation intensity has not ever been previously explored in clinical research. This area of home program intervention now more that ever warrants more research because it may be related to parent perceptions of success; the corresponding self-selected home program participation intensity; and the outcomes achieved. Parents of children with disabilities are known to seek out intense hands-on therapy for their children, believing that ‘more is better’ (Hinojosa, 1990). Australian mothers describe feeling anxious, angry and frustrated because of difficulties in accessing therapy services at their desired intensity level. These mothers are typically involved in an ongoing cycle of seeking, waiting for, participating in, and evaluating intervention services, which they sense is a detriment to their child’s development (Thompson, 1998). Parents seek sustained intense
‘hands-on’ therapy based on a belief this is in the best interest of their child, although, therapy intensity literature shows that a higher frequency of therapy is not necessarily better (Orphius, 2003).

Intense ‘hands-on’ therapy for children with cerebral palsy, has been found to have no additional benefit over routine amounts of therapy received in a six month period (Bower et al, 2001). Rather, increasing the intensity of therapy only intermittently, for a two to four week period, leads to better outcomes (Bower & McLellan, 1992; Bower et al, 1996; Trahan & Malouin, 2002). Four weeks of intensive therapy (four times per week) separated by eight-week breaks has been found to lead to improvements in motor skills during the intensive therapy and continued improvement during the break (Trahan & Malouin, 2002). Researchers have therefore concluded that children with cerebral palsy require opportunities to practise skills regularly in daily life activities (Bower et al, 2001) because what children do at home with their parents is just as important as the amount of ‘hands on’ therapy they receive (Bower et al, 2001; Trahan & Malouin, 2002). Given the literature recommendations about optimal therapy intensity it has therefore been assumed that ‘the more home program therapy the better’.

The lack of relationship between participation intensity and the magnitude of child’s change may be explained by the “idiosyncratic” nature of goal attainment scaling (Palisano et al, 1992). The GAS instrument is known to account for the various potential impacts of child; family; and program factors when setting goal scales (Palisano et al, 1992). It is therefore possible that when the participant’s goal scales were set, the team accurately predicted the child’s ‘potential’, and set the achievement scales accordingly. If this were true it mattered little what participation intensity the family adopted, high or low, because this did not solely contribute to the extent of the child’s achievement.

The present study provides compelling new evidence to conclude that implementing a home program for any length of time greater than five minutes per day, leads to positive health outcomes for children with hemiplegic cerebral palsy. Five minutes is recommended as the minimum threshold for effective intervention based upon this time interval being the lowest participation level by any family in this study who achieved their desired outcomes. It is important that this new finding is communicated to families
because qualitative research (Hinojosa & Anderson, 1991) has shown that parents perceive that intervention of consequence is delivered by therapists. Mothers of children with cerebral palsy have a tendency to discount parental adaptations to a home program, not considering it as ‘intervention’ because their actions do not exactly replicate the therapists (Hinojosa & Anderson, 1991). It is as if they regard their own interactions as “second rate” in terms of therapeutic value, compared to that which they pay for or seek from a professional. This view is, however, challenged not only the family-centred practice approach, but by the findings of this study which demonstrate clear therapeutic outcomes from the home program. Parental caregiving skills and expertise can be enhanced through a ‘best practice’ home program intervention. Any increasing use of home program intervention should therefore not be viewed by therapists or parents as a “second-rate” service delivery option, but rather as a useful strategy for executing family-centred practice principles. Health professionals who recommend home programs, can now reinforce the real value of parental caregiving to families.

5.3.7 Implications of Study Findings

This study has built a foundation for understanding home program efficacy. A ‘best practice’ home program was developed based on best available literature evidence. The effectiveness of this program was measured by means of robust instrumentation when the program was implemented on a representative homogeneous sample. The results of this study have established that children with cerebral palsy make meaningful positive gains whilst participating in a home program, not the unwanted regression or plateau in skill development that mothers perceive from a lack of intense ‘hands-on’ therapy (Thompson, 1998). It was essential that this pre-post study be conducted, to develop an understanding of the level of efficacy to be expected from a family-centred occupational therapy home program that uses a ‘best practice’ approach. This study has therefore provided much needed ‘level 3 evidence’ (Lloyd-Smith, 1997) to inform clinical practice and research in an area currently characterised by even lower levels of evidence. Through this research study, it is now possible to identify the factors worthy of an in-depth examination in a randomised controlled trial using estimates of effect size that are empirically based.
5.4 Delimitations and Limitations

The results of this study must be interpreted with delimitations in mind. This was an absence of a controlled comparison group in this study’s pre-post methodology. The optimal research design for clinical efficacy trials is the ‘randomised controlled trial’ (Bower & McLellan, 1994). Randomised controlled trials are however acknowledged to be difficult to conduct and are at times inappropriate in the evaluation of therapy with children who have cerebral palsy (Bower & McLellan, 1994). This study used a single group, pre-test post-test design, because:

(1) the design allowed the family to self-select their preferred level of participation in a home program, which was necessary for the study to be intrinsically family-centred and to differentiate it from previous ‘compliance’ research;

(2) prior to this study there was no research literature describing a ‘best practice’ home program for children with cerebral palsy, or the effectiveness of occupational therapy family-centred home programs for children with cerebral palsy, so it was not even possible to design a randomised controlled trial, with precision; and

(3) a randomised controlled trial design was not feasible because of the service provider organisation constraints and requirements at the time of the study commencement. The researcher determined that given the current beliefs about parents not providing home program intervention to the detriment of their child, it would be almost impossible to practically establish a ‘true’ control group, where the parents withdrew intervention from their child. Such a randomised controlled trial design would require the parents in the control group to withdraw providing therapeutic ‘help’ to their child, for the duration of the study. It could be reasonably anticipated that the type of therapeutic ‘help’ provided by all of the parents, prior to enrolment in the study, was based on the belief that it was in the best interests of their child.

The researcher therefore adopted the ‘pre-test post-test design’. This design is known to be the simplest form of experimental research (Campbell & Stanley, 1963). Participants were measured
against the dependent variable (attainment of goals); then exposed to the independent variable (home program); and then remeasured against the dependent variable (Campbell & Stanley, 1963). This research methodology threatens the study's internal validity, because the researcher can only presume that cause of any change between the pre-test and post-test measurements is the independent variable i.e. the home program (Campbell & Stanley, 1963). It does not prove that the home program categorically caused the change; rather it indicates that a difference between pre and post scores exists, which may point to the independent variable being the cause (Campbell & Stanley, 1963). This is why the preferred methodology where practically possible, is the randomised controlled trial. This was not however possible within this study, for the reasons discussed.

Of the twelve sources of threat to internal validity to research that have been identified in the literature (Campbell & Stanley, 1963), there are three pertinent to this study: history; maturation; and testing. Each of these three potential threats will now be discussed:

(1) The change in pre-test and post-test scores seen on the GAS; PEDI; and QUEST instruments may have been caused by ‘history’ not the home program. Historical changes during the study’s implementation could have affected the study's results, changes such as: media releases about exercise benefits for children; and research publications about home programs. Parental access to new information once commencing the study could have positively or negatively influenced their perceptions about the perceived importance of the home program and thus affected their self-selected home program frequency and intensity.

(2) The change in pre-test and post-test scores seen on the GAS; PEDI; and QUEST instruments alternatively may have been caused by a ‘maturation’ effect. Children are continually growing and changing and therefore it is not possible to account for the naturally occurring ‘maturation’ effect within this study because no control data was collected.

(3) The change in pre-test and post-test scores seen on the GAS; PEDI; and QUEST instruments may have been caused by repeated ‘testing’, as participants may learn to anticipate test items and therefore may have practised or modified their response before retesting. This flaw however, is unlikely to have occurred given that the QUEST instrument measures
‘impairments’ which cannot be altered volitionally and the GAS scales were scored by a blinded rater from task performances.

5.5 Recommendations

Recommendations for the future development of and implementation of home programs are outlined below with specific strategies given for education, policy, practice and research.

5.5.1 Education

In order to enhance the quality of occupational therapy service and prevent future inappropriate and incomplete occupational therapy services being provided to children with cerebral palsy (as described in 5.3.3) it is recommended that:

- Occupational therapists who work in paediatrics in relevant populations receive more training in clinical assessment of upper limb hypertonicity; splinting prescription; and casting application.

Specialist undergraduate and postgraduate training in splinting is known to increase occupational therapist splinting prescription to children with neurological disabilities (Reid, 1992). The evidence to support this recommendation is found in a national Canadian survey, where therapists who had undertaken specialist training or received undergraduate splinting training were more likely to manufacture and prescribe splints (Reid, 1992). Canadian occupational therapists that regularly provided splinting interventions articulated that the major contributing factor for their uptake of splinting intervention was having been taught how to make the splint in undergraduate study (Reid, 1992). Therapists who do not to provide splints to their clients with neurological disabilities identify lack of familiarity with the appropriate splints as the major reason (Reid, 1992). Specialist undergraduate and postgraduate splinting programs could therefore bridge this knowledge gap by training therapists to: (1) appraise the scarce and conflicting paediatric splinting evidence base (Hill, 1998; Naganuma & Billingsley, 1990); (2) accurately identify indicators and goals for splinting (Hill,
1998; Naganuma & Billingsley, 1990); (3) understand precautions and risk management (Exner, 1996; Hill, 1998); and (4) develop familiarity with splint manufacture techniques (Reid, 1992).

5.5.2 Policy

In order to prevent future inappropriate and incomplete occupational therapy services being provided to children with cerebral palsy (as described in 5.3.3) it is recommended that:

- Cerebral palsy service providers who employ occupational therapists may benefit from systematically appraising their employee’s clinical competency in upper limb assessment and splinting and casting intervention. If it is identified that the occupational therapist requires additional training and mentoring in order to deliver these standard but specialised efficacious treatments (Copley & Kuipers, 1999, Exner & Bonder, 1983, Langlois et al, 1991, McPherson et al, 1982), employer support may be required to achieve this goal. This support may include: mandatory training; financial support for continuing education and paid work time to engage in such training. Provision of specialist postgraduate training to paediatric occupational therapists results in greater utilisation of splinting interventions to children with cerebral palsy (Reid, 1992). Employer support for this additional staff training is likely to result in longer-term increased quality of care, increased ‘customer’ satisfaction and therefore better outcomes for service users.

- Lack of access to the required materials for manufacturing splints has been specified by occupational therapists as one of the major reasons why splinting services are not provided to children with neurological disabilities (Reid, 1992). This may mean that service providers need to review budget resource allocations to enable purchase of splinting and casting materials for occupational therapists working with children with cerebral palsy. Without these physical resources, the types of interventions occupational therapist can provide to children with cerebral palsy may be limited and therefore potentially in ineffectual and inappropriate.
5.5.3 Practice

- Occupational therapists who provide therapy to children with cerebral palsy may need to consider undertaking appropriate postgraduate training in upper limb assessment and splinting and casting intervention, if they have a knowledge/or skill deficit in this area of clinical practice. Postgraduate training is known to increase the likely usage of splinting interventions to children with cerebral palsy (Reid, 1992) and thereby improve the quality of services that the therapist is providing.

In order to further advance the home program evidence base which has so far lagged behind clinical practice, undergraduate occupational therapists may benefit from exploring mindsets in existence about the usefulness of home programs. Two issues worthy of consideration and re-interpretation in light of the new evidence this study presents are: (1) the value therapists place on home programs in a continuum of service delivery options; and (2) ‘compliance’ versus family-centred thinking.

- Home programs have been traditionally viewed as a secondary intervention strategy, prescribed to support the ‘expert’ direct services provided by an occupational therapist. In this study, goals meaningful to the family were achieved (GAS p<0.000) by means of home program intervention not ‘hands-on’ therapy. This result indicates that the ‘expert’ caregiving of parents imparted through a home program is highly effective, when supported by ‘best practice’. These findings could be used as a learning tool to encourage undergraduate therapists to examine the added value of parental input via home programs and understand the potential implications for families who use therapy services. Undergraduate instruction in the ‘best practice’ home program approach and examining the new underpinning evidence base may help therapists better prepare for interactions with parents of children with disabilities. Parents generally seek intense hands-on therapy, instead of home program intervention, believing that ‘more is better’ (Hinojosa, 1990) thus creating service delivery pressures. Therapists however, who understand and use the ‘best practice’ home program approach are not only likely to predispose any home programs they instigate to being successful but also to communicate to parents that this approach is worthwhile. Through academic adoption of
the best practice model, home programs could be presented to students as an effective strategy for (1) enhancing parental caregiving skills, the focus of family-centred intervention; and (2) achieving meaningful therapeutic outcomes for the child. Not only are both of these achievable outcomes essential for effective intervention but importantly are now underpinned by the ‘best available’ evidence.

- Another prevalent belief amongst qualified therapists is that parents demonstrate low home program follow-through to the detriment of their child’s health (Molineux, 1993). This issue is also likely to be worth exploring. The belief seems to be developed or at least supported from occupational therapists appraisal of pharmacology compliance literature (Law & King, 1993; Mayo 1981; Molineux, 1993). The findings of this study suggest that: low pharmacology type compliance is not evidence of low home program participation because parents of children with cerebral palsy in fact engage in home programs with self-preferred high intensity rates. The idea of ‘non-compliance’ is a former medical approach to care, where the therapist knew what was best for the child (Bazyk, 1989; Hanna & Rodgers, 2002), compared to family-centred thinking where there is respect for and fostering of the parental care-giving role (Viscardis, 1998). Learning activities that encourage students to weighing up the subtleties of ‘compliance’ versus family-centred thinking is likely to stimulate the student to adopt an intervention approach that truly facilitates a central parental role. The findings of this study suggest that when the family-centred approach of a ‘best-practice’ home program is adopted, the therapist is likely to achieve highly effective intervention results.

- Occupational therapists that work with families and children with cerebral palsy will benefit form updating their current practice to include implementation of the ‘best practice’ home program approach presented here, as a strategy for maximising clinical outcomes. Until this study was conducted, little was known about the effectiveness of home programs; despite home programs being used extensively with children with cerebral palsy and being considered an essential aspect of care (Hinojosa & Anderson, 1991; Howison, 1988). This study has shown that home programs
conducted using the ‘best practice’ approach are effective for: (1) achieving goals meaningful to the family; (2) improving performance of self-care skills; (3) reducing the amount of parental assistance required for self-care; and (4) improving quality of upper limb movement in children with hemiplegic cerebral palsy. The achievements of home programs are significant because these accomplishments reflect what parents and therapists identify as most clinically important for children with hemiplegia. The results of this study now provide the evidence base to support home programs that use the ‘best practice’ approach to be considered an essential aspect of practice.

- The ‘best practice’ approach to home programs involves the occupational therapist providing active support to the parent to implement the home program intervention. This is perhaps a paradoxical concept to therapists who view home programs as an ‘indirect’ therapy approach. The ‘best practice’ approach recommends that occupational therapists remain involved with a family while they are engaging in a home program rather than become progressively less involved. This study seems to suggest that the ‘implementation support’ aspect of the ‘best practice’ approach (described in chapter two) is of vital importance to the family achieving and perceiving a successful outcome. Families implementing a home program therefore do not have an ‘inactive’ case status; rather, more support may be required from the occupational therapist. The potential clinical gains from this increased support however, appear highly worthwhile. The provision of increased support may initially generate expenditure implications for service providers but longer term cost benefits of a potential reduction in requests for ‘intense hands-on therapy’ may offset this initial cost outlay.

5.5.4 Research

- The specificity of future paediatric intervention effectiveness studies may be improved through quantification of the parental contribution to the child’s outcome in addition to the intervention being measured. This study has demonstrated that the parental contribution to successful intervention outcomes is significant. The extraneous variable of parental input can be successfully measured using a log calendar. This study has demonstrated that what parents do at home with their children
is of vital importance and significantly influences the child’s outcome. Researchers therefore must consider that the parental input naturally given through caregiving also positively contributes to any clinical outcome that is achieved.

- Further home program efficacy research is needed in the form of a randomised controlled trial design. This is essential for quantifying the ‘maturation’ effect that may have also positively contributed to the encouraging results found in this home program study. A randomised controlled trial will automatically control for the maturation variable though random assignment to groups and by the very existence of a ‘placebo’ group. The present study has made it possible to now identify the factors worthy of an in-depth examination in a randomised controlled trial using estimates of effect size that are empirically based. Prior to this study, effect size calculations were not feasible.

- The issue of optimal home program intervention intensity also requires examination in a further research study. It is possible that home program intervention for children with cerebral palsy follows the same ‘optimal intensity’ blueprint as hands-on therapy. Intense ‘hands-on’ therapy has no additional benefit over routine amounts of therapy for children with cerebral palsy (Bower et al, 2001). Rather, intermittently increasing the intensity, separated by short rests leads to better outcomes for children with cerebral palsy (Bower & McLellan, 1992; Bower et al, 1996; Trahan & Malouin, 2002). It is therefore essential that optimal home program ‘intensity’ is researched, to determine whether or not using an intensive phase of home program intervention, dispersed with short breaks, may lead to even better outcomes. The findings of such a study will help health professionals answer questions typically asked by parents such as: ‘Could I have done something?’; ‘Should I have done more?’ (Miller & Bachrach, 1995).

### 5.5 Synopsis

Chapter five discussed the study’s findings into the effectiveness of home program intervention for achieving desired health outcomes in children with hemiplegic cerebral palsy. To date this study is the only investigation examining the effectiveness of this extensively implemented intervention practice.
The descriptive findings highlighted firstly, that families carry out home programs with high intensity, when the ‘best practice’ approach to home programs is implemented. Secondly, families of children with hemiplegic cerebral palsy generate home program goals that focus on enhancing their child’s self-care skills and the use of their affected arm. Thirdly and more alarmingly, inappropriate, inadequate and incomplete therapy clinical services are being provided to children with cerebral palsy. The overall inferential statistical findings indicate that home program intervention for children with hemiplegic cerebral palsy effectively achieves goals meaningful to the family and that children demonstrate clinical change in self-care skills and their ability to use their affected arm. These important clinical changes can be detected using standardised instruments. Somewhat interestingly, no relationship was found to exist between the intensity of home program participation and the child’s outcomes. Any level of participation greater than five minutes per day is worthwhile. It is recommended that cerebral palsy service providers and occupational therapists adopt the ‘best practice’ home program approach developed from literature as their model of practice because it is proven to work. Further research is however needed. A randomised controlled trial is recommended for confirming the efficacy findings of this study and to quantify the effect of maturation. In addition, further home program research needs to identify an optimal intensity rate and communicate these findings to families.
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APPENDIX A: Definition of Terms

The following terms are used throughout this paper. The purpose for defining them is to provide an understanding of their meaning and the context in which they are used in this research study.

**Activities of Daily Living:** “Activities or tasks that a person does every day to maintain personal independence in the home and the community” (Reed & Sanderson, 1980).

**Best-Practice:** “is a continuous, collaborative, and systematic process for measuring and examining internal program’s strengths and weaknesses” (Lewis & Latney, 2002, p.25)

**Cerebral Palsy:** “Cerebral palsy is a disorder of movement. The term relates to the physical condition of a person who has difficulty either producing movement, preventing movement or controlling movement following injury to the brain before or during birth or in the first five years of life…there is no cure for cerebral palsy” (Stanton, 1992, p.2). Cerebral palsy is a static, non-progressive disorder. There are four types of cerebral palsy, spastic, athetoid, ataxic and mixed. Dependent on which parts of the body is affected, further sub-classifications are made. ‘Quadriplegia’ is where all four limbs are affected, ‘diplegia’ is where both legs are affected and ‘hemiplegia’ is where one side of the body is affected (Stanton, 1992; Dormans & Pellegrino, 1998; Bleck 1987).

**Clinical Reasoning:** “Clinical reasoning is the process used by practitioners to plan, direct, perform, and reflect on client care” (Schell, 1998, p.90).

**Effectiveness / Efficacy:** is the "usefulness of a particular treatment to the individuals receiving it under typical clinical conditions" (Domholdt, 2000, p.503). Effectiveness is determined through non-experimental outcomes research, in contrast to efficacy, which is determined through a randomised controlled trial (Domholdt, 2000).
**Family-Centred Practice:** Family-centred practice is where, “professionals become agents of family priorities… families determine the interventions that are appropriate based on their knowledge of their child and their own circumstances…. Family-centred care gives appropriate emphasis to the parental right to determine what is best for the child, regardless of professional opinions that might differ” (Dornans & Pellegrino, 1998, p.61).

**Functional:** “Pertaining to function; an act, process or series of processes that serve a purpose. To perform an activity or task properly and normally” (Mosby's Medical, Nursing, & Allied Health Dictionary, 1998, p. 665).

**Functional Splints:** “Splinting is the term used to describe the use of a removable orthoses in order to maintain the limb in a specific position for a period of time or to stabilise particular joints and encourage desirable patterns of movement during activity” (Copley & Kuipers, 1999, p.83). Specifically, “the main purpose of a functional splint is to promote active use of the upper limb. A functional splint is one that immobilises selected joints in the wrist, thumb, and hand and usually allows the finger joints free movement. It maintains joint alignment during activity, thus providing appropriate mechanical advantage for compromised muscle groups” (Copley & Kuipers 1999, p.134).

**Goal Attainment Scaling (GAS):** Goal attainment scaling is an individualised evaluative measurement tool designed to measure clinical change. “One of the most widely used individualised approaches is goal attainment scaling (GAS), which provides an individualised, criterion referenced measure of change. The GAS procedure involves: (a) defining a unique set of goals for each child, (b) specifying a range of possible outcomes for each goal (on a scale recommended to contain five levels, from –2 to +2), and (c) using the scales to evaluate the child’s functional change after a specified intervention period” (King et al, 1999, p.32).
**Hemiplegia:** Hemiplegia is a type of cerebral palsy where, “one side of the body is affected” (Stanton, 1992, p.7). “Most of these children begin independent walking between the ages of 18 months and 21 months, gain independence in activities of daily living, are able to talk, can participate in peer group activities and attend regular school” (Bleck, 1987, p.213).

**Home Program:** “activities / exercises and / or paper and pencil worksheets completed at home by the child with parental supervision, between treatment sessions” (Molineux, 1993, p.23).

**Outcome:** refers to the quantifiable achievement of change in health or function, attributable to a given intervention (Hall, 1996).

**Pediatric Evaluation of Disability Inventory (PEDI):** The PEDI is a standardised measurement tool designed to measure “the acquisition of skills of individuals with physical disabilities… The PEDI includes the evaluation of self-care, mobility and social function” (Henderson & Pehoski, 1995, p.167).

**Quality of Upper Extremity Skills Test (QUEST):** The QUEST is a standardised measurement tool which, “evaluates quality of upper extremity function in four domains: dissociated movement, grasp, protective extension, and weight bearing. It is designed to be used with children who have neuromotor dysfunction with spasticity and has been validated with children from 18 months to 8 years of age” (DeMatteo et al 1993, p.1).

**Range of Motion:** “Each joint is potentially able to move in certain directions and to certain limits of motion due to its structure and the integrity of surrounding tissues” (Trombly & Scott, 1989, p.184). Range of motion is the numeric measurement of a joint’s capability.

**Passive Range Of Motion (PROM):** “The amount of movement available at a joint when it is moved by an assistant” (Copley & Kuipers, 1999, p.298).
Active Range Of Motion (AROM): “The amount of movement available at a joint when the limb is moved voluntarily by the person” (Copley & Kuipers, 1999, p.297).

Spasticity and Hypertonia: The terms spasticity and hypertonicity are used interchangeably in some literature. For the purpose of this study they have been separately defined in line with the literature precedent of Copley and Kuipers (1999).

**Spasticity** is “a motor disorder characterised by velocity-dependent increase in tonic stretch reflexes with exaggerated tendon jerks, resulting from hyperexcitability of the stretch reflex” (Lance, 1980). In practical terms, Lance’s (1980) definition means, “velocity-dependent increased resistance to passive muscle stretch” (Albright, 1996, S2).

**Hypertonia** includes a “neurological component (spasticity), which is an exaggerated reflex response to a stimulus. Hypertonicity also includes non-neurological components, which are related to the physical properties of muscles and soft tissues” (Copley & Kuipers 1999, p.4).

Upper Limb Retraining: “Upper limb retaining refers to a range of handling and stimulatory techniques that are used to reduce the influence of hypertonicity and/or facilitate the learning or relearning of active movement” (Copley & Kuipers, 1999, p.83).
APPENDIX B: Pilot Study Summary

**Aim:** To investigate the self-selected home program participation rates of parents of children with hemiplegic cerebral palsy over a six-month period and to quantify the child’s clinical change, if any, in function and quality of upper extremity movement, using a range of robust instruments. **Method:**

**Participants:** The pilot study comprised of three children with hemiplegic cerebral palsy, aged 3-5 years, who lived at home with both parents. The participants had all previously accessed occupational therapy services and had previously been involved in a home program. All participants lived in rural and remote New South Wales and at the time of the pilot study did not have access to hands-on direct occupational therapy services. **Intervention:** after a comprehensive assessment, the investigator collaboratively developed a family-centred home program with the child’s parent. This program was provided to the family in written format, with supporting diagrams. The therapeutic activities selected by the occupational therapist for the home program were based on the ‘best available’ evidence and were embedded into everyday functional tasks. The therapist gave permission to the parent to exchange the selected therapeutic activities with new activities that the parent developed in the home context. This was done to acknowledge the parent’s expertise in selecting therapeutic, functional and successful activities that fitted the family’s routine and were enjoyable for their child. Participant’s were asked to carry out the home program for six-months. Over the course of the study, the investigator provided support to the family to implement the home program. This support involved three face-to face review assessments where the investigator: relayed the child’s improvements to the parent; provided feedback and reinforcement to the parent about how they were implementing the program; as well as providing the family with information about how to identify improvements in their child’s development. In addition, the home program was adjusted if necessary to account for the child’s improved ability level. **Instruments:** The child’s improvement in function in response to the home program was measured using the Pediatric Evaluation of Disability Inventory (PEDI); and the child’s quality of upper limb movement was measured using the Quality of Upper Extremity Skills Test (QUEST). In addition, a range of home program log calendars were provided the parents to enable them to record the amount of
home program intervention they chose to engage in. These calendars were based on literature recommendations but contained slight variations in layout and details. Interviews were conducted with the parents to ascertain which calendar layout features were the easiest to use and what they would recommend for use with another family. The baseline parental interview, which was in open-ended question format, also sought to establish the family's history of participation in home programs. From these interviews, a series of questions based around discrete topic areas were developed for inclusion in the ‘parental self-report survey’ in the larger study. **Results:** Over the six-month study duration, all child participants showed improvement in their PEDI self-care functional skills score (p=0.03) and QUEST scores (p=0.01). Parent’s reported participating in the home program for a mean of 10.04 minutes per day. They also reported that log calendars: which were quick to complete; could be attached to the fridge by a magnet as a reminder system; and also could be photocopied and pasted into the pre-school communication book were most useful. These features were incorporated into the larger study home program log calendars, where each program was supplied with a magnet and pen attached. **Conclusion:** Families of children with hemiplegic cerebral palsy choose to engage in home programs with regular intensity. Over a six-moth period, children with hemiplegic cerebral palsy make functional and upper limb movement improvements that are meaningful to their family, in response to home program intervention. These improvements occur even when direct hands-on occupational therapy services are not available.
The Effect of a Standardised Occupational Therapy Home Program for Children with Spastic Hemiplegic Cerebral Palsy

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of living.
Abstract

One commonly utilised occupational therapy intervention for children with cerebral palsy is a “home program”. Despite the popularity of home program interventions there is little evidence to demonstrate effectiveness, particularly when an explicit family centred practice framework is adopted. This single-group pre-post design study evaluates the impact of a standardised occupational therapy home program implemented with a group of 20 children (2-7 years, mean age 3.8) with spastic hemiplegic cerebral palsy. The study measured the effect of the program using: goal attainment scaling (GAS); pediatric evaluation of disability inventory (PEDI); and quality of upper extremity test (QUEST). In addition, parent participation intensity was measured through a home program log. The study found that there was a significant change following the intervention: GAS (p<0.00); PEDI functional skills (FS) (p<0.002); PEDI caregiver assistance (CA) (p<0.003); and QUEST (p<0.004). There was no relationship between home program intensity and outcome: GAS (r=0.00); PEDI FS (r=-0.10); PEDI CA (r=0.01); and QUEST (r=-0.38). The use of a standardised occupational therapy home program for children with cerebral palsy is recommended as an effective method to achieve therapy goals. Further research using more rigorous designs is required to fully explore treatment efficacy.
This thesis is submitted to complete the requirements for a Masters of Science (Honours) degree.

I certify that this original work has not been submitted for examination for a higher degree at any other institution.

Iona Novak

7th July 2004
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