POSTURE AND SLEEP IN CHILDREN WITH CEREBRAL PALSY

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A thesis submitted in partial fulfilment of the requirements of the University of Brighton for the degree of Professional Doctorate in Physiotherapy

July 2010
ABSTRACT
This case study explored the factors that influence the experience of night-time postural management equipment by children with cerebral palsy in the South-West of England.

The aims were to explore the views of children on using a sleep system, the role of their parents and therapist in its use and the quality of sleep experienced before and during use of a sleep system. Further objectives were the identification of factors that affect the use of sleep systems and the production of findings to guide therapists’ clinical practice.

Seven subunits made up the whole case, with each one consisting of a child, aged 18 months to nine years who had just been prescribed a sleep system, the child’s therapist and parents. All participants, excepting children under three years old, were interviewed. Talking Mats, an innovative communication tool, was used to enable children with little or no verbal communication to give their views.

Children as young as three years old were able to express their views on sleeping in a sleep system and to provide reasons for waking in the night. The findings included sleep difficulties in six out of seven children, two of whom improved with the use of a sleep system. Six children were thought to experience regular pain or discomfort, two of whom were more comfortable when sleeping in their sleep system. Factors were identified that influenced whether a child and family were able to continue using a sleep system at night including the finding that some of the therapists who were prescribing sleep systems did not have the necessary knowledge and experience.

It was concluded that when children are given the appropriate tools they can have a voice and be able to practice making decisions about their healthcare. It is suggested that when considering prescription of a sleep system, use of the ICF framework model would assist clinicians in focussing on those factors that predict the child and family are most likely to continue to use it. Therapy services should consider the role of a specialist clinician to lead local postural management services and to put in place training and competency measures for generalist therapists to ensure that they have the necessary knowledge and experience.
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Acknowledgements

Thanks are due to many people for their help and support during the process of this study. First and foremost thanks go to my supervisors, Dr Anne Mandy and Dr Terry Pointney, for their guidance and enthusiastic encouragement, their ability to criticise in a positive manner and for always being quick to respond to requests for help. Thanks also go to Col. Graeme Wheeler, Chief Executive of Vranch House, for his generous assistance with funding and for allowing me sufficient time away from the workplace to get it done. Thanks are due to the Posture and Mobility Group who provided funding to purchase some sleep systems. Cat Ward, Speech and Language Therapist, kindly helped me by sharing her knowledge of the Talking Mat and by expertly interviewing the children. Thanks go to colleagues and friends who read parts of the thesis, for their time and constructive comments. Finally, my immense thanks go to my husband, Colin, who has patiently lived with this doctorate for five years and who always expressed his absolute faith that it would get finished and would be of worth.
Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated in the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

Dated
CHAPTER 1: INTRODUCTION

1:1 Rationale for the study

It has been reported that cerebral palsy “is a condition with which one lives rather than a condition from which one dies” (Evans et al 1990). Common sequelae of living with cerebral palsy are postural deformity and pain and these, with other factors, can cause difficulties with sleep.

Cerebral palsy is currently defined as; “A group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum et al 2007 p.9).

Cerebral palsy can cause significant problems for the children affected and their families and places a considerable burden on health, education and social care services. The demographics of cerebral palsy indicate that a high percentage of children with moderate and severe cerebral palsy will survive into their late teens and twenties (Bax and Brown 2004; SCPE 2000; Crichton et al 1995). In order to increase the comfort, participation and quality of life of the child, and adult that child will become, it is vital that management of posture and the associated difficulties of the motor disorder are carefully planned. It is also important that financial and time resources are directed towards those interventions likely to achieve the most benefit for the child.

Postural management is an approach used in practice by therapists (physiotherapists and occupational therapists) for children with moderate and severe cerebral palsy to maximise functional ability and minimise the progression of deformity. It encompasses a range of principles including postural support in specialist equipment over 24-hours in sitting, standing and lying, the promotion of active exercise and the use of orthotics, botulinum toxin injections and surgery when necessary. Evidence for postural management is limited (Pountney et al 2009) but its use is becoming widespread amongst therapists who recognise its potential efficacy. Children with cerebral palsy
characteristically exhibit muscle weakness, fatigue and poor coordination as well as stiffness, spasticity and changes in muscle length. Using specialist equipment to provide postural support assists in overcoming some of these difficulties. Postural management equipment includes specialist seating, standing and lying supports and examples of these are given in Appendix 1. A child’s functional ability can be enhanced in sitting with the provision of supportive seating in an upright, symmetrical position. The support enables a child to concentrate on the functional or cognitive task required rather than on balance and the physical exertion of maintaining an upright position. In standing, a standing frame braces knees, hips and spine enabling a child to achieve an erect posture. Alongside the social aspects of standing, weightbearing through the joints of the lower limbs is thought to aid bony development of the hip joint, stretch tight muscles and improve function of the inner organs (Pountney et al 2004). Lying supports, commonly called sleep systems when used at night, can also be used for resting or playing in during the day. The child is positioned in a symmetrical posture in supine, prone or side-lying depending on the design of the equipment and the child’s preference.

Children with cerebral palsy have many associated difficulties that can affect their ability to sleep and their sleep hygiene. The term ‘sleep hygiene’ describes the habits, routines and environmental practices that prepare for and promote appropriately timed and effective sleep (Jan et al 2008). Children with severe cerebral palsy lack the ability to change position at night. Lack of movement combined with asymmetrical habitual postures can cause discomfort and hence difficulties with sleep. Gastro-oesophageal reflux may also cause discomfort. Epilepsy, breathing problems, incontinence and night-time gastroenteral feeding can also interfere with a child’s ability to sleep (Jan et al 2008). Moreover, behavioural factors can also play a part in causing sleep hygiene difficulties. Children with cerebral palsy may take longer to learn the rules of appropriate night-time behaviour and parents may believe their child is unable to sleep well because of medical problems rather than considering the behavioural aspects that may be involved (McDaid and Sloper 2008).

The effects of chronic sleep deprivation can be profound for both the child and the parents. A child may experience difficulties with concentration and demonstrate behavioural problems at school while parents may feel stressed, tired, anxious and
angry (Quine 1997). A sleep system may be prescribed by the therapist because of concerns about the child’s posture; however, where there are already sleep problems, the sleep system may be less acceptable to both the child and parents than other pieces of postural management equipment.

At birth, children with cerebral palsy do not have muscle contractures, hip dislocation or spinal curvature. Such deformities can be classified as postural, which may be fixed and result from altered muscle tone, or positional, which are due to the positions habitually adopted because of the influence of gravity and growth (Pountney 2007).

Physiotherapists have long been concerned with the prevention of deformity and work to keep muscles elongated and the skeleton symmetrical (Pope 1992; Goldsmith 1992; Scrutton and Baird 1997; Pountney et al 2002). During sleep muscles are relaxed and are therefore more amenable to stretching (Graham 2004). Night-time positioning in a sleep system enables a child to be supported in a symmetrical posture for a significant period of time, enabling gentle stretching to take place without interfering with functional activities during the day. Sleep systems are prescribed by physiotherapists not only to protect posture but also to enable better sleep by seeking to reduce the potential causes of discomfort.

A considerable burden of care is involved in parenting a child with cerebral palsy and positioning a child for sleep in a sleep system is yet another task to perform. Parents are thought to be more motivated to carry out treatment programmes with their children if they are well informed about how to do it and the reasoning supporting it (Law and King 1993). Therapists, however, may not disseminate this information to parents adequately. Furthermore, therapists need to have the necessary knowledge and skills to make judgments about which child should have a sleep system and which sleep system would be appropriate. Inappropriate prescription by therapists may lead to abandonment of the sleep system and the wasting of financial resources as well as therapists’ and families’ time and effort.

Moreover, the provision of sleep systems is not equitable across the UK (DFES 2007) and the reasons for this are unknown, however funding may be a key issue.
In addition to limited evidence of the efficacy of postural management equipment, little is known about the views of both the children and the parents who use it. The expectation is that children will participate in decision-making in matters that concern them (UN Convention on the Rights of the Child 1989) and yet it seems children are rarely asked for their views about therapy interventions. Children with communication and/or cognitive impairments are further excluded from research and yet it is these children, with moderate or severe cerebral palsy, who are likely to be prescribed a sleep system. It is also unknown whether children find sleep systems comfortable and whether being supported in one position all night is acceptable. Parents’ views on the use of sleep systems have also not been thoroughly explored. These experiences could provide an invaluable insight into why sleep systems might be successful for some and unacceptable to others.

There is also little known about the various roles that the therapist plays in facilitating use of the sleep system. The organisation of postural management within community therapy services and the knowledge and skills of therapists may impact on the rates at which sleep systems are accepted and used successfully.

1.1.1 Summary

Cerebral palsy causes significant difficulties for children and their families, one of which is postural deformity which leads to increased pain and decreased participation in community life, education and recreation.

Postural management is a planned approach that is increasingly adopted by therapists to increase function and reduce the progression of deformity although there is currently little evidence to support its use. This is particularly the case for sleep systems for which there is especially limited evidence of acceptance and efficacy.

Children with cerebral palsy are known to have a higher incidence of sleep difficulties than typically-developing children. This is likely to affect the child and family’s use of the sleep system. Experience from clinical practice and some evidence from available literature (Pountney et al 2009) suggests that families abandon sleep systems more frequently than other postural management equipment. There are several factors which may contribute to this, all of which need exploring.
Notably, the voice of the child is rarely heard and yet, as the user of the sleep system, their view is central and may elucidate why some families abandon their sleep system. There is similarly little research in which the views of children with communication and or cognitive difficulties are sought. The techniques used to gain such views require testing as there is little in the literature to date. The views of the parents have also yet to be explored and the role of the therapist in facilitating a child and family’s use of a sleep system may be influential but has similarly not been examined to date. Finally, factors that affect the use of sleep systems in children with cerebral palsy and their families need to be identified to enable therapists to facilitate their use effectively.

1.2 Background of the researcher

Working as a community paediatric physiotherapist for many years, evidence of the progression of debilitating deformity in children with moderate and severe cerebral palsy is all too common. Equipment to support children in symmetrical and functional positions in sitting and standing has been available since the late 1970s. More recently, sleep systems to support children in lying at night have also become commercially available. However, due to the complex nature of their difficulties and the social environments of home, school and respite care in which they live, there are challenges to the organisation of postural management programmes for this group of children. As part of a Master’s degree in Physiotherapy, an integrated care pathway for 24-hour postural management was developed to address some of these challenges (Humphreys, Master’s thesis 2004). This pathway was implemented in North Devon and caused a significant change in multidisciplinary practice. Parents and all other carers around a child received formal training in postural management. The therapists involved perceived an improvement in the services for these children (Humphreys and Pountney 2006) and the numbers of children and families abandoning their sleep systems in North Devon are low. The care pathway was adopted by other therapy departments in Devon and elsewhere in the country. It has been developed recently to include an X-ray policy for the surveillance of hips which is used in paediatric clinics in Exeter and North Devon (Bunney and Humphreys 2009).
It is evident in discussions with clinical colleagues in other therapy departments, however, that this good practice is not widespread and that provision of postural management programmes is patchy and flawed. Further guidelines are required to enable therapists to identify key factors that will affect the use of sleep systems by children and their families.

1.3 Assumptions of the researcher

Transparency of the research process demands that the researcher’s assumptions about the subject in question are made clear at the beginning. The award of a Professional Doctorate requires scholarly inquiry into the researcher’s specialist field of practice. It is vital, therefore, for the researcher to be steeped in the practice knowledge of that particular field and inevitable that assumptions about it will have been developed.

In this case the researcher assumed that sleep hygiene, training for parents, the clinical reasoning of the therapists and the comfort of the child were key factors in the continuing use of sleep systems by children and their families.

In terms of sleep hygiene, environmental factors such as housing and the proximity of siblings at night were assumed to be factors, as were the child’s health problems. Whether training for parents was offered was thought to be dependent on the ethos of postural management in the local therapy departments and the ability of the teams to work in a multidisciplinary manner. The clinical reasoning of therapists, it was assumed, would be dependent on their knowledge and skills. It was also acknowledged that the sales representatives of the companies marketing the sleep systems may have an influence on therapists’ clinical reasoning. The comfort of the child within the sleep system was thought to depend on the therapists’ ability to prescribe the appropriate sleep system for the appropriate child while taking into consideration the child’s usual sleeping position. Pain may be a factor. These assumptions are presented in figure 1:1 below.
Figure 1:1 Framework of initial assumptions

- Environmental factors
  - Housing
  - Siblings
- Discipline and routine
  - Single parent
  - Parenting skills
- Child’s health
  - Reflux
  - Epilepsy
  - Pain
  - Spasm

- Ethos of therapy team
- Postural management embedded in practice
- Multidisciplinary approach
- Wider family and carers included

- Influence of manufacturers
- Knowledge and experience of therapists
- Trial period of using sleep system

- Support from manufacturers
- Child’s usual position for sleep
- Instruction from therapists on use of sleep system e.g. acceptance of small start
- Clinical reasoning to provide appropriate sleep system

Sleep hygiene → Training for parents → Clinical reasoning of therapists → Child’s comfort → Child and family’s experience of sleep system
1.4 Conclusion

This chapter has outlined the rationale for the study, commencing with a brief description of the difficulties faced by children with cerebral palsy including postural deformity and continuing with an introduction to the postural management approach adopted by therapists to address these issues. The use of sleep systems in particular and the factors that may be involved when sleep systems are abandoned are the focus of this study. The gaps in knowledge, including the views of the child and parents and the role of the therapist, are described. The background of the researcher presents the reasons why this topic was seen initially as a personal concern requiring investigation. The assumptions of the researcher are stated to aid the transparency of the research process.

The aims of this study are, therefore, to explore the views of children using a sleep system, the roles of their parents and therapist, any differences in quality of sleep when a child uses a sleep system and the factors which influence a child’s continued use of a sleep system.
CHAPTER 2: LITERATURE REVIEW

2.1 Cerebral palsy

Cerebral palsy is a complex condition affecting two to three in every 1,000 live births and is one of the most common causes of serious childhood physical disability (Stanley 2000; SCPE 2000). Its causes are becoming clearer as understanding of developmental neurobiology increases with advances in brain imaging (Rosenbaum et al 2007). Babies born very pre-term and those with very low birth weight have a higher risk of cerebral palsy than others. Maternal infection and pre-eclampsia are also known to be factors (SCPE 2000). Fifty percent of children with cerebral palsy are born before 36 weeks gestation but also 1 in every 1,000 babies born at full term will have cerebral palsy (Bax and Brown 2004). It is thought there may be a genetic tendency for the brain to be vulnerable to hypoxic damage to the nerve cells and that more than one causal factor is often involved (Bax and Brown 2004).

Cerebral palsy is classified into the types, spastic, dyskinetic (dystonia and choreoathetosis) and ataxic (SCPE 2000). The spastic sub-type is further described by its distribution; unilateral or bilateral and the number of limbs involved. The severity of movement disability can be classified into levels I-V using the Gross Motor Function Classification System (GMFCS), a system well tested for reliability and validity (Palisano 1997). Children described as being in Level I can walk, run, jump and climb stairs but have impairments in speed, balance and co-ordination. Children in Level V require maximum assistance with activities of daily living, do not have the ability to maintain anti-gravity head and trunk postures and are very restricted in independent mobility. Children described as having moderate or severe cerebral palsy would be at Levels III to V on the GMFCS.

2.1.1 Natural history

Children with cerebral palsy are vulnerable to the development of secondary postural deformity and those with the most severe impairments, i.e. those in GMFCS Levels IV and V, are most at risk (Morton et al 2006; Soo et al 2006; Scrutton et al 2001; Saito et al 1998). The asymmetrical deformities that commonly occur include hip subluxation
and dislocation (refer to glossary), pelvic obliquity and spinal curvature. The term ‘windswiping’ describes the commonly adopted posture in which hip adduction (refer to glossary) occurs on one side and hip abduction (refer to glossary) on the other resulting in hip dislocation of the adducted hip. This is associated with spinal curvature. These deformities often result in secondary problems such as pain, sleep disturbance, reduced function and participation in life situations, respiratory problems and swallowing difficulties (McKearnan et al. 2004; Seddon and Khan 2003; Chalkiadis 2001; Hodgkinson et al. 2001).

At birth a typically-developing infant adopts asymmetrical postures and is unable to maintain a balanced symmetrical posture until the age of three to four months. As motor co-ordination develops the infant learns to move into and out of symmetrical postures (Pountney et al 2004). The child with cerebral palsy, however, may lack the ability to move and early asymmetrical postural patterns may become habitual and fixed. The direction of postural deformity may be determined as early in life as the last trimester of pregnancy in the foetal presentation at birth (Porter et al. 2008, 2010; Haminishi and Tanaka 1994). There is some evidence that foetal presentation at birth is correlated with preferred head turning in supine lying in typically-developing children which in a few children led to hip dislocation or contracture of the sternomastoid muscle (Haminishi and Tanaka 1994). A correlation between preferred position in lying in infancy and subsequent direction of deformity in children with cerebral palsy was suggested by Porter et al. (2008). They also suggest a correlation between foetal position, preferred position in lying and the subsequent direction of spinal curvature and hip dislocation (Porter et al. 2010). The findings rely, however, on parents’ memories of their child’s preferred lying position up to 18 years later which is highly susceptible to error. The authors hypothesise that whereas typically-developing children can move out of preferred asymmetrical postures, children with severe movement difficulties cannot and the postures becomes fixed. It is recommended by an expert group that efforts are made to support babies with movement difficulties in symmetrical lying postures as soon as practical after birth (Gericke 2006).

In addition to postural deformity, epilepsy is also frequently found in children with cerebral palsy. In a review paper, findings are reported that between 50 and 94 percent of children with spastic quadriplegia experience seizures compared with 33 to 50
percent of children with hemiplegia and 16 to 27 percent of those with diplegia (Wallace 2001). Epilepsy is linked with reduced cognitive ability, and Wallace (2001) suggests that “almost all” children with quadriplegia and epilepsy have severe learning difficulties, although figures are not given to substantiate this claim. Epilepsy is known to disturb the physiology of sleep and is likely to predispose children to having increased difficulties with sleep (Stores 2001; Newman et al 2006).

Visual impairment is common in children with cerebral palsy with seven to nine percent of children affected (Guzzetta et al 2001). The effect of visual impairment on melatonin secretion in addition to a lack of light perception can cause difficulties with the timing and maintenance of sleep (Newman et al 2006).

Children with cerebral palsy commonly experience gastro-oesophageal reflux which is painful and can cause sleep-related breathing disturbances (Kotagal et al 1994). Recurring aspiration pneumonia can be a feature of reflux and to prevent this children often require a gastrostomy for enteral feeding (Newman et al 2006).

2.1.2 Posture

The development of postural deformity is closely associated with the child’s type and distribution of cerebral palsy and those with quadriplegic cerebral palsy are the most affected. Factors contributing to the development of deformity include the negative signs of the upper motor neurone lesion, those of muscle weakness, fatigue and poor selective motor control, in addition to the positive elements of spasticity. The presence of muscle weakness, fatigue, poor selective motor control and spasticity induces immobility and changes in muscle length (Graham 2004; Damiano 2004). Spasticity is defined as the velocity-dependent resistance to passive movement of a joint and its associated musculature (Graham 2004). In normal muscle, growth occurs when relaxed muscles are stretched during normal movement. In children with cerebral palsy, spasticity prevents relaxation of the muscles and stretching is limited by the child’s inability to move joints through their full range (Graham 2004). As a result, as the long bones grow, longitudinal muscles fail to keep pace leading to muscle contracture and loss of joint range of movement (Graham 2004).
Much has been documented about the aetiology and progression of hip subluxation in children with bilateral cerebral palsy (Vidal et al 1985; Cornell 1995; Scrutton et al 2001; Soo et al 2006; Morton et al 2006). Contractures of the hip adductors, hip flexors and the medial hamstring muscles creates muscle imbalance around the hip joint and causes osseous deformity of the femoral neck and dysplasia of the acetabulum. This leads to progressive subluxation and eventual dislocation of the hip. Periarticular connective tissues are also prone to contracture possibly as a result of a general lack of movement (Graham 2004). The long bones suffer from torsional and angular deformities and growth inhibition (Graham 2004).

In a large prospective population-based study, Scrutton et al (2001) confirmed earlier findings (Cooperman et al 1987; Lonstein and Beck 1986) that the incidence of hip subluxation is highest in children with the spastic type of cerebral palsy and where there is four limb involvement rather than two. A more recent large population-based study (Soo et al 2006) found that 90 percent of children with the most severe form of cerebral palsy, i.e. those in GMFCS Level V, had developed hip subluxation and that there was a clear linear relationship between the progression of hip displacement and level of GMFCS. There is a discrepancy between the definitions of hip subluxation between these two studies. Scrutton et al chose to follow Reimers’ definition in which hip migration is more than 32 percent (Reimers 1980). Soo et al chose a hip migration of more than 30 percent, partly for the pragmatic reason that surgical intervention occurred in that population at that point, following others in the field. The hip surveillance programme recommended by Scrutton and Baird (1997) is a recognised method of detecting changes in hip status early on in life. Soo et al (2006) postulate that the children in GMFCS Level I escape having hip problems because of their relatively normal muscle tone and their high levels of activity. This concurs with the theory that weakness, fatigue, poor selective motor control, spasticity and hence immobility are the dominant contributors to postural deformity.

The sequelae to immobility can be extensive. Immobility causes osteoporosis which may result in fractures while changes of the joint structures provoke the onset of degenerative arthritis (Graham 2004; Noonan et al 2004). Function is severely affected and care of the child is made more difficult when range of movement is lost, e.g. perineal hygiene when hips have lost range of abduction. Pressure sores may become a
problem when load-bearing in sitting and lying is unevenly distributed over a small area of the body (Noonan et al 2004; Pountney et al 2004). All these ramifications have the potential to cause pain (Graham 2004; Pountney 2006; Noonan et al 2004; Pope 2007).

2.1.3 Pain

There is limited research into pain in young children with cerebral palsy (McKearnon et al 2004) despite the fact that a high percentage of adolescents and young adults with cerebral palsy (47.2 percent) are known to have chronic pain (Hodgkinson et al 2001). A recent Delphi survey found that pain is considered by people with cerebral palsy and their families, to be an important focus for future research in the field of cerebral palsy although it was not identified as such by a professional group consisting of researchers, clinicians, policy makers and managers (McIntyre et al 2010).

There is some evidence that children with cognitive impairment experience significant pain of long duration on a regular basis (Royal College of Nursing 2009). It is suggested that pain is subjective and dependent on prior experience and on the ability to communicate that experience (Houlihan et al 2004). Adults trying to understand a child’s pain are challenged, particularly when the child has communication and or cognitive difficulties and may have limited experience of pain. Typically-developing children have a word for pain from as young as 18 months, however, and studies show that children from four years can reliably report intensity of pain using a visual analogue scale (Houlihan et al 2004). There is a recognition that more needs to be done to ensure that clinicians are alert to the possibility of pain in neonates and very young children (Royal College of Nursing 2009).

In a phenomenological study of pain, Castle et al (2007) highlighted the importance that young adults with cerebral palsy attributed to being able to communicate their pain in order to ensure effective treatment. One large European study of 500 families, aiming to explore the differences in child self-report and parent-proxy reporting of quality of life, detected that parents of children in pain significantly overestimated their child’s perception of their quality of life in the domains of psychological well-being, physical well-being, autonomy, school and emotions (White-Koning et al 2007). In another large study of 148 families in California, an extremely low correlation was found between the
child and the parent reports of the child’s emotional functioning. Children’s scores identified that they were significantly more ‘angry’, ‘anxious’ and ‘sad’ than their parents appreciated (Varni et al 2005). This finding had some limitations to its generalisability, however, as it was conducted in one specific region of the country and there was no accounting for comorbid conditions or the differences in the mode of administering the outcome measure. A recent well-conducted study, part of the SPARCLE project, discussed in more depth in section 2.2, reported that 73 percent of parents of 818 children with cerebral palsy across 8 EU regions considered that their child had been in pain in the previous month while 60 percent of the children able to self-report responded that they had been in pain in the previous week (Parkinson et al 2010).

Children who cannot verbalise their pain display common behaviours. Parents reported that children in pain tend to cry, are less active, seek comfort and are less easy to pacify. The children are less prepared to co-operate and are irritable (Hadden and von Baeyer 2002). They may become more stiff and tense and their sleep may be affected as they become agitated and fidgety. Cognitive abilities, communication, daily living, social and motor skills are all affected by pain (Breau and Burkitt 2009). Houlihan et al (2004) found that pain adversely affects quality of life in children with cerebral palsy. These children were more absent from school, spent more days in bed and were less able to participate in their normal daily routines and family activities. The parents of these children reported increased levels of anxiety about them compared with the parents of healthy children. Fear and anxiety are closely linked to having had the experience of pain (Houlihan et al 2004). The psychological consequences of untreated pain may lead to a decrease in motivation, a sense of loss of control and a learned helplessness.

The causes of pain in children with cerebral palsy include spasticity and immobility. Sustained muscle contracture by hypertonic muscles causes pain in those muscles and in the joints they cross (McKearnon et al 2004). In a large study, (198 participants), exploring the frequency of pain in children with cerebral palsy and its association with participation, function and health-related quality of life, parents suggested the causes of pain include reflux, constipation, gastrostomy feeding, positioning, spasticity, hip problems and dental pain (Houlihan et al 2004). Two large studies by Hodgkinson et al (2001) and Schwartz et al (1999) including 234 and 93 participants respectively,
investigated the frequency, duration and intensity of pain in adolescents and adults with cerebral palsy and found that 47 percent and 39 percent of interviewees reported musculo-skeletal pain persisting on a daily basis for over twenty years. The pain was particularly located in hips and backs and was present in both dislocated and in-tact hips. Pain was linked to position with pain being experienced from being in one position and on being moved from that position.

There is a suggestion that pain is caused by the interventions frequently employed by physiotherapists and others in rehabilitation, for example hip movements and standing (Hodgkinson et al 2001). Hadden and Von Baeyer (2002) reported on a postal survey, with a low response rate, in which 34 out of 43 parents identified that assisted stretching was the activity in their child’s daily life which caused the most pain. Additionally, range of movement stretches were the intervention most likely to cause pain. Parents were asked to rate their child’s pain retrospectively over the previous month using the Caregivers’ Pain Survey, a non-standardised tool which had been developed for the study. This outcome measure was designed to capture specific daily living situations and routine healthcare procedures that may cause pain by adding three questions to a previous tool, the Non-communicating Children’s Pain Checklist. It is suggested by the authors of the study that the results are viewed as exploratory and that further research with a larger sample of parents would be required before any generalisations could be made. They also suggest that an exploration of therapists’ perceptions of children’s pain during treatment would provide valuable information. Breau et al (2003) studied 94 caregivers and suggest that pain is largely a result of the chronic medical condition and infrequently a result of medical interventions although rehabilitation techniques were not specifically mentioned in this study. In a pilot study, school staff expected to position children in standing frames and to implement stretching programmes expressed concerns and anxieties about inducing pain and discomfort (Hutton 2008).

Evidence is also limited for the effectiveness of both manual and sustained stretching of muscles to achieve greater length although the technique is commonplace in practice. Two well-conducted reviews of the literature up to 2003 on the effects of passive muscle stretching, summarised the evidence as being inconclusive (Pin et al 2006; Leong 2002). The studies that have been done to date all have small numbers of heterogeneous participants and insufficiently rigorous research designs. Any reported
effect sizes are small. Moreover, the clinical significance of any reported increases in
range of movement is unknown as are the effects of passive stretching on functional
skills. Incorporating stretching into active participation rather than passive manual
stretching is an alternative option and there is a growing enthusiasm amongst clinicians
and researchers as to how this can be achieved for children with severe difficulties,
including the use of partial body-weight supported treadmill training and supportive
static exercise bikes (Mutlu et al 2009; Williams & Pountney 2007). The effects of
these treatment interventions on function are promising, the relationship to muscle
length, however, has not been explored.

Children with cerebral palsy are likely to undergo various surgical procedures when
they are still young. Early work by Bricher (1999) suggests concerns that, as surgery is
often performed with the aim of enhancing health and ability in adulthood, the pain
experienced by the child is overlooked. The surgical intervention itself is a cause of pain
as are the postoperative problems that frequently accompany surgery such as nausea,
muscle spasm, constipation and skin breakdown (McKearnon et al 2004). Rehabilitation
following surgery is a painful and stressful experience for these children. Long term
pain at the site of hip surgery is reported by adults with cerebral palsy (Hodgkinson et al
2001). Older children and those with higher cognitive abilities are able to develop
strategies to help cope with a painful post-operative stretching regime but younger
children and those with developmental delay required more active promptings and
distractions to help them cope with regular pain (Miller et al 2001).

children with cerebral palsy report parent observations and do not employ any child
self-reporting methods. Difficulties is accessing the views of children with intellectual
impairment are mentioned and the validity of self-report is questioned (Breau and
Burkitt 2009; Houilhan et al 2004). The Paediatric Pain Profile, an observational tool
for the assessment of pain in children with severe neurological disability, was developed
through four stages of interviews and surveys with parents and healthcare professionals
and testing in domestic and clinical settings, to be a reliable and valid measure (Hunt et
al 2004).
White-Koning et al (2007) and Varni et al (2005) in two large, relatively well conducted studies have ascertained that parents are unreliable assessors of their child’s quality of life and their degree of pain. The authors suggest that children’s views should be sought wherever possible and in cases where it is not possible that additional proxy-reports are obtained from other caregivers, teachers or clinicians. The way society views children and values what they have to say has perhaps limited the practice of seeking their views to date.

2.2 Children and childhood

Studies of childhood have been dominated by biological and developmental psychological theoretical approaches (Bricher 1999). Children have been seen as incompetent, incomplete adults and childhood as a preparatory stage for membership of adult society (McDonald 2009). This view has informed political, economic and healthcare agendas and has legitimised the power that adults have exerted over children. However, a new sociology of childhood is emerging in which childhood is viewed as a social and cultural institution, a permanent feature of society and a part of the social order (McDonald 2009). This is not totally different from before, however it is an approach in which children are understood as social actors in their own right and seen as part of a minority group in social, political and economic terms (McDonald 2009). This new perspective views childhood as an entity but also acknowledges the differences that history, culture and social variance make in the lives of children bestowing a uniqueness to each one (McDonald 2009). It acknowledges the evidence that children are competent to inform adults of their lives as social actors (Alderson 1992).

Viewing children as embryonic adults has led to policies and interventions concerned with their impact in the future, i.e. when the child becomes adult. This dual status of children as children and children as future adults can be seen as human capital investment but needs to be balanced with concerns about the child’s present well-being (Mayall 1998). McDonald (2009) has concerns that this does not always happen and states: “children have rights to human self-realisation as children” and that we can be “deaf and blind to issues experienced in the present and their impact in the present” (p. 245). The new sociology of childhood views children as people today and in an on-going series of consecutive ‘todays’ (McDonald 2009).
The quality of life of children with cerebral palsy has only recently become to be seen as an essential outcome in the description of health status and in the assessment of the effectiveness of therapeutic interventions (Colver 2006). The World Health Organisation states that quality of life is “the individual’s perception of their position in life in the context of their culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (WHOQOL Assessment Group 1998). Quality of life is intimately associated with participation and both these issues are currently being explored in a large European study of children with cerebral palsy, called the SPARCLE project (http://research.ncl.ac.uk/sparcle/index.htm). This study, exploring the influence of the environment on the participation and quality of life of 818 children from cerebral palsy registers in seven European countries, has a robust study design including a new, extensively piloted quality of life outcome measure, KIDSCREEN. It is being conducted by a collaboration of well-respected researchers. Children with cerebral palsy self-report that that they experience a quality of life that is, on average, comparable to children of the same age in the general population. Pain, however, was found to be a factor in reduced quality of life across all dimensions of the measure (Dickenson et al 2007). High levels of stress in parenting were associated with parents’ under-estimating children’s quality of life in a study of 500 children comparing child self-report and parent-proxy reporting and, as previously stated, over-estimating quality of life when the child self-reports severe pain (White-Koning et al 2007). Similarly, there was disagreement in assessment of quality of life in a study comparing professional and parent reports, with professionals acknowledging the effects of pain on quality of life and rating quality of life higher than parents in the absence of pain (White-Koning et al 2008). The reliability of children’s self-reports and the status of proxy-reporting pose challenges to the assessment of quality of life in children compared to that of adults.

2.2.1 Models of disability

Until recently, the medical model of disability that equates disability with illness has been the dominant model in professional practice and policy-making (Connors and Stalker 2003; Morris 2003). By focussing on impairments it defines people in terms of their diagnosis. The personal tragedy model of disability is closely linked to the medical
model and is very evident in the ‘lay’ population. It views children as having to cope continuously with the tragedy that has befallen them. Children with disabilities who succeed in life ‘despite everything’ are viewed as ‘heroes’ (Connors and Stalker 2003). Children themselves, however, do appear to separate these models and although those interviewed by Connors and Stalker (2003) talk about the impairments inherent within themselves they did not see themselves as victims and were content with who they were.

The more recent social model of disability views the causes of disability as resulting from the interaction between individuals and their respective environments rather than the intrinsic impairments of the individual (Colver 2006). The children in Connors and Stalker’s study (2003) identified barriers such as inaccessible transport which prevented them attending after-school clubs, inaccessible buildings that prevented them participating in certain lessons in school and a lack of adult support and time for communication. Children appear to be adept at identifying social barriers but want to be seen as ‘normal’ and often resist being labelled as disabled (Shakespeare and Watson 2002). The social model of disability has politicised the way adults with disabilities see themselves and are seen by society but has not yet had much impact on the way children with disabilities are viewed (Connors and Stalker 2003). Since its proposal the social model of disability has been criticised for the lack of acknowledgment of impairment and the role it plays in people’s individual lives (Shakespeare and Watson 2002).

Extreme views of the medical and social models of disability exaggerate respectively the effects of both the intrinsic impairment and the environment on the participation of the disabled person (Forsyth et al 2007). The World Health Organisation’s (WHO) International Classification of Functioning, Disability and Health (ICF) (2001) changed the emphasis in describing and measuring disability from disease and impairment to body functions and structures, activities and participation (refer to Fig. 2:1 below).
It achieves a synthesis of both the medical and social models by recognising the importance of both intrinsic impairment and the environment on participation (Colver 2006).

Participation is defined as ‘involvement in life situations’ (WHO 2001). There are difficulties in measuring participation in children because outcome measures were developed primarily for adults (McConachie et al 2006). Findings from the SPARCLE study demonstrate that participation varies substantially across EU regions, as predicted by the social model of disability. In those countries where legislation and policy have been strongly directed towards equality e.g. Denmark, children had higher levels of participation (Fauconnier et al 2009). Importantly, pain was found to be strongly associated with lower participation in children in all the regions studied (Fauconnier et al 2009).

Personal factors, such as gender, race, age, lifestyle, habits and coping strategies, are not classified in the ICF and choice is similarly not specified although there is an assumption that it is covered in the personal factors (Morris 2009). If a child has real, effective opportunities and freedom to participate then whether they do or not is a matter of choice. Wright et al (2008), authors of a well-designed study of 35 ambulant children undergoing Botulinum toxin injections, concluded that the relationships
between changes in the different ICF levels of body functions and structure, activities
and participation following intervention, are complex, unpredictable and likely to be
influenced by the child. Therapists commented, informally to the authors, that
increasing participation was out of their control but that by increasing activity it was
hoped that participation would also increase. These authors conclude that the
development of a specific intervention-based ICF framework model, with parents
during goal setting, might assist in clarifying factors that might be amenable to
modification and the outcome possibilities across the ICF levels.

2.2.2 Power relationships

Children with disabilities are particularly vulnerable to the abuse of power. The
prejudices of society allow barriers to be created that affect their participation.
Professionals they encounter commonly act in a paternalistic rather than a consultative
manner. Similarly, parents can be over-protective and provide high levels of
surveillance that limit risk-taking and socialising (Connors and Stalker 2003). Thus
Bricher (1999) suggests that children with disabilities are doubly disadvantaged in
society, powerless because of their status as children and because they are disabled.
This lack of power affects their rights to participation and protection.

Foucault (1983) describes the dynamics of power relationships at an individual rather
than state level and identifies power as being localised and typically disguised through
the social system in the day-to-day practices of, for example, doctors, social workers,
lawyers and the church (Turner 1997). He states that the medical profession is criticised
because it exercises an uncontrolled power over people’s bodies, their health and their
life and death (Foucault 1983). He also suggests that doctors are not considered ‘figures
of domination’ but that patients themselves collude and invest in that power (Lupton
1997). The scientific / medical discourse does, however, continue to dominate the health
arena. It has embedded within it the power and the knowledge that both produce and
maintain it as the dominant discourse (Cheek and Porter 1997).

It is difficult for children to attain autonomy when others make decisions about what is
best for them. Passivity and unnecessary dependence can result. Children with
disabilities may make the assumption that their bodies are public property because of
the help they require for many aspects of self-care (Bricher 1999). This makes these children very vulnerable to abuse (DCSF 2009). Low self-esteem induced by these circumstances increases the potential for abusive practices. Conversely, children who are empowered and accustomed to being consulted in decisions regarding their own bodies are inherently less vulnerable than those who feel powerless (Bricher 1999). Foucault suggests that once the existing dominant discourse in healthcare is recognised, such assumptions can be challenged and resisted (Cheek and Porter 1997). Professionals can help by readdressing the power issues in healthcare by consulting children and their parents about treatment options. In order to play their part children will need to have knowledge shared with them from which they can make sense of the options before them.

The importance of children acquiring knowledge and decision-making skills within the context of personal relationships and social experience has been identified by Alderson (1992) when considering the gaining of consent from children. Colver (2006) suggests that children’s services may be at fault in delivering children into adult services without the necessary motivation and independence to be able to be partners in their care. He criticises children’s services for making children passive partners in their own care, rendering them unable to take on the task of decision-making during transition into adulthood. If children are to be active rather than passive partners in their care they need to have a voice.

2.2.3 Seeking the voice of the child

Communication is seen by children with communication impairments of all ages as being fundamentally important and as providing opportunities to socialise and to be active (Sloper, Beresford and Rabiee 2009). It has been stated previously that in studies investigating quality of life and pain, poor correlation was found between the self-reporting of children and parent-proxy reporting (White-Koning et al 2007; Varni et al 2005; Dickinson 2007). This is an important reason for seeking the child’s voice whenever possible. Communication impairment is one of the factors leading to a reduced quality of life, particularly with regard to a child’s relationship with parents (Dickinson 2007) and later in adulthood (Morris 2002).
There are various Augmentative Alternative Communication (AAC) aids available for children and adults with little or no speech. Complex electronic aids can be accessed through touch screen, joystick or switches and may produce voice output whereas simple tools consisting of alphabet, symbol or picture boards are accessed through finger, stick or eye pointing. Talking Mats, developed by the AAC Research Unit at the University of Stirling, consists of a Velcro mat to which picture symbols can be attached and moved around. (Refer to Appendix 2 for further details). It is designed to help people with communication difficulties to focus on the issues being discussed and to provide a method with which they can effectively communicate their opinions (Murphy 1998). It has been used in research to find the views of children, who do not use speech, regarding social care and support service priorities (Rabiee et al 2005) and in clinical practice to enable a young man to report details of sexual abuse (Venditozzi 2007).

Until the Children's Act (1989), children with disabilities were excluded from mainstream childcare legislation (Connors and Stalker 2003). The Act requires local authorities to provide a range of services for children “in need”. Children with disabilities were included in this term. A key principle of the Act is that “due regard” should be given to the views of the child in decisions made on his or her behalf (Children’s Act 1989). In 1992, the UK Government ratified the UN Convention on the Rights of the Child to express an opinion, and to have that opinion taken into account in any matter concerning them. Moreover, in Article 13 it is clearly stated that appropriate means of communication must be provided for children. This is re-iterated in the Quality Protects initiative (DoH 1998) in which people working with children should ascertain the child’s wishes and feelings and take them into account when providing services. The National Service Framework for Children: Emerging Findings document (DoH 2003) specifically states that provision needs to be made to enable children with communication difficulties to be involved in decision-making. As a result of these legislative statements children in general are more involved in policy-making, but children with disabilities continue to be excluded (Rabiee et al 2005; Morris 2003; Cavet and Sloper 2004). Efforts have been made by a small number of researchers to gain the views of older children and adolescents with learning difficulties (Rabiee et al 2005; Morris 2003; Marchant et al 1999; Ward 1997). Children with communication difficulties continue to be largely excluded although when specifically made the focus
of research such children report that they believe they have particular communication strengths; those of perseverance, patience and an ability to read other people’s communication (Rabiee et al 2005). Children who are excluded from consultation and from being active participants in decision-making are vulnerable, powerless and further disadvantaged (Morris 2003).

Parents and other carers of children have an important role in preventing them coming to harm. Negative attitudes towards children with communication difficulties, however, can lead to disabling barriers affecting the child’s involvement in research. Adults will often make judgements about a child’s ability to understand and communicate. Morris (2003) reports commonly being told: “You won’t get anything out of him. He can’t communicate so you won’t be able to interview him” (p. 340). Adults who did encourage children to be included in research sometimes wrongly assumed that the focus would be directed at the parents or carers of the child rather than the child (Morris 2003).

While there are examples in the literature of children not having appropriate communication tools (Sloper et al 2009; Morris 2003), it is frequently the lack of adult time, experience and commitment to try to understand the child’s communication that is the greatest part of the child’s communication difficulty (Rabiee et al 2005). Communication enables children to be independent, raises self-esteem and helps to ensure that basic physical, social and emotional needs are met (Sloper et al 2009). Children need all those involved in their care to have the knowledge and skills to be able to understand their method of communication. Those children who used communication aids reported wanting them to work faster and to have a wider vocabulary (Sloper et al 2009). Children with disabilities and communication impairments are often socialised into having low expectations of being given choices or expressing opinions. Morris (2002) found that these children often experience very low levels of interaction with peers and adults. Under these circumstances they often ‘switch off’ and give up trying to communicate. Other researchers found that when children are included in research and are asked for their opinions, teachers and parents are sometimes surprised by the child’s ability to concentrate and to understand the questions posed (Rabiee et al 2005).
In a rare study of the impact of disability on the day-to-day lives of 26 children and their siblings, Connors and Stalker (2003) explored feelings of self-esteem. Children reported how being made to feel different made them sad and gave examples of how being left behind in the school building during a fire drill or being excluded from school trips because of transport difficulties challenged their feelings of self-worth. This study into posture and sleep in children with cerebral palsy endorses the importance of including children with disabilities into research.

2.2.3.1 Involving all children

The difficulties of including children with profound cognitive impairments in research are demonstrated by the lack of literature (Cavet and Sloper 2004). However, Morris (2003) insists that by adapting the research tool it is possible to include all children in research. Instead of asking a child questions, it may be more appropriate to ask those questions of all the people who spend time with the child on a daily basis. A picture could then be gained without relying on a single informant. More weight would be given to the views of those who clearly liked / loved and respected the child. Spending time with a child and observing their reactions is also a useful form of information-gathering (Morris 2003).

Moreover, there was no literature found that reported children as young as three being interviewed. Four-year-olds have been included in research, however, and have been able to provide insights into their experiences of living with domestic violence, of being homeless and of living with chronic illness and pain (Irwin and Johnson 2005). Nelson and Fivush (2004) suggest the onset of autobiographical memory is at about the age of four years and that most three-year-olds have not mastered language as a representative system. This may explain the absence of research literature including this age group. The use of a pictorial system, such as the Talking Mat method, to aid questioning has not been reported on with young children but may assist children with immature language to give their views.
2.3 Evaluation of postural management

The use of postural management programmes as a means of promoting function and managing deformity in children with cerebral palsy has become widespread (Wynn and Wickham 2009). A postural management programme is described as “a planned approach encompassing all activities and interventions which impact on an individual’s posture and function. Programmes are tailored specifically for each child and may include special seating, night-time support, standing supports, active exercise, orthotics, surgical interventions and individual therapy sessions” (Gericke 2006 p. 244). Active exercise to counteract immobility is an important part of a postural management programme. The beneficial effects on muscle strength from cycling and from walking on a treadmill are beginning to be reported (Mutlu et al 2009; Williams & Pountney 2007). Orthoses are commonly used to provide muscle stretch and support against the effects of gravity. Spinal braces can help provide stability in the upright posture and facilitate handling and function (Pope 2007). The use of Botulinum toxin A is a common adjunct to the management of spasticity although its use is not without controversy (Graham et al 2008; Gough 2009).

The natural history of deformity in cerebral palsy has been clear from the posture of adults who grew up in the UK before the advent of specialist supporting equipment and during the early days of orthopaedic surgery. Graham (2004) reflects on untreated populations in rural Australia who exhibit higher levels of spinal deformity and hip dislocation than those who have had access to physiotherapy, orthoses and orthopaedic surgery. Without intervention, even ambulant children demonstrate a progressive increase in deformity leading to decreases in walking speed and increases in flexion contractures and joint stiffness (Graham 2004).

A wealth of surgical intervention has been devised to ameliorate the progression of deformity by trying to balance the muscle forces across the hip joint and centralising the head of the femur in the acetabulum (Cornell 1995; Hagglund et al 2005). The effectiveness of soft tissue surgery is questionable (Stott and Piedrahita 2004) and some studies report the need for further surgical intervention in over 60 percent of cases (Reimers 1980; Turker and Lee 2000). Bony surgery involving femoral osteotomy as well as acetabular reconstruction appears to have the best results although comparison
between studies is compromised by the use of different outcome measures (Pountney and Green 2006). Recent conference presentations (Graham 2010; Hagglund 2010), however, reported on the successful outcomes of programmes of carefully targeted orthopaedic surgery on populations of children on cerebral palsy registers in Sweden and Australia. These outcomes are discussed in Chapter 5.

Only a small number of studies have reported on the outcomes on hip subluxation as a result of intervention using non-operative, postural management programmes (Pountney et al 2002; Hankinson and Morton 2002; Pountney et al 2009). The potential wisdom of introducing the management of posture as early in a child’s life as possible is acknowledged by a consensus statement based on clinical experience of experts in the field and available scientific evidence (Gericke 2006). This statement recommends that children with cerebral palsy in GMFCS Levels IV and V should have their posture supported when placed in age-appropriate positions. This includes supported lying from birth, supported sitting from six months and supported standing from a year.

Supportive seating equipment is important in terms of function and mobility for children who lack the ability to sit independently and rely on a wheelchair for mobility. Postural support in seating enables the maintenance of postural alignment, provides a stable starting position for activities, facilitates normal movement, decreases fatigue and enhances physiological function (Pope 2007; McDonald et al 2004). The key components of supportive seating enable a child to have an upright pelvis, a straight spine in the lateral plane, horizontal femurs, hips, knees and ankles at 90 degrees and hips in neutral or slight abduction (Pountney et al 2004). Examples of supportive seating systems are presented in Appendix 1A. Objective evidence is lacking for the efficacy of supportive seating as a single intervention in managing posture (McDonald et al 2004). A systematic review of the literature, however, did conclude that there is some descriptive and mostly qualitative evidence of its efficacy in improving dexterity, cognitive ability, communication, pulmonary function and quality of life (Farley et al 2003).

Standing supports are routinely prescribed in clinical practice to enable children to weightbear in the upright position. There are three main types of standing equipment which position children in upright, supine or prone positions. The upright and prone
standers were found, in a questionnaire, to be the most popular with physiotherapists (Wintergold et al 2008). Examples of standing supports are presented in Appendix 1B. The benefits of standing are often cited as being musculoskeletal, biomechanical, physiological, sensory, psychological, emotional and social but there is little evidence to support any of these claims (Pountney 2007). A randomised controlled trial investigating the effects of increased duration of static standing on bone density in 26 young children with cerebral palsy, reported that vertebral bone density did increase but proximal tibial bone density did not (Caulton et al 2004). A review of the evidence suggests that apart from findings of increased bone density and a temporary reduction in spasticity, evidence supporting the effectiveness of static weightbearing exercises remains very limited due to the paucity of studies conducted, the inadequate attention to rigour and the small number of participants involved (Pin et al 2007). There are no guidelines available that recommend the optimal position a child should be placed in or the frequency and duration of standing (Pountney 2007).

The aim of a sleep system is to support a child in an optimum posture to promote symmetrical growth of muscles and to allow joints to rest in a neutral position (Pountney et al 2004). Spinal posture as well as that of the hips, knees and ankles is addressed. There are six sleep systems currently available on the market in the UK, most of which are easily available in the South-West. However the Snooooooze system is more commonly used close to its manufacturing base in the North of England. Sleep systems consist of a base layer or sheet with various components attached either permanently or removable and repositionable (Polak et al 2008). Similar therapeutic aims are intended but the design and materials potentially impact on both effectiveness and acceptability (Polak 2008). Four of the five sleep systems in use in the South-West are designed to be used in side-lying positions (the Chailey Lying Support is not) as well as in supine and prone. Examples of the different sleep systems are available in Appendix 1C. In a small well-constructed pilot study, Hankinson and Morton (2002) who explored the use of night-time postural management equipment reported favourable results for children sleeping in a Dreama sleep system for 12 months. This small study involving seven children showed a statistically significant 11 percent mean improvement in hip migration from baseline. Improvements in the children’s posture were supported by parental questionnaire scores that indicated an overall slight increase in the number of hours asleep and a slight reduction in the number of awakenings per
night. This triangulation of quantitative and qualitative data strengthens the findings but the small sample size is a limitation and there was a high drop-out rate of 50 percent. In a feedback study, the majority of parents reported that their child slept as well, if not better, in a Symmetrisleep night-time lying support (Goldsmith 2000). Children were reported to lie in a straighter position, had reduced muscle tone and experienced a little less pain. There were, however, no baseline measurements taken and the improvements were not quantifiable. This study also lacked clarity of method and the reliability, validity and strength of evidence is thus questionable. The researcher did not acknowledge any bias with regard to the choice of the Symmetrisleep equipment. The study is helpful to clinicians by highlighting the need for follow-up advice and support for families to enable them to continue using a Symmetrisleep at night. With only one small study measuring the effects of using a sleep system for 12 months, critics of the 24-hour postural management concept are able to quote a lack of substantial evidence (Gough 2009). Key authors in the field also argue that further research to determine the effect of postural management at night is necessary (Pountney et al 2009).

While evidence for the effectiveness of each element of 24-hour postural management, i.e. supportive seating, supported standing and sleep systems, is limited, studies investigating the effectiveness of all three together provide more information. Pountney et al (2002, 2009) are key figures in this field of research and have conducted two major studies, one a retrospective (Pountney et al 2002) and the other a prospective study (Pountney et al 2009). Their results from 41 and 39 participants respectively suggest that children are more likely to maintain hip integrity if they use Chailey Adjustable Postural Support (CAPS) equipment in sitting, standing and lying prior to hip subluxation than if they do not.

The aim of the retrospective study (Pountney et al 2002) of notes and X-rays of children with bilateral cerebral palsy was to determine the effect on hip migration from the postural management programmes children had been following. The variety of equipment used necessitated delineating children into 3 categories; those who had used CAPS equipment in sitting, standing and lying, those who had used CAPS equipment in two of those three positions and those who had used either the CAPS seating alone or no CAPS equipment at all. Some of the latter group may have used other sleep systems and or different standing equipment. The results showed that significant benefit is gained from using the CAPS
equipment in all three positions prior to hip subluxation. This group of children were significantly more likely to maintain hip integrity than children in the other categories. CAPS equipment is designed to position children at a higher level of ability than they could otherwise achieve (Pountney 2002). Movement can then take place from a symmetrical starting position allowing more normal movement patterns and enabling neuronal selection of those more normal movement patterns (Pountney et al 2002). The authors state that it is necessary to identify children at risk of deformity very early in life in order to alter the process of changes in muscle length and strength leading to aberrations in bony development around the hip. The strength of the evidence of the retrospective study suffers, however, from reliance on records that may be inaccurate or in some cases missing. The complexities of analysing the different types of equipment used in different services and families were overcome by rationalising them into three groups which greatly aided the clarity but may have over-simplified the results.

The prospective study (Pountney et al 2009) of 39 children investigated the impact of introducing 24 hour postural management programmes to children of eighteen months or younger. The results showed a decrease in the percentage of children with hip problems at five years of age in the intervention group (36.8 percent) compared with an historical control group (58 percent). Children who used the equipment moderately (two items of equipment for a minimum of six hours a day) or as recommended (three items with seating used for six hours and standing for one hour a day) were more likely to have both hips safe than those who did not follow recommendations. The control group, taken from historic data collected by Scrutton et al (2001) is likely to be too different from the intervention group to be a useful comparison. With the passage of time, treatment modalities have changed. Botulinum A toxin and intrathecal Baclofen were not available for the control group and techniques for surgical intervention have developed. The results, similar to other studies investigating the effects of postural management equipment, are limited in their generalisability to other makes of equipment. Despite these limitations, the study provides valuable evidence of the progression of hip subluxation in children using postural management equipment which adds to the small body of knowledge in this specialist field.

Forty-one percent of the five-year-olds in the prospective study had one or both hips subluxed (Pountney et al 2009) and 34 percent of the retrospective group despite recommended or moderate use of their postural management equipment (Pountney et al 2002). For those children who appeared to benefit, the long term outcomes of the approach are still not clear. Pountney et al’s retrospective study (2002) had follow-up periods of between 1.2 and 16.9 years. To date the prospective study (Pountney et al 2009) has reported on children up to the age of five. It is known, however, that there is a continuing risk of hip subluxation into adolescence (Vidal 1985; Morton et al 2006). Further long term data are required before there can be confidence in the postural management approach. This has been identified as an important gap in knowledge and an area for further research (Pountney 2009).

It is unclear which children are most likely to benefit from postural management. Graham (2004) suggests that it is difficult to prevent progressive deformity in the more severely affected children even with optimal treatment. Gough (2009), a critic of 24-hour postural management programmes, postulates that the children most at risk of deformity are the least likely to be able to tolerate the equipment, sleep systems in particular, and suggests children experience discomfort and pain from muscles being stretched during the use of such equipment. Gough (2009) quotes a study exploring the effects of Botulinum Toxin A and a hip abduction brace on hip migration (Graham et al 2008) as an example of the lack of effect of postural management. The use of the hip abduction brace, however, was for a mean duration of only 5.6 hours a day. The other positions adopted by the children in the study for the remaining 18.4 hours would need to be taken into consideration. The results did demonstrate a small effect and the authors suggest that combined treatment may delay the need for surgery. They did not consider the treatment effect worthwhile pursuing. This compares with the findings from Pountney et al. (2009) in which an effect was recorded with ‘moderate’ use of postural management equipment, i.e. six hours a day. These authors state that the size of the effect at this level of usage could not be quantified precisely. They suggest that a combination of different approaches including postural management, Botulinum toxin injections and surgery may achieve successful long term outcomes. Hankinson and Morton (2002) reported their impression that the burden of care was reduced for those children who could tolerate the Dreama sleep system. Burden of care was based, however, on the answers to questions asking about ease of positioning of hips in sitting,
sleeping and cleaning. Analysis of the care required for using the sleep system was not given. Gough (2009) asserts that postural management increases the burden of care for families. This is not an evidence-based opinion, however, as parents and children were not questioned about their experiences of using a sleep system.

Twenty-four hour postural management programmes involve the use of supportive equipment in sitting, standing and lying but while seating systems and standing frames are popular amongst therapists and prescribed routinely, sleep systems do not engender the same level of enthusiasm.

2.3.1 Use of sleep systems

A national stakeholder survey of paediatric physiotherapists’ views on the current sleep systems, gave some insight into why such equipment was not always used (Polak et al 2008). In this postal survey, which had a 24 percent response rate, 68 percent of therapists participating in the survey used sleep systems. Fifty-five percent, however, reported having a child on their caseload who needed a sleep system but did not have one through parental choice or lack of funding. Rejection of sleep systems by parents, according to the physiotherapists, was due to reluctance to alter a child’s sleep pattern, concerns about comfort, lack of an immediate tangible benefit, aesthetics of the sleep systems and concerns about night-time postural management in addition to that during the day. Portability of the sleep system was also an issue for parents.

Some studies (Hankinson and Morton 2002; Pountney et al. 2009) investigating the effects of postural management report the drop-out rate in use of night-time positioning equipment as particularly high. Hankinson and Morton (2002) reported that six out of 14 were unable to sleep in the Dreama sleep system either before the start of the study or within three months. Of these children, five were nine years or more of age which may account for an increased difficulty in adapting their sleeping posture due to habit or muscle contractures, two of whom, with limited hip abduction, could not achieve the desired position within the sleep system, and another had poor sleep. Reporting on the prospective study, Pountney et al. (2009) conclude that the sleep system was the least used piece of postural management equipment. Twenty three percent of their cohort (nine out of 39) had abandoned it by the end of the study. The reasons offered for this are that seating and standing equipment provide obvious functional and inclusive
positions for activity whereas sleep systems may have caused an increase in disturbances at night and have been, therefore, less acceptable. In-depth interviews with parents and children would have provided useful insights into the children's and parents' reasons for abandoning their sleep system.

On the other hand, the Mansfield Project (Goldsmith 2000) reported a low drop-out rate, attributed to the thorough training and support of parents, with only three out of 31 families (9.7 percent) abandoning the sleep system after a year. This latter percentage was mirrored in local practice in North Devon where the drop-out rate of families using sleep systems was two out of 22 (9 percent) over a three year period (2004-2007). This anecdotal evidence is not reliable but formal training for parents and regular contact and support is also a key feature in this service (Humphreys and Pountney 2006).

No studies to date have examined precisely why families either do not adopt, or adopt but then abandon, the use of a sleep system although in a postal survey therapists suggest that one reason is that parents are wary of interfering with children’s sleep (Polak et al 2008).

2.4 Sleep difficulties

The term sleep difficulties is defined as follows: 1) the child wakes in the night three or more times a week, disturbing the parents and taking more than a few minutes to go back to sleep; 2) problems three or more times a week when the child takes more than one hour to settle to sleep, disturbing the parents; 3) waking before 5.00 a.m. three or more times a week (Wiggs and Stores 1998).

2.4.1 Prevalence and aetiologies of sleep difficulties

Estimations of the population of children with cerebral palsy with sleep difficulties vary depending on the thresholds used. In a large, well-designed study using the standardised normative Sleep Disturbance Scale for Children (Bruni et al 2005) with 173 children, it was reported that approximately 23 percent of children with cerebral palsy had severe sleep problems compared with five percent of typically-developing children (Newman et al 2006). In a study of 505 families, 48 percent reported current sleep difficulties, with 23 percent defining them as severe and chronic (Hemmingsson et al 2009). In a
A review of the literature, Jan et al (2008) suggest the figure may be as high as 75 percent to 80 percent in a wider population of children with neurodevelopmental disabilities.

The sleep problems described in studies of children with neurodevelopmental disorders and poor sleep tend to fall into two categories; physical problems related to their medical condition and behavioural problems that may include environmental issues (Jan et al 2008).

The physical problems affecting sleep are described in section 1:1 and include muscle spasm, pain, and inability to change position at night (Newman et al 2006; Hemmingsson et al 2009). Epilepsy is known to interfere with sleep physiology while anti-epileptic medications frequently cause daytime sleepiness (Jan et al 2008; Stores et al 1998). Severe visual impairment affects melatonin secretion in addition to the child’s ability to perceive the onset of darkness, a visual clue to impending bedtime (Newman et al 2006).

Sleep hygiene, the habits and behaviours around the bedtime routine, is important for good sleep. There is some evidence that the emergence of the ‘24-hour society’ is affecting the sleep of many children and teenagers world-wide (Jan et al 2008; Moran-Ellis and Venn 2007). Transition for children between waking and sleeping often involves issues of power with parents and siblings (Moran-Ellis and Venn 2007). The impact of irregular bedtimes and wake times and lack of bedtime routines may be compounded by other medical problems affecting sleep in children with cerebral palsy. Problems associated with settling for sleep and problems with night-waking may be caused by the child not having learned the rules of appropriate night-time behaviour (Quine 1997). Behaviour problems are the primary cause of reduced psychological and physical health of carers of children with cerebral palsy and family functioning is the key factor in regulating these health outcomes (Raina et al 2005).

Environmental factors, such as noise from other family members and bedroom-sharing are also known to play a part in sleep problems (Jan et al 2008; Moran-Ellis and Venn 2007). Newman et al (2006) reported an association between single-parent households and increased sleeplessness in children with cerebral palsy as well as an association between bed-sharing and difficulties of initiation and maintenance of sleep. They
acknowledge, however, that bed-sharing may be a coping strategy for parents when children have poor sleep rather than poor sleep being an outcome of bed-sharing.

### 2.4.2 Sleep-related breathing problems

Breathing disturbances at night are another factor known to affect children with cerebral palsy particularly those with obstructive and central sleep apnoea (Hill et al 2009; Newman et al 2006; Seddon and Khan 2003; Kotagal et al 1994). Oropharangeal motor problems, gastro-oesophageal reflux, poor cough and airway clearance and abnormalities in the functioning of the respiratory centre are contributing causes (Seddon and Khan 2003). In a seminal paper, Kotagal et al (1994), using 16-channel polysomnography, report that children with severe cerebral palsy have a significantly greater respiratory disturbance than nine similarly-aged children with sleep apnoea (mean age of three and a half years). The respiratory disturbances were reported as being a mixture of central and obstructive apnoeas and obstructive hypopnoea. These children also demonstrated significantly fewer changes in body position despite dangerously low oxygen saturation levels. This study is limited by the retrospective nature, the small sample size and the single night’s recording but it highlights the difficulties and dangers with breathing experienced by these children during sleep.

In a pilot study, Hill et al (2009) report a high prevalence of mild obstructive sleep apnoea in children with cerebral palsy. They suggest that the emerging evidence of cognitive impairment in typically-developing children with mild obstructive sleep apnoea makes their findings a cause for concern.

The inability to change position to compensate for disordered breathing poses a particular risk for children with cerebral palsy (Kotagal et al 1994). Securing children in a sleep system, commonly in supine, may increase the risk of respiratory compromise (Hill et al 2009). The Chailey Sleep Questionnaire has recently been developed as a tool to facilitate the assessment of risk for a child using a sleep system (Khan and Underhill 2009), and is currently in the process of being evaluated.
2.4.3 The effects of impaired sleep

Impaired sleep can adversely affect mood, causing irritability and depression. Behaviour can be altered with children becoming hyperactive, impulsive and aggressive. Learning, memory, attention and executive functioning are affected if sleep is insufficient or inefficient (Jan et al 2008). Sleep fragmentation caused by the child’s inability to maintain sleep is commonly found in children with cerebral palsy and is known to be detrimental to memory consolidation (Hill et al 2009; Kotagal et al 1994). Children with cerebral palsy lack the cognitive reserve to compensate for poor sleep and are therefore particularly vulnerable to its effect on learning (Hill et al 2009). Impaired sleep also impacts on a child’s physical health. It predisposes children to cardiovascular and metabolic dysfunction and difficulties with co-ordination. Children who lack sleep are also more likely to sustain accidental injuries (Jan et al 2008). High muscle tone is reduced in deep sleep and relaxation can occur. If sleep is disrupted and fragmented this beneficial effect is lost (Lin 2004).

The effects of parental chronic sleep deprivation have also been described and include feelings of helplessness, frustration, anxiety, anger and depression (Jan et al 2008; DH 2004; Quine 2001; Quine 1997). Mothers of children with additional needs report high stress levels, increased irritability, poor marital relationships and negative attitudes towards their spouses, their children and themselves (Quine 1997). In a postal survey, 51 percent of 375 respondents with severely disabled children reported that lack of sleep impacted on the relationship with their partner (Cowdell and Parrott 2007).

Women continue to be the primary carers within families and provide not only physical care but also emotional involvement, anticipating the needs of family members and worrying about them. They are more likely to get up in the night to provide both physical and emotional care for their children than their partners (Venn et al 2008). Differences in caring behaviours are suggested, with fathers, for example, providing physical care while mothers tend to have emotional engagement as well. Whereas fathers were reportedly getting up when their children required physical care they were not anticipating those needs as the mothers would (Venn et al 2008).
Parents may get up once or more every night but not report that the child has a sleep problem (Hemmingsson et al 2009). Hislop and Arber (2003) suggest that women may consider that to get up in the night to provide care for a child is just a part of ‘a woman’s lot in life’. Mothers of children with medical diagnoses affecting their sleep may feel this responsibility even more keenly. In a study of women in mid-life, Hislop and Arber (2003) found women expected to continue to fulfil their responsibilities to their families through the night. The fact that they were woken by young children during the night was seen as part of the role of caring for their family. The women interviewed also responded to their teenage and even adult children at night to the detriment of their own sleep. These women appeared to accept that they had no control over their sleep. Instead they tended to adapt to the situation and had a pragmatic approach towards it. They judged ‘normal’ sleep against what was likely for them rather than an imposed norm set by others.

Identifying those parents who are having very fragmented sleep but are not reporting sleep difficulties requires clinicians to enquire not only about a child’s sleep problems but also about the attention at night that parents are giving their children (Hemmingsson et al 2009).

2.4.4 Support services available for families with poor sleep
Interventions for children with sleep problems have typically involved the use of medication although there is little evidence to support the efficacy of this approach (Quine 2001). Programmes to advise parents on how to improve their child’s sleep hygiene have recently been advocated (Jan et al 2008) but support for families struggling with poor sleep is frequently unavailable. This situation is acknowledged in the National Service Framework for Children, Young people and Maternity Services (DH 2004) and reiterated in the Aiming High for Disabled Children programme (DES 2007). It is proposed that behavioural sleep programmes to help families manage their child’s sleep pattern should be available early on to prevent parents experiencing the consequences of chronic sleep difficulties.

Sleep intervention services in the future may be informed by the outcomes of research currently being funded by the newly formed government-funded Centre for Excellence.
and Outcomes in Children and Young People's Services (C4EO). This body has commissioned research into the effectiveness and costs of early identification and behavioural intervention for sleep problems in children with disabilities. A systematic review of the existing evidence suggests that providing information on behavioural techniques for sleep problems to parents in a booklet, in a single face-to-face interview or with more intensive personal programmes can be effective (McDaid and Sloper 2008). This corresponds with anecdotal evidence from the MENDS Trial, a current study on the effectiveness of melatonin in children with learning disability, in which 50 percent of the potential participants had improved sleep following preliminary intervention with a face-to-face interview and a booklet on behavioural techniques (Smith 2009). McDaid and Sloper (2008) conclude that more research is needed across different types of disabilities and on the long term outcomes of the cost-effectiveness of different interventions and parental preferences. Much of the previous research has focussed on children with learning difficulties rather than those with physical difficulties (Wiggs 2004; Didden et al 2002; Quine 2001). This is identified as a gap in knowledge and an area for future research (McDaid and Sloper 2008).

‘Sleep Scotland’, a charity, pioneered a national programme of training to ‘sleep counsellors’ for children with additional needs on behavioural and cognitive techniques. They claim to have made a difference in 16 out of the 17 families followed up, some of whom exceeded their initial goals. More than half of these parents felt their child’s sleep problems had significantly improved (Ansell 2009). ‘Sleep Solutions’ has similar ambitions in England. The stated aim of both charities is to work in partnership with the statutory services. They both have substantial information resources on their websites. Cerebra, a charity working to support families with children with disabilities, also have a sleep support service. Their three sleep nurses cover England and provide a telephone counselling service and face-to-face clinics.

2.5 Competency of therapists

The knowledge and skills of the prescribing therapists were assumed by the researcher to be important factors in how children and parents experienced sleep systems. The therapists need to be able to identify whether a child is suitable for a sleep system, match that child to an appropriate sleep system and then to inform the parents how the sleep system may help reduce the risk of future deformity.
Clearly, parents rely on therapists on the grounds of their professional status, specialist knowledge and experience with similar children. Therapists are expected to be able to inform parents of the appropriate choices in interventions and to guide them in decision-making (Young et al 2006). The Department of Health states that therapists should offer treatment choices based on sound assessment of the child’s clinical picture, functional status, pain levels and long term prognosis. The social and emotional implications and the predicted outcomes and financial costs should also be taken into account (DoH 2004). Physiotherapy’s regulatory body, The Chartered Society of Physiotherapy (CSP), requires that “individuals can demonstrate knowledge and understanding that is relevant to their individual scope of practice”. It also acknowledges “that an individual’s knowledge will develop according to their experiences and context of practice” (CSP 2009 p.3). However, pattern recognition is an essential part of expert clinical reasoning (Doody and McAteer 2002) and unless therapists are regularly addressing these issues in their clinical practice pattern recognition is not possible.

It is evident that therapeutic practice and prescription of orthoses for children with cerebral palsy vary among different therapy teams (Morris et al 2002) and it could be assumed that this is also the case in the prescription of sleep systems. Well-established models of treatment, such as the Bobath approach, may have little evidence of efficacy but challenging them can be controversial (Kollen 2009). In his 2005 report on The State of the Nations’ Health, Sir Liam Donaldson suggests that variation is caused by the personal preference and habits of clinical decision-makers (DH 2006). He recommends that commissioners of health services reaffirm their commitment to the NHS principle of equity. A group of experts convened to consider how to get evidence into practice stated that ‘inappropriate variation may be a function of poor knowledge, the flawed application of the correct knowledge, a lack of resources, or the inappropriate allocation of extant resources’ (DH/CMO 2007 p. 8). The group recommended further use of guidelines to embed evidence into clinical practice.

To consider the issue of variation in clinical practice literature was reviewed to investigate the guidance provided by national bodies.
2.5.1 Documentary guidance on postural management

2.5.1.1 National policy

Postural management is identified as an important element of early intervention for the prevention of the development of deformities in children with developmental disabilities (DH 2004). Children may suffer “irretrievable loss of function or ability” if early intervention is delayed (p. 23). Further warnings about the consequences of a lack of early postural management are described in Aiming High for Disabled Children: Better Support for Families (DES 2007 p. 48):

“Postural management and other occupational therapy and equipment services for disabled children can prevent deformities (which can start to develop at three months old), which may be more life-limiting and painful than their original condition, and might impact on digestion and respiration which can lead to costly and painful surgery.”

Children should have timely access to postural management at night according to the government recommendations (DES 2007; Franklin 2009) and an expert consensus of opinion (Gericke 2006). In a government document a mother describes her frustration:

“My son needs a sleep system – a very basic set of pads he needs in his bed – which the PCT has decided it won’t pay for. We have had to ask a charity to provide it. We know that other PCTs do fund this kind of equipment – it seems to be a complete postcode lottery.”

Suzanne (Franklin 2009).

Healthcare for All (Michael 2008), states that children with complex disabilities are commonly not receiving early intervention to prevent postural deformities and families are not receiving the support they need to manage their child’s sleeping position.

“There ... appears to be a gap in services for children with profound disabilities and complex needs who have musculoskeletal problems. Early interventions are not undertaken to prevent postural deformities from developing. Many families receive no support or advice about how to manage the sleeping position of their child and the Inquiry heard examples of cases where later wheelchair use and/or back surgery could have been avoided if effective early intervention had been provided.” (Michael 2008 p. 19)

It is evident that there is a variation in provision of postural management equipment around the UK.
A search for guidelines on postural management for children with cerebral palsy, from the National Institute for Health and Clinical Excellence (NICE), produced no results. Postural management is also not mentioned in a guideline for spasticity in children which is currently under development and which includes, in the scope document, the intention to investigate the effectiveness of physiotherapy interventions to reduce spasticity and its direct musculoskeletal consequences, such as muscle shortening (NICE 2010).

2.5.1.2 Clinical Interest Groups

Clinical interest groups, within the profession of physiotherapy, exist to provide practice guidance for clinicians. The Association of Paediatric Chartered Physiotherapists (APCP) recommends that children at risk of hip subluxation should have access to postural management equipment including sleep systems. It states that the importance of positioning, during the day and night, increases inversely with the age of the child but should continue throughout life. Emphasis is placed on the importance of correct positioning for infants who are born prematurely, suggesting that it can prevent muscle shortening and femoral anteversion which can lead to hip subluxation (Monterosso et al 2006; Downs et al 1991). It reports evidence suggesting that 24-hour postural management programmes can reduce hip subluxation if introduced sufficiently early (APCP 2001). A practical guide to the prevention and management of hip dislocation in children with cerebral palsy recommends that postural management, during the day and at night, is started as soon as risk factors are identified and before there is clinical evidence of hip dysplasia (APCP 2002).

2.5.1.3 Regional Provision

Evidence of variation in clinical practice and funding for sleep systems was obtained from key children’s therapy managers in South-West England. Within this region some therapy services had developed a pathway and guidelines to facilitate the provision of postural management. North Devon, for example, where postural management has been embedded in practice since 2003, has an integrated care pathway for 24-hour postural management (Humphreys and Pountney 2006). Further to that an X-ray protocol to guide the process of hip surveillance has been developed (Bunney and Humphreys 2009). Another service, in Cornwall, had written guidelines which were being updated.
Other therapy managers in the region, however, have no such guidelines and one suggested at a local Paediatric Physiotherapists in Management meeting, having a regional policy on postural management to assist in raising the profile of this clinical area with their commissioners. This request was made in October 2008, seven years after the guidance was published by their clinical interest group. This demonstrates the difficulties with and time taken for evidence to reach and influence clinical practice if there is no local champion to drive it.

2.5.1.4 Integrated care pathways

Integrated care pathways are a means of incorporating research into practice, reducing variation and of empowering patients and staff (CSP 2002). A pathway is defined as that which “determines locally agreed multidisciplinary practice, based on guidelines and evidence where available for a specific patient/client group. It forms all or part of the clinical record, documents the care given, and facilitates the evaluation of outcomes for continuous quality improvement” (CSP 2002 p.2). Integrated care pathways are a recommended route for delivering a systematic service (DH 2005).

The benefits following the implementation of a care pathway depend on the focus of the pathway and are cited as including reductions in length of stay in hospital and readmission rates, improved patient information and improved clinical outcomes (De Luc 2000; Johnson et al 2000). Humphreys and Pountney (2006) report that clinicians perceived that their intervention had become proactive rather than reactive and that team working had been enhanced as a result of developing and implementing an integrated care pathway for 24-hour postural management. The care pathway acted as a signpost for junior staff through the complexities of managing this client group and enabled a sustainable training package to be developed for parents and all carers. Participants in the Humphreys and Pountney study concluded that the service for children had improved as a result of the care pathway.

2.5.2 Organisation of therapy services

The government agenda for people with long term conditions, including cerebral palsy, has two underlying premises; patients and their families will be informed and empowered and services need to be prepared, pro-active and integrated, health with
social care. Services should provide personalised, yet systematic, continuing support built on evidence-based national and local guidelines (DH 2005).

The triangular model of healthcare adopted from Kaiser Permanente, a private provider of healthcare in the US, has been seen as a useful way forward in managing people with long term conditions (DH 2005). The model is a three-tier system of increasing intervention in which the majority of patients self-manage when informed and empowered at the base of the triangle. Kaiser principles include having committed and engaged leaders, having a highly committed workforce and placing the patient, who has a sense of responsibility, at the centre of the services provided (DH 2005). The tenets of the triangular model can be adapted for the provision of postural management services. This is presented in figure 2:2.
Figure 2: Kaiser Permanente triangular model of healthcare, adapted for provision of postural management services

The aspiration from government for people with long term conditions contrasts with the findings of the independent inquiry, Healthcare for All (Michael 2008) which states that good practice is patchy and far from common. The report continues by suggesting that:

“*For the most part, innovation and good practice owes more to the enthusiasm of energetic individuals than to any structured and systematic engagement by health services.*” (p. 9)
2.6 Summary of gaps in current knowledge

Prevention of pain and deformity remain priorities in treatment for the most severely affected children with cerebral palsy. Twenty-four hour postural management is a conservative, non-invasive approach commonly adopted by therapists to try to achieve this although there is, as yet, limited evidence of its effectiveness.

Night-time postural support is recommended on available evidence by an expert group although similarly, there is little evidence to date of its role in the prevention of deformity (Gericke 2006). There is evidence that some sleep systems are not tolerated, however, and are either not initially adopted or are adopted but then abandoned. Poor sleep and inability to adapt to a change in sleeping position is thought to be a cause of abandonment (Hankinson and Morton 2002). Pountney et al (2009) propose that sleep systems may cause children to be more disturbed at night and that as they may already be poor sleepers this extra disturbance is not acceptable to their parents. It is also suggested that children with severe difficulties experience pain while using sleep systems, resulting in parents abandoning the equipment (Gough 2009). There is some controversy as to whether the burden of care is increased (Gough 2009) or decreased (Hankinson and Morton 2002) by the use of sleep systems. The in-depth experiences of children using sleep systems and their parents have not been explored and would inform the causes of non-adoption or abandonment of sleep systems and the level of care required for their use.

Children are rarely consulted on therapy interventions and the techniques required to consult with young children with little or no verbal communication, who may also have cognitive impairments, are not well-tested or described.

It is expected that therapists should have the knowledge, skills and experience to be able to competently assess a child for the requirement for postural management at night (DOH 2004). Despite guidance from national bodies and specific interest groups, therapists’ provision of sleep systems continues to vary across the country. The clinical reasoning, knowledge, skills and experience of therapists who are prescribing sleep systems have not been investigated.
Provision of equipment that may be quickly abandoned is wasteful both in terms of public finances and time which the child, parents and therapist could have spent more usefully. If postural management at night is an appropriate means of reducing or preventing painful deformity then the reasons for the non-adoption or abandonment of sleep systems by some and the successful use by others need to be more clearly understood.

2.7 Aims and objectives of the study

The aims of the study are:

1: To explore the views of children on using a sleep system.

2: To explore the role of the parents in the use of a sleep system.

3: To explore the effects on quality of sleep in children with cerebral palsy using a sleep system.

4: To explore the role of the therapist in the child and family’s experience of using a sleep system.

The objectives are:

1: To identify factors which influence:
   - A child’s use of a sleep system at night.
   - The role of the parents / carers in the use of the sleep system.
   - The role of the therapist in prescribing the sleep system.

2: To produce findings to guide clinical practice.
CHAPTER 3: METHODOLOGY, METHODS AND DATA ANALYSIS

3.1 Methodology

3.1.1 Ontology and epistemology: Constructivist realism

Methodology underpins the construction of a research study. Brown et al (2003) suggest that the researcher frames the research question in the way they do because of their world view. This researcher, however, had not previously, consciously, considered her world view and the research question had been the starting point of the study. From there the working went backwards considering first the methods and then the theoretical perspective and overarching epistemology and ontology. Interviews were the method for answering the research question but there had to be consideration, for the first time, of personal assumptions about reality and human knowledge. To begin with such notions were discarded as unnecessary and that a pragmatic, common sense approach to the research question was all that was required. With further reading and reflection, however, personal beliefs about the nature of reality became more obvious. Although philosophically interesting and challenging, the notion that there is no external world but instead multiple internal worlds, each created by individual observers and that if an object is not being observed it does not exist, is not plausible. Acceptance of the concreteness and solidity of a real world which exists independently to the observer is fundamental to the belief system of this researcher. However, while an external world exists it would seem that individuals do have different interpretations of it, or different experiences of it, depending on their personal histories, social backgrounds and cultural assumptions. Endeavouring to place these tenets of belief within the major paradigms became problematical as they appeared to reach into the domains of both positivism and constructivism.

Pacifists in the ‘paradigm wars’ of the 1970s, 1980s, and 1990s argued that both positivism and constructivism are compatible and that this ‘compatibility thesis’ can be
based on a new and different paradigm, pragmatism (Tashakkori and Teddlie 1998). Cupchik (2001, p.3) also argues that the two opposing academic communities “have different albatrosses dangling from their epistemological necks”. The positivists use measurement and can “transform meaning into nothingness” while for the constructivists the “priestly use of impenetrable language can generate meaning but only for the initiated”. The relevance of accommodating both approaches is evident. Cupchik suggests an alternative ontology, constructivist realism, so called because both approaches “construct” data and both live in a real social world which is reflected in daily life and which exists prior to and independent of analysis.

Under the auspices of constructivist realism, objective and subjective views of the world are brought closer together. The stance of positivism, in which the knower and the known are distinctly separate, is challenged by scientists themselves with Heisenberg’s principle in quantum physics demonstrating that phenomena are transformed by the act of observation and measurement (Cupchik 2001). Likewise, a social order could be said to exist externally even though, as constructivists would claim, individuals might subjectively construct interpretations of events differently (Cupchik 2001). Discussions of “truth” can also be seen to have arbitrary boundaries with positivists accepting that new theories replace old ones over time, bringing them closer to the constructivist view that truth is relative. Physiotherapy training, in the medical tradition, had bestowed the assumption that truth is knowable and measurable; that scientific knowledge is objective and empirically verifiable. In clinical practice, however, an effective practitioner requires a world view that acknowledges that individuals hold a variety of values and world views. Experiential and tacit knowledge bring an understanding of the wide diversity in human behaviour and motivation (Higgs et al 2004).

Consideration of an ontological and epistemological position is not an obvious starting point for a research study that is based in clinical practice (Morgan 2007; Cupchik 2001; Tashakkori and Teddlie 1998). Pragmatism, however, is a practical research philosophy for research in the real world.
3.1.2 Theoretical perspective: Pragmatism

The philosophy of Pragmatism has its roots in the United States with American scholars William James, Dewey and Peirce who stated that “practical application is all” (Bragg 2005). Dewey contended that philosophy should lead to social change and that how we discover or create knowledge should be a collective and social effort that begins from a practical problem that needs to be solved (Bragg 2005).

The pragmatic viewpoint fits with this author’s philosophy that the method and paradigm follow the research question. Trowe (1957) in Tashakkori and Teddlie (1998, p.21) encourages researchers to “get on with the business of attacking our problems with the widest array of conceptual and methodological tools that we possess and they demand”. And Howe (1988) asks “… why should paradigms determine the kind of work one may do with inquiry ...?” House (1994) similarly states there is “no guaranteed methodological path to the promised land” (Tashakkori and Teddlie 1998, p.11). This type of approach would seem to be very relevant to the health sciences as it is so closely tied to practice and action (Brown et al 2003).

Pragmatists rejected the metaphysical idea that truth is static, absolute and eternal, preferring to think of truth as temporal. “Truth is what works” said Peirce (Bragg 2005) and “Truth is the opinion which is fated to be ultimately agreed to by all who investigate” Russell (1946). They deny that Truth can be determined once and for all and are unsure if one explanation is better than another but that “one approach is better than another at producing anticipated or desired outcomes” Cherryholmes (1992).

Howe (1988) suggests that truth cannot be taken out of the context of “current beliefs, interests and projects”. This explanation of truth would seem to fit well with the study in question and the researcher’s world view in which individual experiences, values and beliefs are likely to create multiple realities and “truths”.

The notion of causality in pragmatism is very down to earth and practical. They believe that there may be causal relationships but that they can never be pinned down completely (Tashakkori and Teddlie 1998). House (1994), however, coming from a post-positivist standpoint, in Tashakkori and Teddlie (1998, p.29), thinks that this is
“overly pessimistic” and that scholars do create new explanations of the physical world and that these new explanations are simply better than previous ones but are not finally correct. Pragmatism does accept the notion of an external reality and that causal relationships should be explored (Tashakkori and Teddlie 1998). Both postpositivists and pragmatists would agree that the results from data could be explained by multiple theories but postpositivists would strive for constantly better explanations whereas pragmatists would recognise that since we cannot ever understand them completely the researcher should accept the explanation that most closely fits with their world view and set of values (Tashakkori and Teddlie 1998). Pragmatists therefore could be seen as overly pessimistic but considering that the researcher would have designed the study it may often be the case that the “better” explanation and that that fits most closely with the researcher’s values are one and the same (Tashakkori and Teddlie 1998).

Pragmatism is often adopted to justify the use of mixed methods in research but its philosophical standpoint appears to this researcher to be a valid means of bridging the gap between positivism and constructivism regardless of which methods are to be used. Recent writing on pragmatism suggests three central tenets to the approach (Morgan 2007). Firstly, that it makes use of both inductive and deductive reasoning, termed ‘abduction’, when moving between theory and data; stating that the research process inevitably includes both. Secondly, the dichotomy between complete objectivity or complete subjectivity of the researcher’s relationship with the research process as in positivism and constructivism is overcome with an ‘intersubjective’ approach which captures this duality. This provides an acceptance of there being a single external world which individuals perceive and interpret differently. Thirdly, the pragmatic approach suggests that findings of research need to be considered in terms of what can be transferable to other settings rather than in terms of findings being so specific as to be context-bound or alternatively a completely generalisable set of principles (Morgan 2007).

Qualitative researchers can and do make efforts to increase the trustworthiness of their conclusions. Green and Thorogood (2004) discuss rigour in terms of transparency, validity, reliability, comparison and reflexivity (see Issues of rigour in Chapter 3) while Yin (2003) uses the terms construct validity, internal and external validity and reliability. This study uses the former. The pragmatic approach, considering the
transferability of findings to other settings, could consider the findings as providing a ‘sensitising’ effect for readers and encouraging new ways of thinking.

The methodological construct for the study is simplified in Figure 3:1. The arrows go both up and down because the research question was the starting point but the ontology provided the framework for the type of knowledge to be produced.

3.1.3 Choice of Methodology: Case study

The practical approach to answering the research question was to use case study which is described by Robson (2003 p. 52) as involving “… an empirical investigation of a particular contemporary phenomenon in its real life context using multiple sources of
Views differ as to whether research using the study of individual cases is in fact a methodology or simply the way in which the sample is selected (Green and Thorogood 2004). Stake (2000) suggests that case study as a methodological approach is most useful when the object of the case is specific, unique and bounded. Merriam (1998) states the interest in case study is in “process rather than outcomes, in context rather than a specific variable, in discovery rather than confirmation”. Yin (2003) also argues that case study involves a specific research design and methodological approach that explicitly includes context and that it is the preferred approach when the researcher has no control over events. This is in contrast to the phenomenological approach in which context is not considered important nor are the antecedents or consequences of the issue under investigation. Phenomenology, as a research approach which seeks to gain a detailed understanding of the lived human experience, produces findings that are less able to be generalised to other situations than other methods of enquiry (Brown et al 2003). In case study, if the case is described carefully and contextualised, or if several cases are studied to give a range of examples, readers can consider if generalisations can be made to other situations (Yin 2003). Stake (2000) remarks that most academics only study individual cases if there is the hope that generalisation can be made and Adelman et al (1980, p.59) describe case study as “strong in reality, down to earth and attention-holding” and as such providing a natural basis for generalisation and they describe “the truths” resulting from good case study as being “guaranteed” by the “shock of recognition.” Kemmis (1980) suggests that case study reports should enable the reader to re-create the case in their imagination. Simons (1980) cites paradox as the point of case study in which study of the unique is paralleled by the requirement to generalise in order to understand the universal.

The beliefs, attitudes and biases of the researcher are explicitly ‘bracketed out’ when using a phenomenological approach to answer a research question (Brown et al 2003). In this study in which the researcher’s beliefs and attitudes, acquired from her clinical background, provided the basis for the investigation and directed the focus of the questioning in the interviews, a phenomenological approach would not have been appropriate.

Case study was particularly appropriate in exploring this research question because of the need for depth, accuracy and richness of data. Alternative methods such as survey
research would not have been able capture this richness. The population of children with cerebral palsy at the point of being prescribed a sleep system is also too small to be appropriate for this approach. The participants in this study were different enough from each other in terms of their function, cognitive ability, family circumstances and home environment to make it a non-homogenous group and therefore not one from which causal relationships could easily be explained. Likewise the numbers involved were too small to allow for an experimental hypothesis to be tested.

On narrowing the methodology down to case study, it was helpful to focus it further. Yin (2003) describes 3 types of case study: the exploratory, the descriptive and the explanatory which considers cause and effect. The aim of this study was to explore the effects of a certain set of very individual circumstances on a child’s experience of sleeping in a sleep system and to set this within the context of local and national agendas. This, therefore, could be said to be an exploratory case study, the case being “The use of sleep systems by children in the South-West of England”. Yin (2003) suggests statements should be in place at the beginning. This could be a theory, or if not enough is known to state a theory, then statements about what is to be studied and the purpose and the criteria by which the exploration will be judged successful. This was thought to be a useful strategy and the following simple theory was proposed:

“There are predictable factors which influence the experience of night-time postural management for a child with cerebral palsy.”

Yin suggests that single case study may be ‘holistic’ in which a global view of the case is taken, or ‘embedded’, involving the investigation of more than one unit of analysis within the case (Yin 2003). In this study multiple units of analysis, or subunits, were studied to make the evidence more robust and compelling. In Yin’s positivist view, case study can be seen in the same terms as traditional scientific enquiry in that the same rules should apply. Kemmis (1980, p.100), however, thinks this is unlikely when he says “those who expect to follow the progress of science in brilliant light will be ill at ease following the case study worker stumbling from lamplight to lamplight in the fog”. He and others offer a creative view of case study research: “Case study consists in the imagination of the case and the invention of the study” (Kemmis 1980, p.119). This
study leans towards Yin and endeavours to show that the results of the study are “trustworthy”. However, given its epistemological underpinning of constructivist realism there will be no claims for the results to be “true” or “valid”.

Case studies have been described as a “step to action, beginning in a world of action and contributing to it” (Adelman et al 1980) with the results being able to be directly interpreted and put to use in the workplace. This description made it a very appropriate methodology for this study which is firmly based in clinical practice. The method of collecting data from the participants in these subunits will now be discussed.

3.1.4 Choice of methods: Semi-structured interviews, an informal group discussion and use of documents

Several methods of data collection were employed to gain a holistic view of the case. Yin (2003) suggests that data gathering skills required for case study include the ability to ask good questions, being a good listener and being adaptive and flexible in order to take advantage of unexpected situations. The questions in this case initially took the form of semi-structured interviews and the unexpected situation was taking advantage of a meeting of children’s physiotherapy services managers, to have an informal discussion about recruitment when recruitment to the study was slow.

Individual interviews were considered to be the most practical method of obtaining the views of children, their parents and their therapists. The geographical area was large and the numbers of potential participants was likely to be small. These children would also be recruited into the study at different times depending on when their therapist prescribed a sleep system for them so a focus group would not be possible or appropriate.

Individual interviews, far from being neutral tools of information gathering, are increasingly being seen as dynamic interactions between the interviewee and the interviewer, shaping the nature of the knowledge generated between them (Fontana and Frey 2000). Empathy should develop between the researcher and participants in order for personal meanings and subjective experiences to be more fully understood. This study required a degree of formality in the interview process to ensure particular areas
of interest were addressed. To access the experiences of participants in depth, freedom to explore issues of individual importance was allowed. Interviews in which the researcher sets the agenda of topics but the interviewee determines the depth of information provided, and the relative importance of that information, are described as semi-structured interviews. This method would deliver data that could be compared across participants while also enabling the exploration of issues in as much depth as each participant chose. While individual interviews were the main method of data collection, data was gathered from physiotherapy service managers by means of an informal group discussion which was followed up with further telephone conversations.

Group discussions or interviews are commonly termed focus groups, however, group interviews range from a formal “consensus group” brought together to reach a decision on a particular issue, to a “community interview” open to the whole or a large segment of the community to discuss a planning or development project. The group in this study could be termed a “natural group” because it existed independently of the study and was used opportunistically to provide data around a specific question (Green and Thorogood 2004). It was an informal discussion and one that would not be unusual with these group members.

The use of documents is also widely used in case study for background context as well as for data that will be analysed to answer the research question. In this study the use of documents is for contextual purposes rather than to produce data for analysis.

3.1.5 Approach to data analysis

3.1.5.1 Framework analysis

The approach adopted for data analysis must be related to the study aims and objectives (Green and Thorogood 2004). This study was rooted in clinical practice and the production of knowledge that would guide clinical practice was an objective. Framework analysis is commonly used in research for the development of practical strategies. The Framework method developed by the National Centre for Social Research (http://www.natcen.ac.uk/natcen/pages/hw_qualitative.htm) is described as “a content analysis method which involves summarizing and classifying data within a
thematic framework” (Green and Thorogood 2004) and was developed to enable the
generation of practice-oriented findings. This was more relevant to this study than an
analysis of the data using a Grounded Theory approach, in which the development of a
theory is the expected outcome. The key features of Framework Analysis have been
described by Ritchie and Spencer (1994). Figure 3:4, below, is taken from them.

| Grounded or generative: it is heavily based in, and driven by, the original accounts and observations of the people it is about. |
| Dynamic: it is open to change, addition and amendment throughout the analytic process. |
| Systematic: it allows methodical treatment of all similar units of analysis. |
| Comprehensive: it allows a full, and not partial or selective, review of the material collected. |
| Enables easy retrieval: it allows access to, and retrieval, of the original textual material. |
| Allows between- and within-case analysis: it allows comparisons between, and associations within, cases to be made. |
| Accessible to others: the analytic process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst. |

Figure 3:2 Key features of ‘Framework’ (adopted from Ritchie and Spencer 1994 p.176)

Analysis of qualitative data is differentiated by some in the research community as
being based on either inductive or deductive logic in that themes are determined either a
priori or that they emerge only from the text (Tashakkori and Teddlie 1998). In this
study it was likely there would be some of both. Grounded Theory relies on moving
backwards and forwards during the data collection phase between the emergence of
theory and new data. New interviewees would be chosen according to the emerging data
during a saturation point in which no new themes are occurring, is reached. This study
did not use theoretical sampling for the subunits of the children, their therapists and parents
and, although constant comparison was used between subunits, the other techniques of
Grounded Theory were not employed. Using the Framework method the individual
participants’ responses are kept intact rather than being subjected to an intense line-by-line
analysis deliberately ‘fracturing’ the data as in Grounded Theory and this was appealing to the researcher.
3.1.5.2 Thematic content analysis

Thematic content analysis was considered to be the most appropriate method for analysing the children’s responses. It was also appropriate in considering information derived from informal conversations with therapy service managers. It is a simple approach adopted when identification of common themes is required (Green and Thorogood 2004).

Having described the epistemological and theoretical perspective, the methodology and the methods, what follows is how these were put into practice to collect and analyse data.
3.2 Methods

3.2.1 Introduction

This section of the chapter will detail the pilot studies that helped inform the main study, the ethical considerations underpinning the study and the gaining of ethical approval. It continues by describing how funding was sought for equipment and how the study was launched. The sampling, recruitment, data collection and data analysis then follows. The interview protocols with local, national and international informants are described as well as the method of searching national documentation.

Throughout this thesis the term ‘parents’ is preferred to the clumsier ‘parents/carers’, but the term refers to the child’s carers and home providers. In one case these were the child’s grandparents.

3.2.2 Pilot studies

Pilot studies were conducted as preliminary work to provide information and guidance for the application for ethical approval and for the main study. They fell within the remit of the researcher’s role as a paediatric physiotherapist and manager working at a special school and in the community. Similar conversations with children and parents were not uncommon events in clinical practice and as such ethical approval for the pilot studies was not required. Three of the pilot studies involved listening to children talking about bedtimes, sleeping and using a sleep system. The intention was that children should be at the centre of this study from its commencement and should continue to be the focus throughout its course.

The views of the children and adult involved contributed to the study and helped with the wording of the information sheets. Public involvement in research and development is strongly encouraged and is considered by INVOLVE (http://www.invo.org.uk/) to make research more relevant to people’s needs and concerns, more reliable and the outcomes more likely to be used. The role of the children involved in the pilot studies was towards the top end of the ‘Ladder of Participation’, a term coined by Roger Hart
(1992), where manipulation is at the bottom and child initiated and directed research is at the top.

The research team for the pilot studies and the main study comprised the researcher and a speech and language therapist who had volunteered to take responsibility for interviewing the children using the Talking Mat method.

3.2.2.1 Pilot study 1

The aim of the first pilot study was to gain insight into the experience of sleeping in a sleep system from a user’s point of view and to explore some of the issues that might be relevant for children and parents. It involved an interview with a long term user of a sleep system, H, aged nine, who was chosen because he had slept in a sleep system for seven years and because he had very good verbal and cognitive skills. He was well-known to the researcher, wanted to have a career in the BBC, and was likely to be interested in being interviewed.

Child H proposed the following:

- That sleep systems are by their nature restrictive of movement and this can be frustrating to a child who wants to be able to (and can) move prior to going to sleep. Child H liked to go to sleep first and to be put into his Symmetrikit sleep system while asleep. He could then read, play etc. without being restricted before going to sleep.

- That it might be important to all children to be told why they need a sleep system. The nine-year-old’s mother had explained very clearly why he needed to use a sleep system and he was in no doubt about the potential benefits.

3.2.2.2 Pilot study 2

The aim of the second pilot study was to gather vocabulary that children used about bedtimes, sleep and sleep systems which could then be translated into symbols for the children with no verbal communication for the Talking Mats interviews. The research team could have guessed at vocabulary children in the study might have wanted but by attempting to gain it from similarly-aged children, the language was more likely to be
relevant and appropriate. It assisted in reducing power of the research team and increasing power of the children in the study.

This pilot study involved seven children who had good language skills apart from one who used his communication book. The children, who were pupils in the special school where the research team were based, had recently been involved in a school project on self-esteem during which they had become used to talking about themselves within the group. The children were similar in age and diagnosis to the children who would be recruited into the study and two of them slept in sleep systems. This group interview took the form of a pass-the-parcel game led by the speech and language therapist who had been part of the self-esteem group in previous weeks, talking with these particular children. When each layer of wrapping was removed it revealed a piece of paper with a statement such as “Before I go to sleep I like to ….”. The child holding the parcel was asked to think and then complete the statement. The group members were also invited to join in with comments. The game continued until everyone had taken part and the prize at the centre was uncovered and the jelly beans shared out. This game was played enthusiastically and resulted in helpful vocabulary some of which the research team would not have thought of in connection with bedtimes and sleeping, e.g. ‘bored’ and ‘alone’.

3.2.2.3 Pilot study 3

The aim of the third pilot study was to test out the interview technique and use of the recording equipment with a parent. The research team also needed to practise interviewing a child who had verbal communication difficulties, using the Talking Mat method. Such a child was identified within the special school of the research team and her mother was an obvious choice of parent with whom to practise interviewing skills. The child had been prescribed a sleep system several years previously by her local therapist and it was known that she did not use it at night but would lie in it during the day to play. It had seemed likely there would be a story to hear about that. The issues raised by that interview with the mother ultimately formed the basis of two conference presentations, one from the platform and the other a poster presentation (Humphreys 2008a; Humphreys 2008b). The interview highlighted the difficulties some families with children with cerebral palsy have with sleep and the gaps in local children’s services to help with this. These findings are discussed in full in Chapter 5.
3.2.2.4 Pilot study 4

The aim of the fourth pilot study was to test out the Talking Mat interview technique with a child. This child, M, aged nine, was the daughter of the mother interviewed in Pilot 3. She had good cognitive abilities, no verbal communication and had been issued with a sleep system but was apparently not sleeping in it.

The interview gave rise to several key issues which were used to inform the method:

- That it was essential to interview parents before using the Talking Mat to interview children. A point could be missed entirely if issues for the child around sleeping were not initially mentioned by the parents. For example, M’s mother reported that M would play happily lying in her Chailey Lying Support on the floor in the sitting room for up to an hour but would scream if she saw it on her bed. It was then possible to ask M:

  “What do you like to do in your Chailey?”

M chose to say “yes” to the symbols of play, toys and video but very definitely chose to say “no” to go to bed (Fig. 3:2).

![Figure 3:3 “What do you like to do in your Chailey?”](image)
When asked “Why don’t you like going to bed in your Chailey”?
She answered “no” to “Is it because you are .... hot, comfy, feel good?” and “yes” to “uncomfy, hurt, hard, cold, angry, stiff and can’t hug?” (Fig. 3:3).

Figure 3:4 “Why don’t you like going to bed in your Chailey?”

It would, however, be essential to keep an open mind and not allow the parent to influence the views of the child.

- That the bed-time routine was going to be an important aspect of whether a child managed to use a sleep system at night or not. For example, M had never gone to sleep alone and had always had to have a parent lie down next to her on the bed so she could fall asleep. When prescribed her sleep system she had been sleeping in her parents’ bed because the flat only had two bedrooms and M would keep her sister awake if they slept in the same room.

The research team also learnt practical tips for using the Talking Mat technique.
- The symbols and the board needed to be bigger.
- Certain new symbols were required and possibly photographs of their particular sleep system and bed would be helpful.
• Taking time to organise the equipment and the space before the interview would be helpful especially if the child is in a wheelchair.
• Audio recording the interview as well as photographing the Talking Mats was essential so that there was a record of the questions as well as the answers.
• Keeping vocabulary relevant and not offering too much was also important in keeping the child focussed.
• Not leaving the most important questions to the end in case the child loses interest or will not continue.
• Being quick at photographing the Talking Mats in between the questions or again the child may get bored and not wish to continue the interview.
• Keeping distractions to a minimum.
• Taking spare batteries for the audio recorder and remembering that when it beeps it stops recording!

Following the pilot studies, Child H and Child M, as well as their parents, were invited to be ‘consultants’ to the main study. They were keen to be involved and helped with the wording in the parents’ and children’s information sheets and also the design of badges that were given to the participant children. Their comments were incorporated into the final designs.

Outcomes from the pilot studies were addressed and the application forms for ethical approval were submitted. Much thought had previously been given to the process of gaining consent and the ethical underpinning for the study. The following sections describe that process and the details of the submission to the ethics committee.

3.2.3 Ethical considerations and governance

Ethical considerations for clinical research laid down in The Belmont Report (1979) consist of three major principles; respect for persons, beneficence and justice. The application of these principles to a research study is through informed consent and the assessment of risks and benefits. Special consideration needs to be given to the protection of vulnerable groups when involved as research participants. Children are a vulnerable group and children with cognitive and or communication difficulties are particularly vulnerable. The Royal College of Paediatrics and Child Health
recommends, however, that research involving children is encouraged so long as it is of benefit and is conducted ethically. They state that research is necessary to ensure children receive fully informed care (Royal College of Paediatrics and Child Health: Ethics Committee 2000).

3.2.3.1 Informed Consent

The research team designed two information sheets for the children: one that could be read by the parents to the older and/or more cognitively able children; the second consisting of simple printed words, symbols and pictures for the younger and/or less cognitively able children. This latter sheet was laminated so the children could hold them easily and if necessary could refer to them during the interview. The children acting as consultants had been asked to comment on the sheets and their ideas to improve them were incorporated. The parental information sheets were given to the ‘consultant’ parents and their comments were incorporated. The therapist information sheet was reviewed by colleagues and approved.

Consent was a process rather than a single event and was requested on an ongoing basis. Consideration was given to the child’s right to be included, balanced against the protection they may have needed from being influenced or coerced onto the study. Some researchers (Rabiee et al 2005; Morris 2003) have found difficulties recruiting children with disabilities into their studies because gate-keepers had negative attitudes about the child’s communication difficulties and therefore their usefulness in being involved. In this study parents were asked to give consent to their child participating in the study as well as the child themselves. The research team checked with the child throughout the interview process that they were willing to continue, by taking notice of their facial expression, vocalisation, eye-pointing and body movement. Ward (1997) suggests that it may be helpful for children to practice beforehand how they are going to let the interviewer know that they want a break, don’t want to answer a particular question or want to finish the interview. There was consideration of using a “Big Mac” switch that the child could press and give the pre-recorded message that they wanted to stop but decided that it could be too much of a distracting toy. The research team members were both experienced in working with children and were confident they would know when a child wanted to stop.
3.2.3.2 Rewards

The National Children’s Bureau suggests that rewards for children who participate in projects are appropriate (Ward 1997). Children who participated in the study received a certificate and a badge after each interview. The two children who helped in the design of the study were afterwards given book tokens to the value of £10 in appreciation of their prolonged help and interest. They also received badges. These rewards were not mentioned beforehand but were offered after their involvement as a thank-you.

3.2.3.3 Risks and benefits

Risk assessment had to be applied to all three categories of participants as the identifiable risks were different for each group.

For the parents there was perhaps a small but nevertheless significant psychological risk that by talking about sleep, sleep systems and family dynamics around night-time behaviour, negative emotions could be experienced. Time was required by the parents to keep the sleep diaries and this might have added a degree of stress to their already busy lives. These small risks were likely be outweighed by the benefits of participating in the study with the feeling of being pleased that someone was taking an interest in their lives and that they had the opportunity to help make services better for other children with cerebral palsy in the future.

For the children in the study the risks would seem to have been relatively low. The benefits for the children might have been that they liked the opportunity to express their views on sleeping in a sleep system and highlighting things they disliked and would like changed. Children are capable at quite a young age of showing a moral sense (Alderson 1999) and they may have enjoyed the idea that their contribution might improve both services and equipment for other children in the future.

For the therapists who were interviewed there were potential psychological and social risks but these were considered to be low. The therapists were likely to have busy caseloads and would need to find time to be interviewed. Having an outside researcher involved with their patient may have concerned some therapists in terms of seeing their
clinical practice as under the spot-light. Efforts were made, however, to make therapists feel it was a positive experience and had benefits for their clinical practice. They were introduced to the Chailey Sleep Questionnaire and encouraged to use it with all patients prior to prescription of a sleep system, not just those included in the study. This may have helped to improve the safety of their clinical practice.

Responsibility for the research team’s personal safety relied on assessing the risk of conducting the interviews with the children and their parents at the family home. All participating children were well-known to their local therapists and relevant information as to the risks of home-visiting was requested.

3.2.3.4 Power relationships

Power relationships were one of the key ethical issues that required consideration in the design of the study. There were issues of power within the relationship between the researcher and the therapists being interviewed. For some of the therapists of children recruited into the study the researcher was their line manager; for others within Devon the researcher was known to them as a senior clinician and professional lead. For therapists outside Devon there may still have been concerns that the researcher had more experience in the subject area and as such could be critical of their work. There needed to be awareness of this when interviewing to make the therapists feel confident that their views were respected.

In the instances where children recruited into the study were from the service managed by the researcher there could have been a conflict of interest. There had to be clarity between the researcher’s clinical role of clinical lead and supervisor of staff, in which the therapist could have been asking for advice about prescription of sleep systems, and the role of researcher. It was necessary to make sure that the clinical role was not compromised in the interests of the research.

There were also issues of power within the relationship between researcher and the child being interviewed. Many children would be unused to being asked for their thoughts. To help in ensuring the children did not feel intimidated, they were interviewed with a parent or familiar teaching assistant present.
The study raised further ethical issues inherent with being both a researcher and a clinician. Participant families knew of the researcher’s obvious interest in and clinical experience of night-time positioning because that information was on the information sheet. They could have asked whether the sleep system prescribed and the treatment they received was appropriate to their child’s needs. The researcher may have seen equipment being used wrongly in the home or unsafe moving and handling techniques being employed. The researcher may have been told about frustrations with local services not providing what the family feels it needs in a timely fashion. In all those circumstances there needed to be a clear understanding that the researcher was not a clinician in this study and as such would not interfere with clinical decisions or give an opinion. Anxieties or frustrations could, however, have been passed on if the family wished.

3.2.3.5 Confidentiality
Confidentiality of the research data and its sources would be adhered to throughout the study. Transcripts of interviews would be anonymised and audio recordings would be destroyed once transcribed satisfactorily. Efforts would be made to ensure that participants could not be identified from the quotes used in the results. An exception to this code of confidentiality was explained in the information sheets and stated that any issues revealed during the course of the interviews that were serious and affected the safety of the child, would need to be disclosed to appropriate agencies, e.g. child protection services.

3.2.3.6 Research Ethics and Governance
The study was approved by the University of Brighton’s Faculty Research Ethics and Governance Committee on the 20th August 2007 (Appendix 3) and the University of Brighton agreed to be the sponsor. The study was submitted to the Devon and Torbay Research Ethics Committee with the reference number 07/H0202/121. (Refer to Appendix 4 for the letter of approval). It was passed without amendments on 1st October 2007.
The Peninsula Primary Care Research Management and Governance Unit administered requests for research governance approval and this was gained in the following trusts; Torbay NHS Care Trust, Plymouth Hospitals NHS Trust, Plymouth Teaching Primary Care Trust, Devon Primary Care Trust, South Devon Healthcare NHS Foundation Trust, Northern Devon Healthcare NHS Trust, Royal Devon and Exeter NHS Foundation Trust, Yeovil District Hospital NHS Foundation trust, Royal Cornwall Hospitals NHS Trust.

The ethical issues having been addressed, possible difficulties surrounding funding for equipment needed to be considered.

### 3.2.4 Funding for equipment

Funding to be able to supply the necessary equipment was sought to avoid time delays and the potential withdrawal of funding from night-time postural management equipment in the NHS.

An application was made to the Posture and Mobility Group, a special interest group of multidisciplinary professionals of which the researcher was a member, to purchase sleep systems for children participating in the study. The application was successful and secured £5,000 for this purpose. The sleep systems were to stay with the children at the end of the study period or if not required by them further, would become the property of their local therapy services. Sleep systems were then purchased with this money when the local therapist for each participating child had made the prescription and had a quote for the system they had chosen.
3.2.5 Launch of the study

Recruitment for the study was dependent on support from local paediatric therapists, both physiotherapists and occupational therapists. It was essential, therefore, that those therapists knew all about the study, felt inclined to be involved and found potential participants from children on their caseloads.

The study was launched to therapists in their teams at convenient times for them, usually at staff meetings or in-service study sessions. The teams were originally in four geographic areas of Devon; North Devon, Exeter, Torbay and Plymouth. A flow chart of the research process (see Appendix 5) was passed around at each meeting to ensure that the same methods for recruitment and the gaining of consent were adopted in each locality. Information sheets for therapists, parents and children and a poster, with the details of participant inclusion and exclusion criteria, were left with therapists. At the Plymouth launch the speech and language therapist also attended and explained the principles of the Talking Mat technique. Therapists were informed that there was funding for some sleep systems and that, therefore, they did not have to go through the usual procedures for ordering equipment. Therapists were introduced to the Chailey Sleep Questionnaire (Khan and Underhill 2006) which when completed with parents highlights potential risks from sleep apnoea, reflux and epilepsy (refer to Appendix 6). Therapists were asked to use the questionnaire prior to prescription of the sleep system and were encouraged to discuss the results with the child’s paediatrician if concerns were raised and before decisions were taken. The study was met with enthusiasm by the therapists who in turn made suggestions concerning the inclusion criteria. These suggestions were discussed later with supervisors and it was decided that the lower end of the age range could be reduced from three years to 18 months.

An email was sent to all paediatricians in Devon informing them of the study. Replies were received from several local paediatricians expressing wishes of good luck and one suggested a child who may have been a suitable participant.

3.2.6 Sampling

The population of children eligible for this study was likely to be small and the sampling, therefore, was purposive. The inclusion criteria were that children had bilateral cerebral palsy, classified as being in levels III, IV or V on the Gross Motor
Function Classification System (Palisano 1997); that they had just been prescribed a sleep system by their local therapist but that it had not yet arrived, and they were between the ages of 18 months and nine years. Children older than nine years being asked to use a sleep system for the first time may be likely to have issues with compliance as they will have more firmly established sleep routines and, potentially, further migrated hips that could introduce an element of pain. The older children in the study by Hankinson and Morton (2002) were more likely to drop out because they could not sleep in the sleep system. This upper age limit of nine years was to some extent arbitrary but was set to include as many participants as possible given that the number of eligible children over the duration of the data collection period was likely to be small. Four years is suggested to be the earliest age at which a child develops an autobiographical memory with which they can comment on prior specific events (Nelson and Fivush 2004). It was anticipated that many children with cerebral palsy would have a sleep system prescribed before reaching that age. It was decided, therefore, that children from three years would be interviewed to see how successfully they could give their views. Children under three years were included in the study but were not interviewed. Children younger than 18 months were excluded because their sleep patterns were likely to be less established.

Determining the sample size of case studies is different to that of experiments or surveys in which generalisation from sample to population is important (Robson 2002). This study focuses on a single case; the use of sleep systems in the South-West, but the children recruited, with their parents and therapist, comprise multiple subunits. The number of children to be recruited was ideally 10, a figure considered manageable by the researcher and her supervisors in terms of the volume of data collected.

Sampling for the key informants was in some ways opportunistic. The study was discussed at a routine meeting of the South-West children’s physiotherapy services managers. From that discussion, using the principles of purposive sampling in which participants are selected for their ability to present a certain view (Robson 2002), key informants with opposite experiences were identified and asked if they agreed to a further informal discussion by telephone.
3.2.7 Recruitment

3.2.7.1 Recruitment of children, their parents and therapists

Local therapists were asked to find suitable recruits from children on their caseloads (as described in section 3.2.5). Once identified, therapists gave potential participants the relevant information sheets and asked them to consider being part of the study. They encouraged the parents to talk to the child about the study and whether the child would be prepared to participate. If interested, parents were given a consent form with a stamped, addressed envelope and asked if their contact details could be given to the researcher, who then telephoned the parents to ensure they understood the aims of the study and what would be involved for them and their child. Parents were asked to sign and return the consent form or hand it to the researcher at the subsequent interview. Careful consideration was given to gaining consent from the child both just before the interview and during it. If the child was three or more years of age, the parents were also asked to give consent for the speech and language therapist on the research team to contact the child’s speech and language therapist for information about the child’s communication skills and level of cognition. The prescribing therapist or therapists were also asked to give their consent by signing the therapists’ consent form.

3.2.7.2 Opportunistic meeting with service managers

The researcher is a member of the Paediatric Physiotherapists in Management Support (PPIMS) group in the South-West and when recruitment to the study was slow, members of the group agreed to discuss the reasons for this. From that discussion group, two managers were identified who had different views and who delivered services in different ways. They agreed to continue the discussion individually, enabling views to be captured across a breadth of practice.

A children’s physiotherapy manager was identified from further afield who had co-ordinated a group to write guidelines for the provision of 24-hour postural management. The guidelines had been posted on the interactive special interest group website and had been generally well-received. She also taught training courses on postural management in the North-West of England. She agreed to discuss postural management by telephone.
An Occupational Therapist working outside the UK in the field of sleep and cerebral palsy was also asked to give a view on her postural management service for children and adults in a sleep clinic in Perth, Australia. She was known to the researcher when she had travelled to the UK on a Churchill Fellowship. The researcher took the opportunity to discuss postural management with her when they were both attending a meeting on sleep in the UK.

3.2.8 Data collection

Data was collected from the therapists who had recruited children into the study, the children and their parents. Sleep diaries were collected from the parents along with the Chailey Sleep Questionnaires. Data was also collected from the key informants and from documentation.

3.2.8.1 Interviews with therapists

Within any one subunit, therapists were interviewed before the parents and children. Knowledge of the particular circumstances of that child and family could then inform the subsequent interviews with the parents and child. Therapists were interviewed at a mutually convenient time and place, usually at their place of work. The interviews were semi-structured and lasted between 20 minutes and an hour. Therapists were interviewed only once. All interviews were recorded with an Olympus WS-100, a small digital voice recorder.

3.2.8.2 Interviews with parents

The parents were usually interviewed prior to their child. The interviews with parents were semi-structured but with the opportunity for parents to talk about their experiences freely if they wished. The first interview was just after prescription of the sleep system but before the equipment was in place. The second interview with the parents was conducted between four and six months after the child received the sleep system. This gave time for the child and family to have settled into a routine and for them to be able to report reflectively on their experiences of using the sleep system. The interviews
lasted as long as necessary, generally between 20 minutes and an hour-and-a-half. All interviews were recorded as above.

3.2.8.3 Interviews with children

All children over the age of three were interviewed using the Talking Mat method (Refer to Appendix 2). The Talking Mat assisted in focusing the child’s attention on the question being asked even when the child could communicate verbally.

Children were interviewed at a convenient location and where they were likely to feel most relaxed. In cases in which children were interviewed at home with either both parents or just the mother present, the speech and language therapist played with the child while the parents were interviewed. This approach worked well, enabling her to form a playful relationship with the child while assessing the child’s level of communication. Usefully, she was also able to hear some of the parents’ responses. Care was taken to ensure the child did not actively listen to the parents’ answers.

3.2.8.4 Sleep diaries

At the first interview the parents were given a diary (Appendix 7) and asked to record how long it took for the child to get to sleep, the number of hours the child slept for at night and the number of times the child woke during the night. A record of whether the child fell asleep in their own bed and whether they needed the presence of a parent to enable them to fall asleep was also asked for. The diary offered space for the parents to write freely if they so wished. The diary recorded information for 10 consecutive nights, a period of time thought to be long enough to capture typical sleep during weekdays and weekends while not being overly taxing for the parents (Stores and Wiggs 2001; Libman et al 2000).

When the parents and child were interviewed for a second time, parents were asked to complete a second sleep diary (Appendix 8) for a further 10 days.
3.2.8.5 Informal discussions with therapy service managers

Therapy service managers attending the PPIMS meeting agreed to discuss the study in terms of the difficulties with recruitment and why they thought so few children had been identified as needing a sleep system during the period of recruitment. This informal discussion about the clinical reasoning for prescription of sleep systems, e.g. who are they prescribed for, at what age and how is postural management organised within their services, was within the realm of the researcher’s usual clinical and professional leadership role and as such was not specified in the proposal for ethical approval. Consent from the managers to use the data was obtained.

Two of these managers later agreed to talk to the researcher individually to enlarge on how they organised postural management for children in their areas and to explain their background in paediatric physiotherapy. The conversations took place by telephone because of time and geographical constraints. Both managers consented to the conversation being recorded with the telephone on speaker mode.

The manager of children’s therapy services in the North-West of England, selected for her experience in postural management (refer to section 3.2.7.2), was contacted by the researcher and she also agreed to a telephone conversation about postural management, how it was organised in her area and what her background was. Similarly this was not specified in the research proposal but was not unusual in the researcher’s clinical, managerial and professional leadership practice.

An informal conversation also took place with an acquaintance, an Occupational Therapist from Australia, following a meeting on sleep and cerebral palsy that both parties attended in the UK. The foci of this conversation concerned the differences in the development and organisation of postural management services between the UK and Australia and her experience of the posture of adults with cerebral palsy who had not been provided with postural management equipment in childhood. This face-to-face discussion was followed up with further information from her sent from Australia by email.
3.2.8.6 Use of documents

A search for information was conducted to set the study in a national, professional and local context. Documents from government, public enquiries and clinical interest groups were perused. Documentation from the therapy departments of the participant therapists was also collected and used as evidence.
3.3 Data analysis

The approaches to data analysis are provided, in brief, in section 3.1.5. This section of the chapter describes the Framework method, employed for the analysis of data sets from the interviews with parents and therapists, in detail. Ritchie and Spencer (1994) provided the clearest description of this method and it is their version that has been followed in this study with each of five stages being detailed below. Following this is a description of thematic content analysis.

3.3.1 Framework analysis

3.3.1.1 Stage 1: Familiarisation with the data

Familiarisation with the data started immediately after the first interview and was enhanced by the researcher reading the transcript while listening to the audiotape. The audiotapes were transcribed by an employed transcriber. Notes were made in the margins of the transcripts of the main points that arose (see Table 4:2). Notes of initial thoughts following an interview were recorded on a contact summary form (see Figures 4:1, 4:2, 4:3). This enabled an immediate view of the main points that arose and suggested avenues to explore in following interviews.

3.3.1.2 Stage 2: Thematic analysis

A list and/or a mind map was then made of the main points identified in the familiarisation stage which enabled the researcher to link chunks of data according to key issues, concepts and themes. In identifying these themes, titles arose from the research aims themselves and also emerged from issues raised by the participants. These themes became the labels for codes.

3.3.1.3 Stage 3: Indexing

The whole data set was systematically indexed using these codes in the third stage of the process. Each section of text was reviewed and judgements made as to its meaning and significance; an appropriate index code was then applied.

3.3.1.4 Stage 4: Charting

In the fourth stage, charting, chunks of data were extracted from the text and arranged in themes together and a chart was formed for each key subject area. This was done within
each subunit. Charts were also made of themes across the subunits. This process involved abstraction and synthesis. Looking across the codes for the whole range of phenomena enabled the researcher to identify emerging correlative patterns.

### 3.3.1.5 Stage 5: Mapping and Interpretation

In the final stage, mapping and interpretation of the charts enabled exploration of the relationships between the themes. Typologies were described and a conceptual framework was created to explain the findings.

### 3.3.2 Thematic content analysis

#### 3.3.2.1 Children’s interviews

The audio tapes of the children’s interviews were transcribed by the researcher. The data from the children’s interviews were quite simple in content because of the age, cognitive ability of participants and the technique for finding out their views. Thematic content analysis, in which recurrent themes are categorised, was considered an appropriate method for analysis of this data (Green and Thorogood 2004). The aim was to report the key elements of the children’s views.

#### 3.3.2.2 Discussions with therapy service managers

The discussions with therapy service managers were informal and the information received was analysed using a thematic content approach to describe the key issues.

### 3.3.3 Analysis of the sleep diaries

Analysis of the sleep diaries was a simple numerical comparison of before and after intervention with a sleep system and consisted of changes in the number of awakenings and the length of time asleep. Inferential statistical testing was not appropriate because the data set was too small, the results were not to be generalised and the relationships between variables were not being investigated for reliability (Polgar and Thomas 2000). The results are presented along with any comments made by parents in the section of the diaries set aside for free writing and with details given in the interviews.
3.4 Issues of rigour

It was important for the researcher to produce findings that readers would consider credible and trustworthy. The methods for achieving this follow the suggestions given by Green and Thorogood (2004).

3.4.1 Transparency

In order for the reader to be able to follow the process of the data analysis, every stage in the Framework method has been clearly described and an example to illustrate each stage is appended. When codes and themes are created or merged the reasoning is provided. The reader may not agree with the researcher’s decisions but the process is made transparent so that a judgement can be made.

3.4.2 Validity

Constructivist realism, the ontological position in this study, has an expectation that readers will have differing views of the interpretation of the findings. It is important, however, for the researcher to justify why this particular interpretation should be seen as credible and legitimate and to demonstrate trustworthiness. The strategies employed to achieve this were as follows:

- Direct quotes are included in sufficient quantity and length for the reader to enter into the worlds of the participants and to make judgements about the findings.
- All the subunits were included and accounted for rather than the selection of data that confirmed the researcher’s early assumptions (see Fig.1:1) or supported the simple theory stated in section 3.1.3.
- Provision of the numbers of people giving similar experiences or views enables the reader to assess the commonality or peculiarity of that observation.
- Transcripts were returned to the therapy service managers to verify that the researcher had understood what they had meant to say in the informal discussions. Transcripts were not returned to all participants because of the time and costs involved. The results of analysis were not sent to participants for verification, however, because it was assumed that the researcher’s background, interests and experience would be likely to provide a different interpretation of the findings than those of others with different experiences.
3.4.3 Reliability

Reliability was demonstrated by giving a clear audit trail with sufficient raw data to enable readers to identify the rationale for the codes and themes and to assess the interpretation. Notes were made throughout the data analysis as a reminder of why certain decisions were taken. Where these notes assist in following the interpretation, they are provided in the account. It is not expected that other researchers would identify the same themes or that if repeated with other participants by other researchers, similar findings would emerge.

3.4.4 Comparison

Constant comparison between subunits allowed themes to be refined as the analysis progressed. Experiences recounted by parents were compared with each other and those of therapists with other therapists. Interesting points raised in early interviews were able to be specifically raised with later respondents. Findings from the children were considered significantly reliable when the same view was voiced at the second interview four to six months later.

3.4.5 Reflexivity

In qualitative research the researcher is intrinsic to the process of data production and analysis. In this study the researcher’s background, interests, knowledge and experience enabled the identification of topics of interest which in turn directed the questioning in the interviews. There was also awareness that the interaction between the researcher and the participants had an effect on the data produced. Assumptions held about the subject have been acknowledged early in the thesis and these will undoubtedly have affected the interpretation of the findings. A conscious reflection on this bias was regularly brought to bear during data analysis. A reflective diary was kept of the research journey, entries from which are presented and further reflected on in Chapter 6.

3.5 Summary

This chapter has described the ontological stance, the theoretical perspective, the methodology and the methods chosen for the exploration of the views of children, parents and therapists on the use of sleep systems. Attention has been focussed on ensuring the study has internal consistency. Good practice guidelines have been
followed to add credibility to the analysis and to increase the trustworthiness of the study. The following chapter will present the findings.
CHAPTER 4: PRESENTATION OF FINDINGS

The previous chapter described the methods used to collect the data and provided a rationale for why it was done in that way. This chapter will present the findings from the study. The chapter will be arranged in four sections. The first presents the findings from the interviews with the children, their parents and therapists and includes the children’s scores in the Chailey Sleep Questionnaire and the results from the sleep diaries. Findings from the informal discussions with therapy service managers from the South-West and North-West of England and the specialist clinician from Australia are provided in the second section. In the third section the findings from all participants are collated to provide typologies and an explanation. Finally, section four revisits the aims of the study with further clarity provided by an illustrative conceptual framework.

4.1 Section One: Findings from the interviews with the children, their parents and therapists

4.1.1 Participants

The details of the children in the study are presented below in Table 4:1. The child’s age, diagnosis and GMFCS Level is described in addition to the type of sleep system prescribed and the outcome at the conclusion of the data collection period.

<table>
<thead>
<tr>
<th>Child number</th>
<th>Age on entry to study</th>
<th>Diagnosis</th>
<th>GMFCS Level</th>
<th>Child Interviewed</th>
<th>Type of sleep system</th>
<th>Prior preferred sleeping position</th>
<th>Sleeping position in sleep system</th>
<th>Outcome at conclusion of data collection period</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6yrs 0mths</td>
<td>CP Spastic diplegia</td>
<td>III</td>
<td>Yes</td>
<td>Chailey Lying Support</td>
<td>Supine</td>
<td>Supine</td>
<td>Child sleeping well in sleep system</td>
</tr>
<tr>
<td>2</td>
<td>3yrs 4mths</td>
<td>CP Spastic quadriplegia</td>
<td>IV</td>
<td>Yes</td>
<td>Leckey Sleepform</td>
<td>Supine or side lying</td>
<td>Supine</td>
<td>Child sleeping well in sleep system</td>
</tr>
<tr>
<td>3</td>
<td>2yrs 2mths</td>
<td>CP or possibly West Syndrome</td>
<td>V</td>
<td>No</td>
<td>Leckey Sleepform</td>
<td>Cuddled up to parent</td>
<td>Supine</td>
<td>Child not using sleep system</td>
</tr>
<tr>
<td>Child</td>
<td>Age</td>
<td>Impairment</td>
<td>Handicap</td>
<td>Symmetry</td>
<td>Sleep Position</td>
<td>Side Lying</td>
<td>Side Lying Status</td>
<td>Other Details</td>
</tr>
<tr>
<td>-------</td>
<td>-----------</td>
<td>-------------</td>
<td>-----------</td>
<td>----------</td>
<td>---------------</td>
<td>------------</td>
<td>-------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>4</td>
<td>2 yrs, 3 mths</td>
<td>CP Spastic quadriplegia</td>
<td>IV</td>
<td>No</td>
<td>Symmetrisleep</td>
<td>Right side lying</td>
<td>Right side lying and supine</td>
<td>Child not using sleep system</td>
</tr>
<tr>
<td>5</td>
<td>3 yrs, 6 mths</td>
<td>CP Spastic quadriplegia</td>
<td>IV</td>
<td>Yes</td>
<td>Jemx Dreama</td>
<td>Supine</td>
<td>Supine</td>
<td>Sleep system not fully set up</td>
</tr>
<tr>
<td>6</td>
<td>4 yrs, 5 mths</td>
<td>CP Spastic diplegia</td>
<td>III</td>
<td>Yes</td>
<td>Chailey Lying Support</td>
<td>Side lying</td>
<td>Supine</td>
<td>Child unhappy but parents persevering</td>
</tr>
<tr>
<td>7</td>
<td>3 yrs, 11 mths</td>
<td>CP, microcephaly</td>
<td>V</td>
<td>No</td>
<td>Chailey Lying Support</td>
<td>Foetal position</td>
<td>Supine</td>
<td>Child sleeping well in sleep system</td>
</tr>
<tr>
<td>8</td>
<td>3 yrs, 8 mths</td>
<td>CP, microcephaly</td>
<td>V</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Child excluded due to identification of risks</td>
</tr>
</tbody>
</table>

Table 4:1 Details of the children participating in the study

Child 4 had recently had a trial of a sleep system and the parents had decided against its continuation. The Child was included because the views of the parents and therapists were considered potentially advantageous to the study. The parents were interviewed once. Child 7 was included although she had already very recently commenced using a sleep system. Her mother was interviewed once. Child 8 was excluded from the study following the researcher’s consideration of the risks to that child sleeping in a sleep system that had been highlighted in the Chailey Sleep Questionnaire (refer to section 4.1.1.1 and Appendix 11).

One child was a pupil at the school where the research team was based and he was interviewed there during the normal school day. He was interviewed three weeks later than his parents the second time, because of an intervening school holiday. Most parents were interviewed at home though one mother was interviewed at a child development centre while her husband stayed with their child who was having therapy in a different room. Both parents of two children chose to be present for the interview while in the other cases it was just the mother. In two cases the parents and children were interviewed on Saturdays for the convenience of the speech and language therapist on the research team.
One of the three-year-olds followed up the second visit by sending the research team a picture she had drawn of herself “In bed dreaming about mummy”.

4.1.1.1 Chailey Sleep Questionnaire Scores

Scoring on the Chailey Sleep Questionnaire is divided into three sections; Bedtime Routine, Night-time Behaviour and Breathing Quality at Night. Scores in each section are categorised as low, no problem, medium, a problem that may need further investigation or high risk in which there is a high level problem in need of attention. The children’s scores are presented in Appendix 11.

Two children, child 2 and child 3, scored in the high risk category for Bedtime Routine and Night-time Behaviour suggesting that they had sleep hygiene difficulties and frequent sleep disturbance. Child 3 also scored in the high risk category for Breathing Quality at Night, a fact of which the paediatrician was aware and no objections to his participation in the study were raised. Child 8 also scored in the high risk category for Breathing Quality at Night. She was awaiting removal of her tonsils and the researcher advised the therapist to discuss the risks with the child’s paediatrician prior to the provision of a sleep system and excluded her from the study.

4.1.1.2 Results from the sleep diaries

Although only three of the seven sets of parents returned the diaries, the sleep diaries were able to provide valuable information on the length of time taken to settle to sleep, the number of awakenings and length of time asleep, both prior to commencement of sleep system use and following it. Child 1 already slept well but in his sleep system he increased the length of time he slept from an average of 11.5 to 12.25 hours a night. This may be maturation over a period of five months or due to environmental factors such as the sleeping patterns of the two siblings with whom he shared a bedroom. Child 3 had very poor sleep both before and after the introduction of the sleep system with an average of eight hours sleep a night recorded in the first diary and only seven in the second. His parents had quickly abandoned use of the sleep system and the reduction in hours asleep was likely to be due to his epilepsy and medication. Child 5 had similar
hours asleep both before and after intervention although her sleep system was still not correctly set up during the period of the second sleep diary and was not influencing her posture while asleep. Details of the sleep behaviour of all the children are provided in Chart 2, (Appendix 12B). Where no sleep diaries were available, details were taken from the interviews with parents and children.

4.1.2 Introduction to methods of analysis

Different methods of analysis were required for the data sets from the different participant groups. As previously described in sections 3.3.2 and 3.3.3 respectively, the data from the interviews with the parents and therapists were analysed using the Framework method developed by the National Centre for Social Research, while data from the children were analysed using thematic content analysis.

The Framework method provides a clear sequence of distinct, though interconnected stages of analysis, which allows transparency for the reader. This systematic process of sifting, charting and sorting material into key issues and themes is clearly described by Ritchie and Spencer (1994) and followed here. The stages are outlined in Chapter 3 (section 3.3.2). Analysis took place of the data collected for each subunit individually.

Yin (2003) names each small unit of analysis within a case a subunit. The ‘case’ in this study is ‘The use of sleep systems in the South West of England’. The multiple subunits within the case are the children, their parents and therapists. The term subunit does not sound appropriate to the researcher when referring to people, however, and therefore the subunits will be named after the child number in the recruitment process e.g. Child 1 (which denotes child number 1, child 1’s parents and therapist), or referred to non-specifically in the singular as Child and in the plural as Children.

The Framework method of data analysis is demonstrated fully using Child 2 as an example. It is demonstrated how the key themes and categories arose from the data, how the thematic framework was produced and how the transcripts from this case were indexed according to the framework. Charts are presented showing the range of attitudes and experiences within Child 2.
Following analysis within each Child, a higher level of analysis between the Children was undertaken. Charts were produced and these enabled identification of key dimensions which are explored in detail.

4.1.3 Familiarisation with the data

Familiarisation of the data started immediately after the first interview and was enhanced by the researcher reading the transcript while listening to the audiotape. The audiotapes were transcribed by an employed transcriber. Active listening to an audiotape was repeated several times. Initial thoughts following an interview were recorded on a contact summary form (see Figures 4:1, 4:2 and 4:3). This provided a ‘gut reaction’ of the key issues and opened further avenues to explore in subsequent interviews.
Interview with: Parents (both present)
Participant child: Child 2
Date: 26.04.08

1. **What were the main themes or issues that arose in this interview?**

   - Demonstration of sleep system (SS) by DVD then company representative brought one to lie in briefly. Not loaned for a trial of sleep.
   - N has poor sleep, parents report they are “shattered”.
   - N wakes up because of pain/cramps in legs
   - Poor sleep hygiene. She doesn’t go to sleep on her own
   - Poor position in bed. Described by parents as “froggy legs”

2. **Did any variables in the framework of initial assumptions occur?**

   - Pain
   - Sleep hygiene
   - Child’s health
   - Support from multidisciplinary team

3. **Did any new hypotheses, hunches or speculations arise?**

   - Outcome for parents = for better sleep
   - No-one has taken a sleep history, so SS is a stab in the dark

4. **What should be asked about as a result?**

   a) **In following interviews with this participant?**

      - How often did the Sleepform need to be readjusted – every night?
      - Was it easy to adjust?
      - Are parents confident they get N in a good position?

   b) **Clarified with this participant?**

      - Nothing yet

Figure 4:1 Contact summary form for first interview with parents for Child 2
### Contact summary form: First interview

**Interview with:** Child N  
**Participant child:** Child 2  
**Date:** 26.04.08

1. *What were the main themes or issues that arose in this interview?*
   - Wakes up at night because of pain
   - Able to communicate that the pain is in her legs not anywhere else
   - Wakes up feeling happy and not tired

2. *Did any variables in the framework of initial assumptions occur?*
   - Pain
   - Sleep hygiene

3. *Did any new hypotheses, hunches or speculations arise?*
   - Pain in three year old children.

4. *What should be asked about as a result?*
   a) *In following interviews with this participant?*
      - Does she still have pain when sleeping in the Sleepform?
   b) *Clarified with this participant?*
      - Nothing yet

---

Figure 4.2 Contact summary form for first interview with Child 2
Contact summary form

Interview with: Therapist
Participant child: Child 2
Date: 15.05.08

1. What were the main themes or issues that arose in this interview?
   - This therapist took over child’s care but prescription of sleep system (SS) made by previous physiotherapist.
   - Therapist worked “very, very part time” and had few complex cases.
   - Reasons for sleep system included “having some problems with sleeping”.
   - This therapist wouldn’t have prescribed it so early saying the child is “quite a battler” and likely to be uncooperative.
   - Physiotherapists in her department tend to use all makes of SS.
   - Discussion re risks of sleeping in SS, child snores loudly but paediatrician happy to go ahead.

2. Did any variables in the initial framework of assumptions occur?
   - Knowledge and experience of physiotherapist
   - Clinical reasoning
   - Sleep hygiene

3. Did any new hypotheses, hunches or speculations arise?
   - Inexperience of physiotherapist affecting decision making?
   - Desired outcomes for SS? Are they the same for parents and therapists?

4. What should be asked about as a result?
   a) In following interviews?
      - Outcomes
   b) Clarified with this participant?
      - Nothing yet

Figure 4.3 Contact summary form for interview with therapist for Child 2
During the familiarisation process, notes of the main points that arose from the interview were made in the margins of the transcripts. For the first few interviews these notes were then transformed into a mind map to draw out key issues arising from the interview and laid the basis of the next stage.

4.1.4 Thematic framework

As data from several interviews became more familiar, some patterning of views was noticeable. Comparison between interviews with parents generated common themes and comparison between interviews with therapists created further themes. These patterns or common themes, as expected, arose primarily from the researcher’s a priori issues stated in the framework of initial assumptions in Chapter 1 (figure 1:1).

The development of a thematic framework for each Child (i.e. subunit of child, parents and therapist) then became possible. The common themes were applied to each Child with some being relevant and others not. Other themes and issues, on analysis, might be specific to only one Child. Ritchie and Spencer (1994) suggest that both logic and intuition are required when devising and refining a thematic framework. Decisions have to be made as to the relevance and importance of issues raised and the connections between ideas. For Child 2 the process of refining the framework required four versions. Comparisons were continuing to be made with the other data sets and these comparisons assisted in the merging of some issues and themes. One example of the merging of themes is as follows: the content of the text under Parental Understanding and Process of Introduction of Sleep System was viewed as being too similar and were merged together under Process of Introduction of sleep System. The relevant sections of the framework are provided below in section 4.1.6, the story of N.

The themes were given codes; for example Clinical Reasoning of Therapist was denoted CR and Sleep Hygiene, SH. The issues listed under the themes were identified by the addition of further letters; for example under the theme of Sleep Hygiene, the issue of Number of Awakenings became SH-NA. The nine themes (with their codes) identified from the data for Child 2 were:

1. Clinical reasoning of therapist (CR)
2. Process of introduction of sleep system (PRO and PU)

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3. Sleep hygiene (SH)
4. Child’s pain (PN)
5. Child’s experience of sleep system (CE)
6. Parents’ experiences / outcomes following sleep system (PE/O)
7. Practicalities of sleep system once arrived (P)
8. Child’s health problems (H)
9. Support for parents (SUP)

When the framework had been developed the transcripts were indexed with the appropriate codes accordingly; see Table 4.2 below for an example. The indexes were colour-coded to enable easy identification in the text. In this table, I is the Interviewer, T, the Therapist, postural management is shortened to PM and sleep system to SS. The child is referred to as N.

<table>
<thead>
<tr>
<th>Notes in margin</th>
<th>Transcript line numbers</th>
<th>Transcript</th>
<th>Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inherited case</td>
<td>4</td>
<td>I So, thinking about N, what did you think about N that made you feel that she needed a sleep system or that a sleep system would be helpful?</td>
<td>CR-INH</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>T Well, I have to be honest, she’s only just come into my care.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>I Right.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>T Her previous therapist had sort of indicated in her notes that she was looking into the Sleepform and the rep was coming so I just went along with that.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>I Right.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>T Partly, I think, because N has got standing frames and chair, you know, supportive chairs and standing both at home and nursery and she’s doing quite well but she has got quite a few difficulties and I felt that probably, to keep her in good position, it might be effective, and I think she had been having some, I think (parent) was having some problems with her sleeping.</td>
<td>CR-INC</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>I Right. So, your outcomes, good outcomes, for N having a sleep system would be what do you think?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>T Well, to maintain her hip symmetry really and her leg position I think and also, possibly to not be so wakeful.</td>
<td>CR-OUT</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>14</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>15</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>17</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>22</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4:2 Example of transcript of therapist interview with notes and indexing

A thematic framework was developed for each of the first four Children.

As data analysis continued it became necessary to develop similar frameworks for the different groups of participants. Consequently, a framework was developed that combined the themes and issues that had arisen in all the interviews with the therapists.
The process was repeated with data collected from the parents. The children’s interviews were analysed separately and are discussed below.

The content of each theme was refined over a period of time. Some themes were combined in the final versions. Some theme titles were altered following further reflection. This occurred after the indexing procedure had taken place and the original remained in the indexing on the transcripts. “Parental Understanding of the Need for a SS” was changed to “Parents’ View of the Need for a SS” for example, but was still indexed as PU rather than PV in the thematic framework. The thematic frameworks for the parent and therapist groups can be seen in the appendix (Appendices 9 and 10 respectively).

The children’s interviews were analysed using the more simple thematic content method. The content of the interviews was dictated by the questions asked and the vocabulary offered to the children in symbol form to which they could answer ‘yes’ or ‘no’, or ‘like’ and ‘don’t like’. The transcripts of the children’s interviews were not indexed but the key themes were identified and are shown in Table 4:3 below.

<table>
<thead>
<tr>
<th>1. BEDTIME</th>
<th>5. SLEEPING IN SLEEP SYSTEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likes/dislikes</td>
<td>Comfort</td>
</tr>
<tr>
<td>What routine?</td>
<td>Temperature</td>
</tr>
<tr>
<td>Boring/alone</td>
<td>Preference of SS or just bed</td>
</tr>
<tr>
<td></td>
<td>Difference to sibling’s bed</td>
</tr>
<tr>
<td>2. ORTHOSES</td>
<td>Being immobilised</td>
</tr>
<tr>
<td>Leg gaiters</td>
<td>6. NIGHT-TIME WAKING</td>
</tr>
<tr>
<td>Night ankle foot orthoses (refer to glossary)</td>
<td>Pain</td>
</tr>
<tr>
<td></td>
<td>Thirstiness</td>
</tr>
<tr>
<td>3. TRIAL OF SLEEP SYSTEM</td>
<td>Being scared</td>
</tr>
<tr>
<td>Likes/dislikes</td>
<td>7. PAIN</td>
</tr>
<tr>
<td>Comfort</td>
<td>Site</td>
</tr>
<tr>
<td>4. WAKING IN MORNING</td>
<td>Before sleeping in SS / while using SS</td>
</tr>
<tr>
<td>Mood</td>
<td></td>
</tr>
<tr>
<td>Pain / stiffness</td>
<td></td>
</tr>
<tr>
<td>Tiredness</td>
<td></td>
</tr>
</tbody>
</table>

Table 4:3 Themes identified from the children’s interviews

Once thematic frameworks had been applied to all transcripts, the range of attitudes and experiences expressed by the participants on individual issues could be charted.
4.1.5 Charting the range of attitudes and experiences within Children

Charting in framework analysis is the method of accumulating and viewing data within particular themes and issues in order to explore the range of attitudes and experiences (Ritchie and Spencer 1994). For each Child (i.e. subunit), data were lifted from their original contexts and rearranged according to the appropriate themes in a ‘cut and paste’ operation to set chunks of text alongside each other. The charts facilitated a broad view of the issues within each Child. The example shown below in Table 4:4 brings together data from Child 2 relating to pain. The transcript was examined for all references to pain, and then chunks of text were grouped keeping all the similarly indexed issues together. This extract shows the references to the site and type of pain (PN-S) from the thematic framework. The transcript descriptors, in this case the parents’ first interview (P1) and the child first and second interviews (CH1, 2), are given in the left column followed by the line number. The middle column contains the text and indicates the speaker, M = mother, I = interviewer and C = child. The right column lists the specific indexed issue for that piece of text.

<table>
<thead>
<tr>
<th>CHILD’S PAIN</th>
<th>PN-S</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P1 44</strong></td>
<td></td>
</tr>
<tr>
<td>M  No. She doesn’t sleep well at all.</td>
<td></td>
</tr>
<tr>
<td>I  Right.</td>
<td></td>
</tr>
<tr>
<td>M  She gets a lot of cramps in her legs…</td>
<td></td>
</tr>
<tr>
<td>I  Right.</td>
<td></td>
</tr>
<tr>
<td>M  … that wakes her up.</td>
<td></td>
</tr>
<tr>
<td><strong>P1 65</strong></td>
<td></td>
</tr>
<tr>
<td>M  Quarter to eight when she goes to bed, you have to stay in the room, sing Teletubbies to her, until she goes off to sleep and then it’s…she’s asleep then from about, what, 10 past/quarter past eight and she’ll sleep until about 10/half past 10, then she’s awake again and if she’d had a lot of pain in her legs…’cos it’s always the crunches that wake her up – she gets a lot of cramp doesn’t she…?</td>
<td>PN-S</td>
</tr>
<tr>
<td>I  Right.</td>
<td></td>
</tr>
<tr>
<td>M  … in her legs and if it’s been incredibly painful for her then it can take us anything from two to three hours to get her back to sleep again.</td>
<td></td>
</tr>
<tr>
<td><strong>P1 103</strong></td>
<td></td>
</tr>
<tr>
<td>M  It all depends. That all depends on N and it all depends on the… you know, how bad the cramps were. If the cramps are really bad all the way up her leg then she will be on her side, curled right up.</td>
<td>PN-S</td>
</tr>
<tr>
<td>I  Right … right.</td>
<td></td>
</tr>
<tr>
<td>M  If they’re just slightly bad, she’ll be on her back trying to kick her legs.</td>
<td></td>
</tr>
<tr>
<td>I  Right.</td>
<td></td>
</tr>
<tr>
<td>M  But it… and it all depends on how tired she is as well.</td>
<td></td>
</tr>
<tr>
<td>I  Right.</td>
<td></td>
</tr>
<tr>
<td>M  If she’s very, very tired then she gets woken up with the cramps then she’s murder to try and get back to sleep… you know…</td>
<td></td>
</tr>
<tr>
<td><strong>P1 128</strong></td>
<td></td>
</tr>
<tr>
<td>M  … and if we say to her “where are you hurting” she’ll always point then to her legs.</td>
<td>PN-S</td>
</tr>
<tr>
<td>I  Right… right.</td>
<td></td>
</tr>
<tr>
<td>M  And when she is awake at night, she appears to be in pain does she – to you?</td>
<td></td>
</tr>
<tr>
<td>M  Yeah. And other times it is a case of sleep pattern and other times it is a case of “I don’t want to be in a room by myself. I want somebody else in here.”</td>
<td></td>
</tr>
</tbody>
</table>
I right… so it’s a mixture of things, it’s not just the pain… you think it’s wanting attention as well.

M yeah, yeah.

<table>
<thead>
<tr>
<th>P1 204</th>
<th>CH 1</th>
<th>CH 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>C</td>
<td>C</td>
</tr>
<tr>
<td>… so that’s another part of pain for her as well – staying in a froggy position…</td>
<td>Wakes at night because of pain in leg, not arm, not foot, not knee</td>
<td>Wakes at night because of pain in hip and knee</td>
</tr>
</tbody>
</table>

PN-S

Table 4:4 Extract of Table of Child’s Pain in Child 2

Displaying the data in the form of vignettes or stories was a method for further comprehending these issues. The story of N in Child 2 is given as an example below.

4.1.6 The story of N

4.1.6.1 Introduction

N was born at 30 weeks gestation, was diagnosed as having spastic quadriplegia and described as being at GMFCS Level IV. N was three years old when first interviewed and lived with both parents. She had no siblings living in the household. She attended a nursery for a few sessions a week. She had supported seating and standing equipment and was starting to take steps with help. She was waiting for a powered wheelchair which had been ordered. Both parents were present for both interviews which were conducted in the family home. N had very little speech when first interviewed. For the purposes of the interview the Talking Mat was used to aid communication. N eye-pointed to the ‘yes’, ‘no’ or ‘like’, ‘dislike’ symbols. Occasionally she nodded her head in agreement. She was a little more vocal in the second interview and answered some questions verbally.

The Chailey Sleep Questionnaire raised a number of issues. (Refer to Appendix 11). Bedtime routine and night-time behaviour were in the ‘high problem’ category. Breathing quality at night was a ‘low problem’. She has recurrent ear/throat infections and had several chest infections in the previous six months, all of which required antibiotics. The local therapy department had already prescribed a Leckey Sleepform sleep system for N, which had been ordered but not delivered.

The nine themes identified for Child 2 are explored below with examples from the transcripts. The relevant section of the thematic framework is presented at the beginning.
of each theme to demonstrate the issues that arose. The text is identified in the brackets following the quote. The indexed issue is given first and this is followed by the person speaking; in this case, M is mother, F is father, C is child and T is therapist. The number 1 or 2 denotes the first or second interview and the transcript line number follows.

4.1.6.2 Clinical reasoning of physiotherapist

<table>
<thead>
<tr>
<th>CR</th>
<th>Inherited case</th>
<th>CR-INH</th>
</tr>
</thead>
<tbody>
<tr>
<td>CR</td>
<td>Gradual increase in PM</td>
<td>CR-INC</td>
</tr>
<tr>
<td>CR</td>
<td>Ethos in therapy team</td>
<td>CR-ETH</td>
</tr>
<tr>
<td>CR</td>
<td>Outcomes for SS</td>
<td>CR-OUT</td>
</tr>
<tr>
<td>CR</td>
<td>Timing of SS</td>
<td>CR-TIM</td>
</tr>
<tr>
<td>CR</td>
<td>Assessment</td>
<td>CR-ASS</td>
</tr>
<tr>
<td>CR</td>
<td>Which SS</td>
<td>CR-WHSS</td>
</tr>
<tr>
<td>CR</td>
<td>Motivation of child</td>
<td>CR-CM</td>
</tr>
<tr>
<td>CR</td>
<td>Knowledge of complex cases</td>
<td>CR-KNCC</td>
</tr>
<tr>
<td>CR</td>
<td>Processes/pathways/protocols</td>
<td>CR-PATH</td>
</tr>
<tr>
<td>CR</td>
<td>Motivation of parents</td>
<td>CR-PM</td>
</tr>
<tr>
<td>CR</td>
<td>Risks</td>
<td>CR-RSK</td>
</tr>
</tbody>
</table>

Table 4.5: Extract of thematic framework for Child 2: Clinical reasoning of physiotherapist

The physiotherapist’s predecessor had suggested the child should have the sleep system. The current physiotherapist worked “very, very part-time” in the community. She had been a paediatric physiotherapist for about 20 years but did not have many complex cases on her caseload. She had herself previously prescribed one sleep system, a Symmetrisleep.

The reasons for prescribing a sleep system for N were two-fold: an increase in the postural management programme to include night-time and to help with sleeping.

“Partly, I think, because N has got …. supportive chairs and standing both at home and nursery and she’s doing quite well but she has got quite a few difficulties and I felt that probably, to keep her in good position, it might be effective, and I think… (parent) was having some problems with her sleeping.” (CR-INC, T1, 12)

The outcomes envisaged for N sleeping in a sleep system were:
“Well, to maintain her hip symmetry really and her leg position I think and also, possibly to not be so wakeful.” (CR-OUT, T1, 20)

If the child had been her patient previously she probably would not have prescribed a sleep system this early.

“I’m not sure perhaps if I’d have done it quite so young as that, no, I’m not really sure ’cos she’s quite a battler really, if you know what I mean, she’s quite a dominant person.” (CR-TIM, T1, 35)

The physiotherapist reasoned why this sleep system was prescribed rather than another.

“I think it was probably just because of the size and age of the child really. She was younger and I don’t think [the previous physiotherapist] had any specific reason for choosing that over anything else.” (CR-WHSS, T1, 107)

### 4.1.6.3 Process of introduction of sleep system

<table>
<thead>
<tr>
<th>2. PROCESS OF INTRODUCTION OF SLEEP SYSTEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Including Parental Understanding of Need for SS)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PRO</th>
<th>Demonstration by company rep</th>
<th>PRO-CO</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRO</td>
<td>Laid in SS for brief trial</td>
<td>PRO-BT</td>
</tr>
<tr>
<td>PRO</td>
<td>Child’s first impressions</td>
<td>PRO-IM</td>
</tr>
<tr>
<td>PU</td>
<td>For sleep</td>
<td>PU-FS</td>
</tr>
<tr>
<td>PU</td>
<td>For comfort</td>
<td>PU-FC</td>
</tr>
<tr>
<td>PU</td>
<td>For posture</td>
<td>PU-FP</td>
</tr>
</tbody>
</table>

Table 4:6 Extract of thematic framework for Child 2: Process of introduction of sleep system

The family had seen a DVD of what the sleep system suggested by their previous physiotherapist looked like and what it was supposed to do. The company sales representative then brought the sleep system to their home and N laid in it.

“Um, when the Leckey bloke came along, he explained to me everything, what it was made up of, how the valves work, the science that went on behind it…you know, he spoke for a good…what?…three-quarters of an hour didn’t he? Explaining the whole science of it behind it, how they’d come about in developing it…you know, how much it does help… because of her whole body staying flat and it will also help her hips ’cos she goes very froggy…” (PRO-CO, M1, 197)
The parents’ view of why a sleep system had been suggested was that it was to make N more comfortable so that she would have better sleep.

“I think it was... that we were absolutely shattered.” (PU-FC, M1, 38)

They had been told why that particular sleep system was appropriate for N.

“That that one’s the best one as well because it stays solid – her little muscles can’t flop and then cramp.” (PU-FC, M1, 50)

They knew the posture they were trying to achieve for N at night with the sleep system.

“Mainly the trunk because N needs so much postural support... I mean, that’s what helps her in day life as well, if her posture’s straight at night. So it’s mainly keeping her backbone straight and making it so that she can’t wiggle about from the middle because if she flops in the middle at night she can get herself into awkward positions. If the hips are twisted then we know we’ve got the back a bit wrong. ‘Cos you can concentrate on just the hips, but if you haven’t got the back right, the hips won’t click into place.” (PU-FP, M2, 146)

4.1.6.4 Sleep hygiene

<table>
<thead>
<tr>
<th>3. SLEEP HYGIENE</th>
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</tr>
</thead>
<tbody>
<tr>
<td>SH</td>
<td>Bedtime routine</td>
</tr>
<tr>
<td>SH</td>
<td>Number of hours asleep</td>
</tr>
<tr>
<td>SH</td>
<td>Pain</td>
</tr>
<tr>
<td>SH</td>
<td>Number of awakenings</td>
</tr>
<tr>
<td>SH</td>
<td>Length of time awake</td>
</tr>
<tr>
<td>SH</td>
<td>Discipline</td>
</tr>
<tr>
<td>SH</td>
<td>Settling for sleep</td>
</tr>
<tr>
<td>SH</td>
<td>Behaviour</td>
</tr>
<tr>
<td>SH</td>
<td>History taking</td>
</tr>
<tr>
<td>SH</td>
<td>Mood in mornings</td>
</tr>
<tr>
<td>SH</td>
<td>Parental sleep deprivation</td>
</tr>
<tr>
<td>SH</td>
<td>Position</td>
</tr>
</tbody>
</table>

Table 4:7 Extract of thematic framework for Child 2: Sleep hygiene

The parents had tried to have some routine at bedtime but N always needed to have an adult with her when she fell asleep and she sometimes fell asleep somewhere other than in her bed. She was waking several times every night with cramps and taking a long time to settle again.

“Well, it’s usually about quarter to eight when she goes to bed, you have to stay in the room, sing Teletubbies to her, until she goes off to sleep and then .she’s
asleep then from about, what, ten past/quarter past eight and she’ll sleep until about ten/half past ten, then she’s awake again and if she’d had a lot of pain in her legs... ‘cos it’s always the crunches that wake her up, she gets a lot of cramp in her legs and if it’s been incredibly painful for her then it can take us anything from two to three hours to get her back to sleep again. And then, once she’s back off to sleep again, then she’ll sleep until about two o’clock in the morning isn’t it? Two/three o’clock in the morning, and then, again, it’s getting her off to sleep and then she’ll go back to sleep for a few more hours and then it’s time to get up.” (SH-NA, M1, 63)

The parents and child were all very tired.

“If we can have sleep for about six hours we shall be so happy.” (PU-FS, M1, 228)

Before having the sleep system N’s parents thought N was waking up at night mostly because of pain but that there was also some element of behaviour involved.

“And other times it is a case of sleep pattern and other times it is a case of ‘I don’t want to be in a room by myself I want somebody else in here’.” (SH-B, M1, 132)

At the second interview four months following the introduction of the sleep system they felt that she was waking up because she wanted attention.

“And that’s usually about two or three o’clock in the morning and that’s not a ‘pain’ cry, that’s an ‘I want to get into bed with (parents) cry. You know, ‘I don’t want to be alone’.” (SH-B, M2, 181)

Before having her sleep system N reported that she liked going to bed and that when she woke up in the mornings she felt “happy” and not tired and that in the morning nothing was hurting. (C1)

Her parents had established a bedtime routine. Although N had them up most of the night before the sleep system was in place, they did not take her out of bed. When she had the cramps they massaged her legs but did not take her out of her bed.

“Just massage her legs, that’s all we can do and give her some cuddles... No, no... no, no. I’ve had two sons before, if she goes to bed, that’s where she stays.” (SH-D, M1, 78)
4.1.6.5 Child’s pain

Table 4:8 Extract of thematic framework for Child 2: Child’s pain

| PN | Site and type of pain  | PN-S |
| PN | Pain as possible cause of waking  | PN-W |
| PN | Tiredness/activity and pain  | PN-T/A |
| PN | Pain during the day  | PN-D |

N does complain of pain in her legs during the day if she is very active, especially at nursery.

“If she’s at school, at nursery, and they do a lot of activity with her then, you know, she does cry out that her legs are hurting and she will, you know, start pointing to her legs. So now what they do is the moment she first starts pointing, they slow everything down for her.” (PN-T/A, M1, 138)

The pain is most often at night. The researcher asked if the parents were sure that it was pain rather than wanting attention in the night, especially as they had mentioned that her cramps were worse when her routine is disrupted.

“Well, we thought it might have been her sleeping pattern but N is incredibly intelligent and we just said to her... you know, we pointed to all parts of her body. If we say to her ‘Where are you hurting?’, she’ll always point then to her legs.” (PN-T/A, M1 122)

Before having her sleep system N reported that she was waking up in the night because she had pain, that she wanted a drink and wanted to see her parents. Using the Talking Mat she specifically indicated that the pain was in her legs but not in her arms, feet or knees. (C1)

4.1.6.6 Child’s experience of sleep system

Table 4:9 Extract of thematic framework for Child 2: Child’s experience of sleep system

| CE | Mood / reaction to SS  | CE-M |
| CE | Comfort  | CE-COM |
| CE | Daytime concentration  | CE-DTC |
| CE | Use of SS  | CE-USE |

N was described by the physiotherapist as “a bit of a battler” and “quite a dominant person” when considering the likelihood of the child being able to adapt to sleeping in a sleep system. N had enjoyed the company representative demonstrating the sleep
system to her. She was comfortable in it and able to relax. She remained excited about her “new bed” coming. When it arrived N took several weeks to adapt to sleeping in the sleep system.

After having her sleep system N reported that she was comfortable in her new special bed. Using the Talking Mat she said the reason for her waking up at night was because something hurts and not because she is too hot, or cold, or that she wants a hug, or because she wants to see her parents or that she wants to play. When asked where it hurts she reported that the pain was in her hips and knees. When she wakes up in the morning she feels “happy” and not in pain and not tired. (C2)

4.1.6.7 Parents’ experiences/outcomes following sleep system

<table>
<thead>
<tr>
<th>PE/O</th>
<th>Achievement of goals</th>
<th>PE/O-AG</th>
</tr>
</thead>
<tbody>
<tr>
<td>PE/O</td>
<td>Perseverance</td>
<td>PE/O-P</td>
</tr>
<tr>
<td>PE/O</td>
<td>Message to child</td>
<td>PE/O-MES</td>
</tr>
<tr>
<td>PE/O</td>
<td>Confidence in positioning in SS</td>
<td>PE/O-CON</td>
</tr>
</tbody>
</table>

Table 4:10 Extract of thematic framework for Child 2: Parents’ experiences/outcomes following SS

N’s parents were determined to persevere with the sleep system until N was happy in it. They had seen that she could be comfortable in it when it was demonstrated. They acknowledged that some of her previous sleeplessness may have been due to behavioural factors. When they were confident she was comfortable they could be firmer about the rules at bedtime and in the night when she woke.

Following the introduction of a sleep system N’s sleeping had improved significantly.

“Well, it took her about, what, three weeks to get used to it? We had screaming hab-dabs most nights, because it’s sleeping in a different way. So it’s, you know, getting her used to that, a bit of perseverance then she settled down into it. You know, which was brilliant and the cramps, they didn’t go straight away did they? We still had a couple of months where it was maybe two or three times a night and now it’s gone down to once a night. And sometimes all through the night she’ll sleep so there is a difference.” (SH-B, M2, 9)

N’s parents feel that she is more comfortable in the sleep system than she was in unsupported lying.

“Far more, far more isn’t she?” (CE-COM, M2, 44)
They felt very pleased with the outcome. They were all sleeping and feeling better.

“Awake! That’s the only way to put it! Awake! I mean, [the physiotherapist] wasn’t quite sure whether it would work, she said, you know, she said it’s a relatively new sort of thing and wasn’t quite sure if it was going to work but it’s worked with N.” (PE/O-AG, M2, 203)

They were particularly pleased that N’s performance at nursery had shown an improvement in terms of concentration.

“And her concentration is longer as well. At school they’ve noticed a difference in her concentration – at nursery, ‘cos she does far more and her concentration levels are actually expanded out because she’s getting good sleep. So everything else is going on hunky-dory isn’t it?” (CE-DTC, M2, 279)

4.1.6.8 Practicalities of sleep system once arrived

| P | Re-setting SS | P-RSET |
| P | Setting up process | P-SUP |

Table 4:11 Extract of thematic framework for Child 2: Practicalities of SS once arrived

The parents and therapist set up the sleep system together when it arrived.

“Yeah. We watched a DVD, we had fun with [the physiotherapist] trying to set it up ‘cos she’d never set one up before… So, we had lots of fun didn’t we? We got the wrong thing about four or five times… N was getting rather annoyed with us all wasn’t she? And telling us, you know, but we got there in the end.” (P-SUP, M2, 245)

“We got it set up but when we put her in it the first night, we’d forgotten that the mattress went on top – we all forgot that! So we had to re-set it again taking into account the bulk of the mattress. That took a lot of… that took a lot of sorting out but once we got it sorted out we thought ‘it’s so simple’ but the simplest things are always the ones to work out anyway aren’t they?” (P-SUP, M2, 76)

The sleep system needed to be re-set once a week but N’s parents had become used to it and managed the process in 10-15 minutes.

“I re-set it once a week. I leave it for a week because after a week it starts… the little bits… the little ball things inside do shift about. And although all the air’s
gone, it will wedge itself into different shapes so once a week we collapse it all down and then we re-set it all up.” (P-SET, M2, 86)

N’s parents felt confident that they were achieving the correct positioning for N.

“Oh, if it’s not right she won’t go to sleep. She likes her legs to be raised a little bit doesn’t she? So, from the ankles to about the calves, if you make it so it’s raised a bit, she’ll, you know, she go down lovely. After you’ve done it a few times, you don’t need to put N in there to say right, ‘Is this right, is this wrong?’ You know, after a few nights sleep, you know which shape and, you know, where it’s got to be.” (P-SET, M2, 110)

4.1.6.9 Child’s health problems

<table>
<thead>
<tr>
<th>8. CHILD’S HEALTH PROBLEMS</th>
</tr>
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<tbody>
<tr>
<td>H</td>
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<td>H</td>
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Table 4:12 Extract of thematic framework for Child 2: Child’s health problems

The Chailey Sleep Questionnaire seeks to identify risks for a child using a sleep system. This child had asthma and frequent chest infections.

“She has... yeah... she’s got asthma, so she has a lot of chest infections which don’t help ‘cos if the oxygen level goes down then it’s the chest and the legs.” (H-CI, M1, 260)

She used to have reflux but has grown out of it.

“They said back then that a lot of the children do grow out of it. Some of them keep it but some of them grow out of it. She’s fine, she eats anything.” (H-REF, M1, 284)

She also once had a seizure but it was not recent and was not repeated.

4.1.6.10 Support for parents

<table>
<thead>
<tr>
<th>9. SUPPORT FOR PARENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUP</td>
</tr>
<tr>
<td>SUP</td>
</tr>
</tbody>
</table>

Table 4:13 Extract of thematic framework for Child 2: Support for parents
N’s parents were well supported by their occupational therapist and physiotherapist and they felt particularly well supported by the paediatrician.

“By the hospital absolutely well supported. You know, ‘cos if she falls ill or anything, we can just whizz her up there and they’ll take a look at her and say whether she needs to stay in or, you know, come home or what have you. [The paediatrician]’s brilliant. She’ll explain through everything.” (SUP-MDT, M1, 254)

They said that they got no help from social services even though the child had a social worker. They were not very impressed with this.

“I can’t cope with them... they drive me up the wall... they honestly do.” (SUP-MDT, M1, 252)

4.1.6.11 Sleep diaries

The sleep diaries were not filled in or returned but in the Chailey Sleep Questionnaire, completed before the first interview, the parents reported that N woke several times a night and would often take longer than 30 minutes to get back to sleep. In the first interview they said that it might take between one and three hours to settle her again. After the introduction of the sleep system N usually woke once and settled within 30 minutes. Occasionally she had slept through the night without waking.

It was possible to examine the data further by looking across the data sets of the Children at the important issues that had arisen.
4.1.7 Raising the level of analysis: Charting across the Children

This section of the chapter now moves on to charting the themes across all the Children. Employing a ‘cut and paste’ approach, chunks of data were lifted from their original contexts and reorganised under themes and issues. In this way attitudes and experiences from all participants were able to be viewed together. Ritchie and Spencer (1996) were helpful in describing this process and for giving examples of charts from several different studies showing how data can be extracted from the sub-cases for comparison. They suggest charts can be drawn up with headings or titles drawn directly from the thematic framework, from the a priori research questions or simply from the way the researcher has decided to best present their findings. For this study the following charts were devised:

1. Process of introduction of sleep system.
2. Sleep hygiene.
4. Child’s experience of sleep system.
5. Parents’ experiences/outcomes following sleep system.
6. Practicalities of sleep system.
7. Therapists’ clinical reasoning – why this child?
8. Therapists’ clinical reasoning – why this sleep system?
9. Therapists’ knowledge and experience of complex cases.
10. Desired outcomes.
11. Therapists’ knowledge of child’s sleep problems prior to prescription.
12. Child’s experience of sleep before and after introduction of sleep system.

Some of these charts, numbers 1, 2, 3, 4, 5 and 6, had titles taken directly from the thematic frameworks. Charts 7, 8, 9 and 10 were expanded from the issues within the theme titled Clinical Reasoning of Therapists. Chart number 11 was derived from the issue of History Taking under the Sleep Hygiene theme in the therapists’ framework. Chart 12 arose directly from the children’s interviews.
The principle part of Chart 3, Child’s pain, is shown below in Table 4:14. The other charts with the most interesting information, chart numbers 1, 2, 4, 5, 8, 10 and 12 can be seen in the Appendix (Appendix 12A-G).

<table>
<thead>
<tr>
<th>Child number</th>
<th>Pain described by child</th>
<th>Causes</th>
<th>Parents’ description of pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not able to describe but agreed that leg gaiters are taken off in the night because they are uncomfortable.</td>
<td>Stretching from orthoses i.e. leg gaiters and NAFOs with SS.</td>
<td>Crying, has to have leg gaiters taken off after 3-4 hours of wearing them at night.</td>
</tr>
</tbody>
</table>
| 2           | 1st interview In leg, not arm not foot, not knee 2nd interview Pain in hip and knee | Cramp. Sleep position. | 1st interview ‘Cramps’ if incredibly painful can take 2-3 hrs to get back to sleep again.  
“If she’s very tired she’s murder to get back to sleep again”  
“If we say where are you hurting she’ll always point to her legs.”  
Staying in a ‘froggy’ position causes pain at night.  
Worse when she’s out of routine.  
Does cry out that legs are hurting during day at nursery if doing a lot of activity.  
2nd interview Cramp has subsided |
| 3           | N/A (child too young to be interviewed) | N/A | Pain not suggested |
| 4           | N/A (child too young to be interviewed) | Inability to change position. Asymmetrical/unsupported positions. | Discomfort at night causing her to wake up. Child gets herself in certain positions and cannot move out of them herself |
| 5           | 1st interview Knees hurt but then also agreed to everything including feet, legs, hands. She specifically looked at her hands to say that they hurt. 2nd interview Legs, arms and hands | “Legs are incredibly tight.” | 1st interview Pain could be part of the reason she wakes up. Just had AFOs and some nights where she is suddenly completely flat she gets shakes in her legs. If she has overdone it in the day, in the evening and at night she’s particularly bad. Parents have to massage her legs and stretch them. Now she’s at nursery and working harder, when she relaxes at night she’s not particularly comfortable.  
2nd interview “Her legs are incredibly tight” |
The organisation of data into charts in this way enabled decisions to be made about the importance and relevance of the issues raised. Those issues that were considered to be important and relevant will now be presented as the key dimensions. The commonalities and differences between Children that were found in the charts are demonstrated.

### 4.1.8 Key dimensions

Five key dimensions arose from the 12 charts. The key dimensions and the charts from which they arose, are as follows:

a) Child’s pain (Chart 3).

b) Child’s ability to adapt and parents’ readiness to persevere (Charts 4, 5 and 12).

c) Knowledge and experience of therapist (Charts 7, 8, 9 and 10).

d) Process of introduction to a sleep system and the practicalities of the sleep system (Charts 1 and 6).

e) Sleep hygiene (Charts 2 and 11).
4.1.8.1 Child’s pain

Of the seven children, six were thought to have pain, or at least discomfort, either during the day or which caused them to wake at night.

Of the four children interviewed, two reported pain at night and were able to identify the site of the pain. Both of these children were only three years old at the first interview and said specifically that the pain was in their legs. One of these children also communicated, by eye-pointing, that her hands were painful too. She reported exactly the same sites of pain at both interviews, which were eight months apart. In the second interview her mother described her legs as being “incredibly tight” and said she consistently complained of her knees hurting. The participation and function of the other child was affected by pain during the day. Staff at her nursery reported to her parents that she often had to stop being active and they had to encourage her to sit quietly until the pain had gone. The parents of both these children took the child’s complaints about pain seriously and had strategies in place to relieve it as far as possible. These children had increased muscle tone and probably the beginnings of contractures in some muscle groups.

The other two children interviewed did not self-report pain and their parents described the pain or discomfort as being associated with orthoses. One of these was seemingly experiencing pain from muscle stretch when wearing leg gaiters at night. It is likely that the other child was experiencing discomfort after wearing ankle foot orthoses all day.

Discomfort at night from being in awkward positions was reported by three out of the seven families. Such discomfort arose from the child being unable to move out of uncomfortable positions without parental help. Before having a sleep system, Child 7 was described as being so stiff in the mornings that she screamed while being dressed. Two children whose photographs were taken by their parents when asleep, as part of the local therapists’ clinical reasoning process for a sleep system, were seen to be adopting extreme positions. One child assumed a tightly curled-up position in side-lying with full flexion at her hips and knees while the other lay in a ‘windswept’ position (see glossary) with full adduction of one hip and full abduction of the other. The two children who experienced pain and consequent sleep disturbance, experienced better quality sleep without pain when symmetrically positioned in a sleep system. This suggests that pain
may not necessarily be caused by staying in one position but that the adopted position may be the cause of pain.

The children interviewed in this study were able to think why they woke up at night which suggests possession of autobiographical memory from the age of three years. Their answers generally correlated with their parents’. One child started crying when thinking about it; it appeared to both her mother and the research team that she was vividly re-living or imagining the experience of waking up in the night which was frightening. These children did answer closed questions about pain. They identified the sites of pain and were consistent in their answers between the first and second interviews which were conducted several months apart.

4.1.8.2 Child’s ability to adapt and parents’ readiness to persevere

The children’s and the parents’ charts are reviewed together. Out of the seven children who tried a sleep system three, at the second interview, were sleeping in them continuously. These children were reported by their parents to be sleeping better or, in the case of one, who slept well previously, no worse. Two of these three children have very significantly improved sleep. One is reported by nursery as having increased concentration probably as a result of the reduction in wakefulness during the night. Another parent reported quality of life improvements for the whole family because the child was sleeping well.

At the close of the data collection period, parents of two of the seven children were persevering in encouraging their child to adapt to sleeping in their sleep systems. One child was becoming distressed and was taken out of it either before she had settled to sleep or later in the evening when she woke. Her parents wanted to continue and hoped that she would become accustomed to it eventually. Her mother commented that the child disliked change. The other child was still awaiting correct set-up of the sleep system seven months after it was delivered although she was sleeping in it. Her parents were frustrated by the wait.

The remaining two children were not using their sleep systems. One was experiencing very severe fits, was very wakeful at night and could not settle alone. The second child
initially slept better in the sleep system but became distressed after two weeks. The parents of both these children thought their child’s sleeping position had been improved in the sleep system.

Two children objected to not being able to change their positions in their sleep systems. One self-reported having to lie in supine but wanting to lie on her side and the other child’s parent reported that she lay on her side and wanted to roll on to her back. One other child was capable of getting out of his sleep system by himself but only did this in the mornings at weekends.

Of the four children interviewed, two said that they liked their sleep systems and were comfortable in them at night; one said definitely that she did not like hers and one was ambiguous. His sleep diary showed that he was sleeping longer in his sleep system although this may just be maturation.

4.1.8.3 Knowledge and experience of therapist
This key dimension includes the charts of therapists’ knowledge and experience of complex cases, their clinical reasoning as to why this child and why this sleep system. The chart of desired outcomes is also included.

In these seven Children (i.e. subunits) there were six therapists interviewed as one therapist had two children in the study. In Child 4, the therapist interviewed was an occupational therapist. The physiotherapist working alongside the occupational therapist was available only briefly and her answers are included where relevant. The knowledge and experience of the therapists ranged from very experienced to very inexperienced. One therapist had worked with children with complex difficulties for 18 years, another for 15 years. They had both prescribed many sleep systems of different types. Both used an evidence base and a care pathway to aid clinical reasoning and to inform decision-making. Two of the remaining therapists had only previously prescribed one sleep system each. One described herself as having worked as a paediatric physiotherapist for 20 years but worked “very, very part-time” and did not have many complex cases amongst her caseload. Another reported a lack of success with using sleep systems. She had little knowledge of the particular sleep system she had prescribed and was unable to set it up satisfactorily. While waiting for the company representative to visit to make
adjustments to the sleep system the child fell out of bed. At the conclusion of the data
collection period the child was still not correctly positioned. This proved to be
frustrating for the parents and an opportunity to improve the child’s posture that was
being missed. One other therapist was newly qualified and had received in-house
training and had attended a one-day course in postural management. She had inherited a
caseload of children using a range of sleep systems. The one occupational therapist
offered a different perspective to that of the physiotherapists. This included taking a
history of the child’s sleep and a sensory profile. The details of the tools used for these
tasks were not given.

From the therapists’ perspective, the desired outcomes for the provision of a sleep
system were:

1. To improve posture, reduce asymmetry and /or hip migration. These were
   mentioned by the six physiotherapists but not by the occupational therapist.
2. Improved sleeping was mentioned by five out of seven therapists.

From the parents’ perspective, the desired outcomes for the sleep system were:

1. Posture, in terms of maintaining hip and / or spinal symmetry, was mentioned by
   three out of seven parents.
2. Comfort and enabling better sleep was mentioned by three different parents.
3. One parent mentioned she wanted the child to have a supported position in side-
   lying and to feel safe.

4.1.8.4 Process of introduction to a sleep system and the practicalities of using it

Out of the seven families in the study, two had previously attended formal training
postural management training. This was a set programme, led by therapists, in a group
setting. One family had received a similar teaching session on an individual basis. The
remaining four participant families had been given varying amounts of information on
an ad-hoc basis as new equipment was being introduced.

Three of the seven children had tried the sleep system at night for a period of time
before it was ordered for them while four had only had the opportunity to lie in it
briefly. Out of the three that had a trial, two went on to use the sleep system successfully, while one felt it was not appropriate.

Five out of seven sleep systems were set up by the therapist when they arrived, one was set up by the parents following DVD instructions; the other was set up by the parents while waiting for the therapist to make a visit. After setting it up three therapists were in close contact with the parents to monitor progress and one parent said they had no need of further help from the therapist.

The sleep systems the therapists chose were as follows:

<table>
<thead>
<tr>
<th>Type of Sleep system</th>
<th>Number of therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chailey Lying Support</td>
<td>3</td>
</tr>
<tr>
<td>Leckey Sleepform</td>
<td>2</td>
</tr>
<tr>
<td>Symmetrisleep</td>
<td>1</td>
</tr>
<tr>
<td>Jenx Dreama</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 4:15 Types of sleep systems prescribed

The reasoning behind the choice of sleep systems is presented in the chart “Why this sleep system” in Appendix 12E. Of the three children who continued using their sleep systems, two had Chailey Lying Supports and one was in a Sleepform.

The parents’ views of the practicalities of using the various sleep systems can be summarised as follows:

a) One out of the three families using the Chailey Lying Support mentioned the difficulty of nappy-changing at night especially if the child was sleeping prone. The other two families made no comment.

b) Both families trying out the Sleepform reported it was easy to use.

c) The parent using the Symmetrisleep mentioned that her child woke up fully when she needed a change of position in the sleep system at night because the child was upset by the loud noise of the Velcro fastenings.

d) The parent using the Dreama was frustrated that it required several visits and several different pieces of equipment at different times from the company sales representative to set the sleep system up correctly.
4.1.8.5 Sleep hygiene

Six out of the seven children in this study had sleep difficulties, details of which are presented in Chart 2, Appendix 12B.

At the first interview, the parents of these six children reported that their child woke several times most nights. Child 3, a two-year-old with uncontrolled epilepsy, was recorded in the second sleep diary as waking between two and eight times a night, waking an average of 5.8 times a night. This was not influenced by his use of the sleep system which was abandoned after a few brief trials. Both parents were on anti-depressant medication to help them cope with the situation. Another parent reported that prior to using the sleep system her child might wake 10 or 11 times a night.

The causes of night waking are presented in Table 4:16 below.

<table>
<thead>
<tr>
<th>Cause of waking</th>
<th>Number of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cramp, pain, discomfort</td>
<td>4</td>
</tr>
<tr>
<td>Needing to be turned</td>
<td>1</td>
</tr>
<tr>
<td>Fits</td>
<td>1</td>
</tr>
<tr>
<td>Behavioural</td>
<td>2</td>
</tr>
<tr>
<td>Night terrors</td>
<td>1</td>
</tr>
<tr>
<td>Having had a nap during the day</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 4:16 Cause of waking

Four out of the seven children had not learned to fall asleep alone at commencement of the study. Two of these four children learned to fall asleep alone when they had their sleep systems.

The therapists prescribing the sleep systems were all aware of the sleep difficulties. They were not, however, aware of the causes. The occupational therapist in Child 4 had taken a history of the child’s bedtime routine. Two therapists asked the parents to take photographs of their child while asleep to ascertain the child’s sleep postures and whether they might be a cause of awakening. None of the physiotherapists had previously taken a sleep history until they were introduced to the Chailey Sleep Questionnaire used in this study.
The advice and support received by parents to help them overcome the sleep hygiene issues were reported as:

a) One parent was referred to a community nurse with a special interest in sleep. The parent reported that the nurse had said the family circumstances were too complex for her to be able to advise.

b) One parent had advice from her health visitor but was very concerned that the advice was to practise ‘controlled crying’. The parent reported that her child had seizures and that her cry was difficult to differentiate from the noise she made when she had a fit.

c) One parent was advised by her child’s paediatrician to have a glass of wine and to take some of her child’s Melatonin to help her sleep when it was her husband’s turn to stay up with the child at night.

The respective advice was considered inadequate by all three parents. The remaining parents of children having sleep difficulties had received no help.

4.1.9 Summary

The data collected from the interviews with the children, their parents and their therapists was analysed using the process of familiarisation and the formation of thematic frameworks. The frameworks enabled the production of charts to display the range of views and experiences both within Children and, on further analysis, 12 charts displaying the range of views and experiences between Children. With further abstraction and synthesis five key dimensions were identified and examined in detail.

Section Two of this chapter will discuss the findings from informal discussions with managers of children’s physiotherapy services and a conversation with an Australian clinician.
4.2 Section Two: Findings from informal discussions with therapy service managers and an Australian clinician

Informal discussions with managers of therapy services in the region took place opportunistically within the researcher’s usual working practice, and were considered appropriate methods of gaining information about the political and organisational issues involved in this case study. Further key people in the field of postural management, a therapy services manager from a different region and an international acquaintance, were contacted informally for their views.

4.2.1 Informal discussions with regional managers

Informal discussion as to why the group felt that the numbers of children recruited to this study was small, took place at the April 2009 South-West regional meeting of the Paediatric Physiotherapists in Management Support (PPIMS). All the members present at the meeting took part in the discussion.

The group comprised seven managers of children’s physiotherapy services across the South-West of England. Localities 1, 2, and 3 were in Devon and Cornwall and, with the researcher, represented the managers of all the children’s physiotherapy services in those counties. The study had been launched in their area with a presentation to staff by the researcher. The study was extended to include Localities 4, 5, 6 and 7 when initial recruitment proved slow. The study had not been presented to staff in those areas, but a request by email to the managers had been made and ethical approval gained in anticipation of participants from one Research and Development department. Localities 1 and 2 had provided recruits to the study. One locality, not represented at the discussion group (Locality 8), had also provided recruits as had the researcher’s own locality (Locality 9). This area was not represented in the discussion group. Localities in which the researcher is the manager of the therapists are identified in Table 4:17. It is acknowledged that this could be a cause for bias.
Table 4:17 Localities involved in the study

<table>
<thead>
<tr>
<th>Locality number</th>
<th>Study launched face to face</th>
<th>Involvement of manager in focus group</th>
<th>Child numbers recruited into study</th>
<th>Therapist managed by researcher?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td>Yes</td>
<td>2, 3 &amp; 5</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
<td>Yes</td>
<td>7</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>Yes</td>
<td>Yes</td>
<td>-</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>No</td>
<td>Yes</td>
<td>-</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>No</td>
<td>Yes</td>
<td>-</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>No</td>
<td>Yes</td>
<td>-</td>
<td>No</td>
</tr>
<tr>
<td>7</td>
<td>No</td>
<td>Yes</td>
<td>-</td>
<td>No</td>
</tr>
<tr>
<td>8</td>
<td>Yes</td>
<td>No</td>
<td>4</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Yes</td>
<td>The researcher is the manager here</td>
<td>1 &amp; 6</td>
<td>Yes</td>
</tr>
</tbody>
</table>

The question posed to the discussion group was: “It has been really difficult to recruit to this study and I wanted to ask you why you think that was?” Locality 7’s manager suggested that financial considerations contributed to the reasons why physiotherapists in her locality were not using sleep systems. Locality 6’s manager agreed, while the manager of Locality 1 had no problems with financing sleep systems. The manager of Locality 2 had prescribed sleep systems for children younger than 18 months old while the manager of Locality 3 did not think physiotherapists would prescribe sleep systems for children younger than 18 months in her area.

Managers with no recruits in the study said the reasons were:

a) That they did not prescribe sleep systems for children early enough. They thought about prescribing them but did not take it further.

b) They thought children would be excluded from the study if the therapist had already talked to parents about sleep systems.

c) They were concerned that their area was too far away from the researcher’s base.

d) Children in their area that had been prescribed a sleep system during the study’s recruitment phase did not have a diagnosis of cerebral palsy.

During the discussion the Locality 2 manager did remember a potential recruit who fitted the inclusion criteria but had recently started using a sleep system. The manager had forgotten about the study and cited the pressure of work as the reason for forgetting.
To follow up the diverse views expressed in the discussion group, purposive sampling of two of the managers was undertaken. These managers conversed individually with the researcher at a later date by telephone.

4.2.2 Conversations with key regional managers

Managers from Localities 1 and 7 both gave consent for individual telephone conversations to be recorded and transcribed. The transcripts were analysed for the main themes. The codes at the end of the quotes denote the speakers’ locality and the transcript line number.

4.2.2.1 Background of manager

The two managers’ backgrounds differed significantly. Locality 1’s manager had a long history of working first with adults with profound disability alongside one of the first protagonists of postural management, and then with children.

“I worked with ...(physiotherapist) at the Home for Incurables in Putney when she was doing some of the initial work on postural management and I saw the difference that it made to a profoundly disabled group of adults who, at that time were, basically, in bed all day, every day, and in the time that I was there she began the postural management programme and one of the things that it really did was have an impact on their quality of life. So I’ve always been interested in postural management. ” (L1, 11)

The other therapy manager had originally worked as a respiratory physiotherapist.

“I came into paediatric physio by the route of respiratory. I was a neonatal intensive carist in the Eighties, and I’d always wanted to be a paediatric physio and I actually worked at special schools part-time in the Nineties and then sort of took on a more substantial role as the head of this department in 1998.” (L7, 9)

For Locality 1’s manager, postural management was a passion.

“So when the Symmetrikit sleep system first came on the market, for me, it was almost like a light bulb moment. I was working in a special school with profoundly disabled children and this was about real 24-hour postural management rather than just positioning in lying during the day, seating, standing, passive movements. It was completing the circle really. ” (L1, 21)
For the other, postural management was something that ought to be done but her passions lay elsewhere.

“I specialised I suppose in early years primarily but have got better about the rest. I’ve got more experience lately.” (L7, 15)

These two managers, with their different backgrounds, manage services that appear to have differing priorities, with Locality 1 using sleep systems routinely and having no difficulty in funding them while Locality 7 rarely uses them and cites funding as a problem. It could be surmised that it is the managers’ past experiences that have led them to view the relative importance of aspects of service provision differently.

4.2.2.2 Leadership

In Locality 1, postural management has been led by the manager with a definite interest in it.

“I’ve led it, as I’ve had an interest in postural management since I worked in my second job when I was in my twenties.” (L1, 10)

She had, however, campaigned locally for a long time to encourage the Primary Care Trust to create a new post for a physiotherapist to work across the locality purely as a lead for postural management. This campaign has recently been successful and the new post-holder will have the responsibility of training staff, parents, carers and children.

In Locality 7 there is no lead post.

“I wouldn’t say we have a lead, but I would say that we are all pretty interested in postural management really. Our expertise is very rounded. It doesn’t belong with any particular person.” (L7, 39)

Without specific leadership, provision of postural management services appears to be ad-hoc and lacking in clear processes.
4.2.2.3 Written guidelines

Locality 1 has an evidence-based written protocol, dated August 1999, for the prescription and use of equipment for postural management in the lying position. The manager proposed that it needed updating but it clearly sets out the criteria for who should have sleep systems and the potential benefits. Locality 7 has no written protocols or pathways available for clinicians when considering postural management at night.

4.3.2.4 Resources

Both managers reported difficulties in following up children with sleep systems regularly enough. The manager of Locality 1 specifically mentions staff resources.

“I think the practicalities of doing a 24-hour postural care programme for families with our current staffing resources is a different matter. I think that it’s very difficult to follow it through effectively if you’re not able to support the parents on a frequent enough basis really, because we all know that you if you don’t keep on going back and checking that everything is OK, then the parents, with the best will in the world, you know, they do tend to have other priorities, and things get left.” (L1, 174)

Financial constraints had been an issue in Locality 7 but there had also been a lack of common agreement about the use of sleep systems among therapists within the county.

“The management as far as sleep systems are concerned was more difficult at the beginning because we did have a slightly different view across the county about what we should be using. Now everybody is agreed to that so in the last two or three years, we have used sleep systems as part of our 24-hour postural management programme as and when we felt it was appropriate.” (L7, 53)

Having discussed the views of two regional managers, a therapy manager with a major influence on postural management services in another region of the UK was approached for her views.

4.2.3 Conversation with a key therapy manager in the North-West

This physiotherapy manager has been responsible for co-ordinating the production of extensive practice guidelines for therapists for 24-hour postural management in the North-West of England. The extracts from the transcript below has the researcher,
asking the questions denoted by R and the respondent as NW which denotes her geographic location. The transcript line number follows.

4.2.3.1 Background
Like the manager of Locality 1, this physiotherapy manager had worked with adults and children with complex difficulties for most of her career and had been affected by their deformities.

“I worked with adults in the community, some of whom had really horrendous postural changes, ribs touching hips, and you kind of feel this can’t be right but this is how it is. I suppose I really started to do something about it when I took over as manager here.” (NW, 14)

4.2.3.2 Leadership
She, again concurring with the manager of Locality 1, was convinced of the need for a local professional to lead postural management. Her influence and passion have encouraged an ethos of postural management in her department and the organisational structure she has implemented has resulted in two clinical specialist posts responsible for leading postural management.

“R And do you feel that it helps to have somebody who actually leads it within the department?
NW Absolutely.
R Yes. It sounds as though you’re all on board but you’ve still got people who actually lead it.
NW Yes, yes, that’s right. And they go out and do the training.” (NW, 64)

4.2.3.3 Inequality in funding
This physiotherapy manager became aware of the need to write guidelines for practice. Although ordering sleep systems in her locality was a straightforward procedure, in others it was not. The guidelines were based on the available evidence.

“It became very clear that different areas had very different routes, and a lot of people couldn’t get finance at all, and parents were using their own money or charity or all sorts. It seemed grossly unfair when I could just put in an order and they came. But there was the other issue of why we were ordering them and if we were going to justify the funding, then we had to have some evidence of actually needing them.” (NW, 28)
The aim of the guidelines was to disseminate knowledge and skills about postural management more widely in the region and provide other physiotherapy managers with the evidence they needed to be able to justify and obtain funding for sleep systems.

4.2.3.4 Influence of manufacturers

Unlike the key informants in the South-West, this manager reported that only one type of sleep system was commonly used.

“We basically use the Symmetrikit. We haven’t really gone down the route of anything else because it works for us.” (NW, 152)

This is probably historical in that in the early days of 24-hour postural management Liz and John Goldsmith, early proponents of postural management, offered training for staff and parents. The Goldsmiths were also involved in the design, manufacture and sales of the Symmetrikit sleep system, the Symmetrisleep.

“We certainly started the whole process with the Goldsmiths so that was what we used and across the North-West, when we looked at what people were using, and the feedback that we got, that was way, way over and above anything else with hardly anything else being used at all.” (NW, 162)

Using one type of sleep system accords with the experience of the key international therapist discussed below, but contrasts with the South-West region experience in which the two managers interviewed reported using all the various sleep systems available. Staff in the South-West may have had individual preferences, however, with location also playing a part. Locality 1, a geographically isolated service, pragmatically used the products of the manufacturers prepared to travel to them regularly.

4.2.3.5 Outcomes

Long term outcomes are not available yet in any service although this manager states that their short-term goals are largely being achieved with children who start postural management when they are young. She did not elaborate as to what those goals might be. Comparison is possible, though not so far by any formal scientific means, with the local Asian population, whom clinicians largely find hard to engage in night-time
postural management because of their cultural differences in family co-sleeping arrangements and the difficulties those cause for the introduction of sleep systems.

“What we’ve identified with that is that it’s a cultural difficulty in that a lot of the children sleep with their parents and therefore, they will not accept sleep systems. We’ve tried putting them into a double bed but even then, they won’t accept it and we haven’t been able to get past that cultural difficulty. So when we look at those children, compared to children who have sleep systems, the ones that have them I would say are clearly better.” (NW, 132)

4.2.4 Conversation with a key international therapist

This international therapist is an occupational therapist who co-founded Sleep Solutions, a sleep service for children and adults at the Centre for Cerebral Palsy in Perth, to offer advice and intervention for sleep problems. Her views on the development of postural management services in Australia and Canada, where she had recently travelled, were sought to put similar services in the UK in an international perspective. The extracts from the transcript of the recorded conversation identify this Australian therapist by the initials AT.

This therapist chose to come to the UK, during a Churchill Travel Fellowship, to meet with therapists because the theory and practice of postural management originated in this country. Postural management services in Australia use products made in the UK and have depended on visiting UK experts and company representatives to introduce the concept and the equipment to Australian therapy staff and families.

“The whole idea of postural management and postural care came to us initially from Liz and John Goldsmith. They came out to Perth and other areas of Australia and New Zealand and ran two or three day workshops. They certainly put postural care on the map for us in terms of our awareness and all we knew about postural care was Symmetrisleep. Since then Pauline Pope has visited and given us a whole different view of postural management.” (AT, 7)

Only one sleep system has been easily available until recently, as a result of which therapists used the product name, ‘Symmetrisleep’, as a generic term for sleep system.

“It wasn’t until I came to the UK and met people like you that I got a really good overview of the alternative systems. What I found was that, when I was with
therapists who are not belonging to the product, the clinical reasoning was very objective and much more family-centred I think.” (AT, 18)

In Canada, where, according to this therapist, postural management services have developed more slowly, they currently only have access to the Symmetrisleep.

4.2.5 Summary

Findings from group and individual discussions with key therapists with regional and international perspectives have been presented. The main themes were identified using thematic content analysis.

The next section of this chapter moves on to multi-dimensional analysis of the data in order to consider the different types of Children (i.e. subunits) studied. The data gathered from the managers and the key international therapist are instrumental in creating typologies of Children.
4.3 Section 3: Creating typologies

The following theory was proposed in Chapter 3, section 3.1.3, in order to provide a focus to the study and to aid its direction:

“There are predictable factors which influence the experience of night-time postural management for a child with cerebral palsy.”

An appropriate method of determining these factors is the consideration of typologies, accomplished through further mapping and interpretation of the charts 1-12 (see section 4.1.7). If the Children (i.e. subunits) could be classified into types, the influencing factors might become apparent.

4.3.1 Child continues to use the sleep system

Children 1, 2 and 7 continued to use their sleep systems. The following have been identified as indicators in these cases although there are exceptions to the rule and these cases are presented in italics:

a) The process of introduction of the sleep system to the child and family included formal training on postural management for parents and the child having a trial of sleeping in a sleep system (Child 1 and 7, also 6 but not 2)
b) The child is able to adapt to sleeping in the sleep system (Child 1, 2 and 7 but also 5 although the sleep system was not correctly set up).
c) Parents are ready to persevere with encouraging the child to sleep in the sleep system even when there is initial protest from the child (Child 1, 2, and 7 but also 5 and 6).d) Sleep hygiene difficulties are accommodated (not relevant to Child 1 but is to 2 and 7 and also 5).
e) There is an ethos of postural management in the local therapy department (Child 1, 2 and 7 and also 3, 5 and 6).
f) The therapist is knowledgeable and experienced in postural management (Child 1 and 7 but not 2).
g) The therapist has written guidelines available which can be used to aid clinical reasoning (Child 1 and 7 but also 6. In Child 2 guidelines were in place although the therapist was not aware of its contents).

4.3.2 Child does not continue to use the sleep system

Children 3 and 4 did not continue to use their sleep systems. The following have been identified as indicators of a case in which a child has been unable to continue using the sleep system although there are exceptions to the rule and these cases are presented in italics.

a) The process of introduction of the sleep system to the child and family did not include formal training on postural management for parents and the child did not have a trial of sleeping in a sleep system (Child 3 and 4 but also 2 and 5).
b) The child is not able to adapt to sleeping in the sleep system because of wanting to sleep in a different position or wanting to be able to move (Child 4 and also 6).
c) Parents are not ready to persevere with encouraging the child to sleep in the sleep system when there is initial protest from the child (Child 3 and 4).
d) Sleep hygiene difficulties not able to be accommodated (Child 3).
e) Child’s health problems significantly interfere with sleeping (Child 3).
f) The therapist is not knowledgeable or experienced in postural management (Child 3).
g) The therapist has no written guidelines available which can be used to aid clinical reasoning (Child 3 but also 2 and 5).

4.3.3 Child continues to partially use the sleep system

Children 5 and 6 continued to partially use their sleep systems. The following have been identified as indicators of a case in which a child is not sleeping a large proportion of the night, most nights, in a sleep system although there are exceptions to the rule and these cases are presented in italics:

a) There are continuing difficulties with sleep hygiene which are only partially accommodated (Child 6 but not 5).
b) Parents are ready to persevere with encouraging the child to sleep in the sleep system even when there is initial protest from the child (Child 5 and 6).
c) The therapist may not be knowledgeable or experienced in postural management (Child 5 and 6).

4.3.4 Providing explanations

The creation of typologies gives rise to the emergence of factors which influence the child’s use of a sleep system at night. Some of those factors contributed to building a case in which a child continues to use a sleep system and some factors contributed to building a case in which a child only partially used or did not continue to use a sleep system. However, it can also be seen that there are exceptions to the rules, which may be explained by the very individual nature of a child’s particular circumstances. The findings, therefore, were not conclusive.

The extent to which the typologies are representative is determined by the extent to which the participants are representative of the population of children with cerebral palsy being prescribed a sleep system as well as the bias of the researcher. The study of other children, parents and their therapists by a different researcher may provide a variety of other factors which influence a child’s use of a sleep system but that does not negate the findings from this study (see section 5.2.1.5).

4.3.5 Conceptual framework

Although it has been stated that the factors cannot be used to predict outcomes, the findings can be used constructively to guide the clinical reasoning of therapists in the prescription of sleep systems. The factors that influence the child and family’s experience of using a sleep system at night can be conceptualised as moderating factors under the three groups of participants; children, parents and therapists. These moderating factors arose during the process of mapping and interpretation of charts 1-12 and are presented in the typologies above. Using the conceptual framework below (Fig. 4:4), therapists could consider, and try to optimise, each of the moderating factors that influence the child, the parents and themselves in order to create a case in which the child is likely to continue using a sleep system. Therapy managers will also need to pay heed to those factors that influence the therapist.
4.4 Section 4: Revisiting the aims of the study

This study set out to explore the effects of a certain set of very individual circumstances on a child’s experience of sleeping in a sleep system and to set this within the context of
local and national agendas. The specific aims and objectives of the study, identified in Chapter 2, section 2.7 are reconsidered here in the light of the findings.

Aim 1: To explore the views of children on using a sleep system
The views of four young children, with limited ability to communicate verbally, were accessed using an appropriate method, the Talking Mat. This method, employed by an experienced clinician, enabled the children to participate in research and to have their voices heard. The children, two of whom had an autobiographical memory at a younger age than has previously been reported in the literature, were able to report their feelings about bedtimes and on morning waking. They also reported on causes of waking in the night, and whether they liked and were comfortable in their sleep systems. Two children expressed that they experienced pain, particularly in their legs and also hands, on a regular basis.

Aim 2: To explore the role of the parents in the use of a sleep system
Factors affecting the role of the parents in the child’s use of a sleep system include the training they have received in postural management, their readiness to persevere with encouraging the child to sleep in the sleep system and their ability to resolve or adapt the child’s sleep hygiene difficulties. The extent of the sleep difficulties experienced by the children and their families was exposed along with the minimal amount of help they had received to resolve them.

Aim 3: To explore the effects on quality of sleep in children with cerebral palsy using a sleep system.
The effects of the sleep system on quality of sleep were explored; however, there were limitations to the study. The sleep system significantly improved the quality of sleep for two children in terms of the length of time asleep and the number of awakenings. For two children, both of whom slept well, the sleep system did not affect their sleep. Of the children who did not sleep well, one was affected by epilepsy and hardly used his sleep system; a further two children were distressed by sleeping in their sleep systems which resulted in them sleeping less well.
Aim 4: To explore the role of the therapist in the child and family’s experience of using a sleep system.

A range of knowledge and experience was demonstrated by the therapists. Some based their clinical reasoning on published evidence and recommended national and local guidelines in addition to their own tacit knowledge, while others had no clear criteria for the prescription of sleep systems. It was established that the background and previous experience of the manager of the children’s therapy services influenced the ethos and organisation of postural management within the therapy department. Organisation within the department determines the level of knowledge and experience of the clinicians, factors which are essential in identifying the appropriate child and the appropriate sleep system. The process of introduction of the sleep system to the family is also important. Formal parent training ensures that the parents understand the rationale for 24-hour postural management rather than simply receiving ad-hoc information about a particular piece of equipment. Integrated care pathways can assist and support clinicians in their clinical reasoning.

Objective 1: To identify factors which influence a child’s use of a sleep system at night, including the role of the parents and the therapist.

Systematic analysis of the data enabled the identification of factors affecting a child’s use of a sleep system. In common with other case studies and qualitative research in general, these factors are not directly generalisable.

Objective 2: To produce findings to guide clinical practice

The identified factors, placed within a conceptual framework (refer to Fig. 4:4), can be considered by therapists as those which have a moderating influence on the likelihood of a child continuing to use a sleep system. The findings can be adopted in clinical practice as a means of optimising the outcome when prescribing a sleep system.

The factors can also be placed within the ICF framework model to guide clinical reasoning towards consideration of a child’s activity of sleeping in a sleep system which in turn may prevent or reduce deformity and pain allowing the child to have greater participation in community life. This is presented in Figure 4:5 below.

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Figure 4: ICF framework model redrawn with factors for consideration prior to prescription of a sleep system

- Health Condition
  - Cerebral palsy

- Body functions and structures
  - Pain
  - Health problems e.g. fits, reflux

- Environment factors
  - Background of manager and ethos of postural management in therapy team
  - Process of introduction, including parent training and trial of SS
  - Written guidelines
  - Resolution or adaptation of child’s sleep hygiene difficulties

- Activities
  - Child sleeps in SS

- Participation
  - Involvement in recreation and leisure is possible because deformity and pain are prevented or reduced

- Personal factors
  - Child’s ability to adapt to sleeping in SS
  - Parents’ readiness to persevere with encouraging child to sleep in the SS.
  - Knowledge and experience of therapist
4.5 Conclusions

This chapter presented the findings of a case study on the use of sleep systems in the South-West of England. An innovative research method, the Talking Mat, was adopted to explore the views of young children with communication difficulties who would otherwise have been excluded from the research process. These children had the unusual opportunity to report their opinions on a new piece of therapy equipment being introduced to them in which they were expected to sleep.

Insights were gained from parents on the incidence of pain in the participating children. Difficulties encountered with sleep hygiene and health-related sleep problems were elucidated, providing a picture of chronic sleep problems in families and a lack of services providing advice or intervention. Information concerning postural management was delivered to parents in both a formal and informal manner and this appeared to have an impact on their understanding of the reasons for the prescription of the sleep system and potentially their perseverance in encouraging continuing use by the child.

Variation in provision of sleep systems was demonstrated across the South-West with a similar variation in the knowledge and skills held by therapists in the field of postural management and their respective therapy service managers. This is contrary to national recommendations from government and professional interest groups.

Factors which influence the use of sleep systems by children have been identified and can be used by therapists to guide their clinical practice. This guidance is the first of its kind to be provided for therapists in the field of night-time postural management.

The following chapter will discuss these findings in the light of the literature and will consider the effectiveness of the methods used.
CHAPTER 5: DISCUSSION OF FINDINGS

The aim of this study was to explore posture and sleep in children with cerebral palsy and to elucidate the reasons why some children and families find they cannot use sleep systems. Asking children for their views was central to the ethos of the study. These subjects are revisited in this chapter in the context of the findings from the study and the literature. Key issues of pain, of seeking the voice of the child and of the organisation of therapy services arose from the study and they will also be discussed.

5.1 Study Findings

5.1.1 Posture and cerebral palsy

At a recent conference Graham (2010) suggested that the natural history of cerebral palsy is stronger than our interventions. Authors of recent studies (Morton et al 2006; Soo et al 2006; Scrutton et al 2001; Saito et al 1998) concur that children with the most severe form of the condition (i.e. GMFCS Level V) have the highest risk of hip dislocation and that the risk is suggested to be as high as 90 percent (Soo et al 2006). Fairhurst (2010) asks whether hip displacement matters and concludes that when considering a neurodevelopmental hierarchy of clinical need, core clinical needs include comfort and the absence of pain and that pain is variously associated with hip displacement with some authors finding that it is (Hodgkinson et al 2001; Boldingh et al 2005; Cooperman et al 1987) and others finding it less so (Noonan et al 2004).

Evidence for the efficacy of various management approaches to early hip displacement is weak, and there is a call for evidence from randomised controlled trials to be combined with cohort studies and for outcomes to be considered at skeletal maturity rather than after a short duration which is common (Graham 2010). Recent encouraging evidence of outcomes from early preventative surgical intervention in cohorts of children on cerebral palsy registers in Sweden and Australia may alter surgical practice in the UK in the future (Graham 2010; Hagglund 2010). Earlier, less complex surgery has been undertaken, keeping hips in joint and fewer salvage operations for painful dislocated hips have been necessary in these cohorts. Registers of populations of
children with cerebral palsy enable not only early identification of need and routine monitoring but also a record of interventions and outcomes providing a necessary and authoritative method of evidencing efficacy of approaches in the future (Graham 2010).

Non-invasive 24-hour postural management programmes may avoid the requirement for surgery for some children if commenced early enough before hip subluxation has occurred and would be of significant benefit for those children. A recent study (Graham 2008) and a review paper (Gough 2009) suggest that postural management equipment is ineffective in preventing hip subluxation especially as those children most at risk of developing deformity may be unable to tolerate it. The findings from this study, however, demonstrate that there are many factors that should be considered by therapists prior to prescription of a sleep system in order that conditions are optimal for its continued use; a method of clinical reasoning that could be adopted for any piece of postural management equipment. In some families optimal conditions may not be achievable and in these cases a pragmatic decision to consider other interventions or recommendations would be appropriate.

5.1.2 Sleep difficulties

Sleep difficulties and its effects were dramatically highlighted in one of the pilot studies. The mother of a nine-year-old child with cerebral palsy agreed to be interviewed to enable the researcher to test out the appropriateness of the questions in the topic guide. This mother described a history of lack of sleep, marital estrangement and feelings of guilt and helplessness. The support received from professionals had been minimal and had only increased her sense of embarrassment about her self-perceived poor parenting skills to the point that she had stopped reporting problems with sleep.

There appeared to be a significant power relationship between child and parents in this family especially around bedtime and during the night, mirroring that found in a study of seven to 11 year-olds conducted by Moran-Ellis and Venn (2007). The power wielded by the nine-year-old child affected the parents’ opportunity to have an evening out together which they had done only once since the child’s birth, and even to share a bed, with the mother having abandoned the marital bed to sleep with her daughter to tend to her needs at night. The cause of these sleep difficulties, involving significant
resistance to settling for sleep and multiple awakenings during the night, may well have been due originally to her medical condition and parents’ anxiety, but latterly had become learned behaviour which was conducive to change once her mother received advice and support on how to effect that change. The first time it occurred, the mother expressed amazement that her child was physically capable of sleeping through the night.

This interview had a profound affect on the researcher. In many years of clinical practice working with families with children with disabilities the topic of chronic sleep deprivation had rarely been raised even though night-time postural management had been high on the agenda. Positioning for sleep was always discussed at length and within those discussions it was identified occasionally that a child fell asleep on the sofa or in their parents’ arms. The working title for this study, in fact, reflects that, as it was ‘Posture, sleep and cerebral palsy: sofa or sleep system?’ The long term effects of difficulties with settling and maintaining sleep, however, had not previously been considered. Paediatric colleagues, and in particular this child’s paediatrician, revealed that a similar lack of attention to sleep problems was seemingly prevalent in their practice within the locality.

In order to raise awareness of the situation, learning from this pilot study was presented initially at a South-West regional meeting of the British Association of Childhood Disability (Humphreys 2008a) and subsequently in a poster at a conference for paediatric physiotherapists (Humphreys 2008b). Several paediatricians in the audience of the first conference acknowledged that they were often aware of sleep difficulties in children presenting in clinic but did not have the time to do anything about it or knowledge of who to refer to for help. General interest in this topic was such that a whole day was assigned for sleep in the forthcoming South-West regional meeting of the British Association of Community Child Health (BACCH 2009). Continuing discussions with the lead community paediatrician resulted in a working group of paediatricians, learning disability nurses, respiratory nurses, a voluntary sector Face-2-Face organiser and the researcher putting together a bid to commissioners, written by the researcher, for funding for a sleep intervention service for families with children with additional needs in Devon. Although results are awaited from the team in York,
their review of literature suggests that improvements in sleep can be made with relatively simple input to families (McDaid and Sloper 2008).

Neither the mother in the pilot study, nor other parents interviewed in the main study had access to structured services to help them improve their child’s poor sleep. This confirms the consensus in the literature that families of children with disabilities struggle with poor sleep and that help is frequently not available. This situation is acknowledged in the National Service Framework for Children, Young people and Maternity Services (DH 2004) and reiterated in the Aiming high for disabled children programme. Box 1, below, is reproduced from the document Aiming high for disabled children: better support for families (DES 2007) under the section Benefits of early intervention. It is proposed in that document that programmes to help families manage their child’s sleep pattern should be available from an early age to prevent parents experiencing the difficulties expressed below.

<table>
<thead>
<tr>
<th>Box 1: A parent’s experience: the consequences of a lack of early intervention to support sleep deprivation</th>
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<tr>
<td>“I get so tired I dream about sleep during the day. Not holidays or having fun, just sleep.</td>
</tr>
<tr>
<td>Some nights I get around 5 hours, others as little as 3. I find it hard to get motivated because I often have aching sensation in arms and legs where so tired. When too tired get weepy.</td>
</tr>
<tr>
<td>I forget things all the time, as you personally know, and am convinced that my lads probably do use this to their advantage, not that I blame them, I would if I could.</td>
</tr>
<tr>
<td>Friendships are few and far between because I have become so lousy at calling people and keeping in touch. I used to be Mrs Efficient And Houseproud, not any more…. real life is here.</td>
</tr>
<tr>
<td>I blunder through each day from one thing to the next. I get side-tracked, on route to doing something I find myself doing something completely different.</td>
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Pending the outcome of the bid for a comprehensive sleep intervention service in Devon, a six-weekly sleep clinic with a Cerebra sleep nurse has been set up for local families at the researcher’s base.
Poor sleep may be an invisible extra burden on many families and go unrecognised by clinicians. The parent in the pilot study reported feeling embarrassed about her inability to solve her child’s need for a close adult presence throughout the night and intimated that health professionals who had intervened with sleep advice had made her feel a failure when the sleep problems persisted after the allotted six-week intervention period. Parents may be unwilling to disclose information about poor sleep in the future when they have this sort of experience early on. Some parents, especially mothers as suggested by Venn et al (2008), and including the mother in the pilot study, accept their plight of sleeplessness pragmatically, often assuming that their child with a disability is unable to sleep because of the medical condition rather than a lack of learned good sleep hygiene. These attitudes may explain why the provision of sleep intervention services has been unforthcoming to date.

In this study five out of the seven fathers apparently regularly took turns with their partners when their child needed care at night. In the clinical situation it is more frequently reported that the mother wakes first and gets up to tend to a crying child. In the study by Venn et al (2008) the woman was the main carer for wakeful children at night in the majority of couples interviewed, although in the two cases involving children with additional needs, as in this study, the fathers also acted as carers at night.

While there is currently little support for parents, in some cases at the researcher’s base where support has recently been offered parents have been reluctant to take it up. Many factors can affect the readiness of parents to engage with changing the sleeping habits of their child with cerebral palsy. The researcher’s own clinical experience and conversation with others (Annie O’Connell, OT with Sleepwise sleep service in Adelaide, Australia, November 2009) point to several examples; a new baby in the family, the child changing schools, bereavement or emotional upset in the family, sharing a room with siblings, awaiting a new bedroom to be built for the child and others. Parents’ readiness to adopt a behavioural approach to address their child’s sleep hygiene difficulties has been identified as an area requiring further research (Wiggs, personal communication 2009). Readiness to undertake change is a necessary prerequisite for success in this area. The mother of one child in this study, who was waking many times during the night due, in part at least, to epileptic seizures, was not ready to take up the paediatrician’s suggestion of help from a specialist sleep clinic. Another
mother who attended an initial information session with the Cerebra sleep nurse has failed to book an appointment in subsequent sleep clinics despite voicing distress at her son’s poor sleeping habits. Some parents report they are too tired to contemplate introducing a new regime that may potentially cause further disruption to sleep, even if the extra disturbance is likely to be temporary.

If early intervention sleep programmes are to become a well-advertised component of every children’s health services’ toolkit it is likely that parents will realise that sleep problems are common in children with disabilities and not something to be endured or ashamed of but can be improved to the benefit of child and family alike.

Therapists and other clinicians may be aware of the fact that a child is having difficulties with sleep but the causes of those problems may not have been explored. Therapists cited the aim of improving sleep in their clinical reasoning for prescription of a sleep system and yet without a detailed sleep history they will not be able to identify the reasons why the child is not sleeping well. Until recently there has been no standardised tool with which the sleep problems of children with complex disability can be recorded. The Chailey Sleep Questionnaire (Khan and Underhill 2009) helps identify the many factors which may contribute to sleep difficulties in these children with complex disabilities and highlights those that may be risk factors, e.g. breathing problems, especially if clinicians are suggesting the child sleeps in a sleep system. This questionnaire covers how and where a child settles for sleep, how long settling takes, how many times the child wakes during the night and how many hours the child sleeps as well as medical factors that may impair a child’s ability to sleep. Best practice would suggest that clinicians use this tool to take a sleep history to form the basis of a discussion of risk with the child’s paediatrician. Subsequent use of the Sleep Profile section of the Sleep Questionnaire would usefully inform the clinician about changes in the child’s quality of sleep following intervention with a sleep system.

5.1.3 The child in pain

Pain arose as a central issue in this study in relation to posture and deformity and difficulties with sleep. It was specifically mentioned by two of the youngest children interviewed. “Acknowledging pain makes pain visible” (Royal College of Nursing
yet there are inevitable difficulties to understanding the experience of pain in young children and more so in children with communication impairments. In the past adults have, perhaps, been reluctant to consider that young children with cerebral palsy and communication difficulties may be in pain and efforts to relieve pain have as a result been inadequate (Royal College of Nursing 2009).

There is little in the literature reporting studies exploring the experience of pain in very young children with cerebral palsy. Most report parent observations rather than child self-reporting methods (Liptak et al 2001). This may be, as argued in section 2.2.3.1, because children as young as three years old are not thought to have an autobiographical memory (Nelson and Fivush 2004) and therefore would be unable to report pain unless it was specifically present when asked. The results from this study challenge that view and suggest that as well as asking parents about a child’s pain, the child should also be questioned and given the appropriate tools with which to answer. Standard self-reporting tools will be inappropriate with this client group (Breau and Burkitt 2009) but the use of the Talking Mat would be one method of accessing a child’s experience of pain. The young children in this study all required methods other than speech for them to communicate their pain. Even for those who had some verbal abilities the pictorial adjunct of the Talking Mat technique afforded greater opportunities for understanding the question and giving an answer. Expecting young children to be able to rate the severity of their pain may be unrealistic but self-reporting the presence of pain and its location may well be possible.

Caution should be observed when relying only on parents to report pain as poor correlation is demonstrated with parents having been found to significantly underestimate their child’s perception of pain and in the cases where severe pain was self-reported, parents underestimated the severity of the child’s pain. In all cases the inaccurate level of pain acknowledged by parents was likely to lead to insufficient pain relief for the child. (White-Koning et al 2007; Varni et al 2005). Underestimation of how well a child is coping is a serious problem especially if the child is not able to communicate. It is essential for children’s physical and mental health to have a means of communication through which levels of pain and discomfort can be adequately expressed. The Talking Mat is a positive outcome from this study and its use by clinicians is strongly recommended.
The causes of pain in children with cerebral palsy include spasticity and immobility (McKearnon et al 2004). Pain in muscles and joints associated with spasticity was exemplified by the findings in this study of a three-year-old who frequently complained of pain, had significantly increased muscle tone particularly around her hips and knees and who falls into the category (GMFCS Level V) of being a likely candidate for early hip displacement. Two other children in this study exhibited pain caused by immobility and the adoption of stereotypical postures as reported by Hodgkinson et al (2001) and Schwartz et al (1999). Both these children were more comfortable when supported in a sleep system.

All physiotherapists will be aware that manual and sustained muscle stretching can be uncomfortable for children. Distraction techniques such as singing, story telling and counting are frequently used to facilitate an increase in duration and intensity of manual muscle stretching. Physiotherapists may not be aware, however, of the evidence reported by children, parents and adults with cerebral palsy associating pain with muscle stretching rehabilitation techniques (Hadden and Von Baeyer 2002). Children positioned in standing frames for sustained muscle stretching are frequently told to endure ‘just a bit longer’ because their physiotherapist is insisting they stand for 30 minutes (Hutton 2008). Hutton also found that school staff involved in children’s standing and stretching programmes are concerned about causing children pain but in the researcher’s experience this is not a topic commonly debated by physiotherapists. The evidence supporting the use of passive stretching of muscles is weak, additionally there is no evidence that the small increases in range of movement that have been reported were correlated with improved function (Effgen and McEwen 2007; Pin et al. 2006). Lack of evidence does not necessarily signify that an intervention is not beneficial but that well-conducted studies measuring the appropriate outcomes have not yet been done. In this case, however, clinicians need to question the wisdom of putting children through uncomfortable procedures while they lack knowledge of the benefits.

Pain caused by surgical procedures and subsequent rehabilitation is common (Hodgkinson et al 2001; Schwartz et al 1999) and children often have to undergo a series of surgical interventions in the attempt to restore hip integrity and reduce pain (Turker and Lee 2000). A recent classification system for hip disease in adolescents
with cerebral palsy describes in six categories the natural history from normal hip development to complete dislocation and degenerative arthritis and will aid audit of outcomes from surgical intervention in the future (Robin et al 2009). There is evidence of encouraging outcomes from early preventative surgical intervention in cohorts of children on cerebral palsy registers in Sweden and Australia (Graham 2010; Hagglund 2010). This surgery, performed while a child is young and has relatively minor hip displacement, is less complex in nature and appears successful in maintaining hips in joint with the result that fewer salvage operations for painful dislocated hips have been necessary in these cohorts. There must be concern, however, that very early surgery in young ambulant children may result in some children, who would not have gone on to develop significant hip subluxation, having unnecessary surgery and the potential for long term pain at the surgical site. Non-invasive 24-hour postural management programmes may avoid the requirement for surgery entirely for some children if commenced before the development of hip subluxation and this would be to their significant benefit.

Pain is reported to be strongly linked with sleep problems in children with physical disabilities (Hemmingsson et al 2009) and this was corroborated by the findings in this study in which five of the seven children were thought to be woken at night by pain. Two of these five children woke less frequently and appeared to be in less pain when positioned for the night in a sleep system.

The consequences of being in chronic pain are profound. Pain is associated with poorer self-reported quality of life in all domains (Dickenson et al 2007). Adolescents and young adults with cerebral palsy living with chronic pain report feelings of social isolation and depression as participation in activities with peers and families reduce as a consequence of overwhelming pain (Castle et al 2007). It is therefore of utmost importance to identify children who are in pain and to make every effort to relieve it.

The finding by McIntyre (2010) that pain was considered an important focus for future research by people with cerebral palsy and their parents but was not identified as such by expert clinicians or professional researchers is perhaps an example of the manner in which pain can be overlooked, even by expert clinicians. This finding is corroborated by parents locally who recently put forward pain management and the communication of
pain as an idea for a future research topic at an advisory group meeting of Exeter’s Cerebra Research Unit.

5.1.4 Seeking the voice of the child

The voices of young children with communication and or learning difficulties are rarely heard in research despite legislation from 20 years ago stating that children’s views should be taken into account in decisions being made about them (Children Act 1989; DoH 1998; DoH 2003). There is more contemporary evidence that children without disabilities also struggle to make their views known. This has been endorsed by the recent UK Government Hear by Right project, an evaluation of the processes needed for achieving the participation of children in decision-making in Children’s Trusts (Percy-Smith 2009). Although there are examples of good collaborative work with children, some of the findings from the Hear by Right project suggest that children even struggle to be heard in schools and that some school staff are not interested in pupils’ views.

The ethos behind this study was to include children with communication and or cognitive difficulties and that their voices should explicitly be included in research. Following the rationale of Morris (2003): “The most important starting point is to assume that all children and young people – whatever their communication and / or cognitive impairment – have something to communicate. It is up to us to find ways of understanding their views and experiences.”

Being able to communicate is at the heart of being human. “To engage someone in dialogue is to recognise him, have faith in him” said the philosopher and peace activist Hildegard Goss-Mayr. These statements were borne out by observing the delight that the children showed when afforded the opportunity to express their opinions. The three-year-old, who followed up the second visit by sending the research team a picture she had drawn, demonstrated a desire to continue the communication beyond the interview.

The children involved in the study were very young and as such were probably not used to being invited to speak. As children with communication difficulties grow older, however, they may continue to struggle to be heard.
The consequences for the child of not having a voice are profound and the reporting of their views by others is often not satisfactory (White-Koning et al 2007; Varni et al 2005). Parents, carers and professionals cannot put themselves ‘into the shoes’ of the child when making decisions that will affect the child’s quality of life. While parents and professionals may be surprised at the positive view children generally have of themselves (Connors and Stalker 2003), they are liable to miss the important negative aspects of their lives if they do not listen to what the children want to communicate (Varni et al 2005).

An aim of the study was to gain the views of children about their new sleep system. There is currently no literature reporting the children’s views of a new piece of equipment that is introduced into their treatment programme. This study has therefore adopted a novel approach in enabling children to have a voice and has also contributed to the literature on communicating with children with disability. The communication tool was the Talking Mat which enabled the children to be partners and contributors to their treatment programmes in a purposive and meaningful way. Small details can transform how a child views physiotherapy treatment or equipment; for example, a four-year-old child in a small evaluation study of a new supportive chair preferred her old chair to the new one because it had her name on it and the new one did not. In a focus group of children being asked about physiotherapy sessions, one child disclosed that he hated having his trouser legs rolled up by the physiotherapist. He felt he had never previously been given the opportunity to provide this information. These two points illustrate how ensuring that children routinely have a voice can help remove a child’s frustrations and enable improved participation in therapy plans.

Children’s feelings of self-esteem are also profoundly affected by the conduct of others. When children are presumed by their carers to be incapable of any form of communication, they experience an extreme form of social exclusion and powerlessness. Denial of their very ‘humanness’ makes them both mentally and physically vulnerable. Children who are unable to report circumstances that make them unhappy are particularly vulnerable. Good practice would see that children practise talking about themselves and how they feel and efforts need to be made in schools to facilitate this. Anecdotal evidence suggests that self-esteem can be raised when children are enabled to talk in groups about how they feel about certain aspects of their lives. In
the special school where the researcher is based, children made a ‘tree of life’ with the
leaves representing what individual children had said. The children were empowered by
seeing their thoughts written down, displayed and where necessary acted upon. They
talked about how they felt about friends and siblings and what they liked and disliked
about school and having therapy. Some issues did arise that needed action. In one case a
nine-year-old boy using a communication aid felt empowered to address with his
teacher issues of bullying in the mainstream school that he attended three days a week.

Children with disabilities have a three to four times greater risk of abuse than other
children, with the abuse often perpetrated by those caring for or living with them (DCSF
2009). Children must therefore be given access to vocabulary that enables them to
communicate about issues of abuse. A speech and language therapist using the Talking
Mat method enabled a young adult with cerebral palsy to report an offence of sexual
abuse by a carer at his residential home. He would not have been able to do this in if he
had not been offered very appropriate and explicit vocabulary (Venditozzi 2007).

The child with a voice has a chance of gaining some control over what happens to them.
Alderson (1992) talks of children needing to acquire the knowledge and skills necessary
for decision-making and suggests these skills are best honed in the context of personal
and social relationships. They are a prerequisite for the child being able to make a
contribution to the decision-making about treatment options open to them. Regular
practice in communicating views is important and the positive feedback children get
when adults listen and adapt plans accordingly will give them the confidence to
continue to want to make their voices heard.

A necessary adjunct to a child being empowered and enabled to have a voice is the
requirement of those around the child to actively listen to what is being communicated.
Parents, carers and professionals may have to reconsider their traditional roles of
‘knowing what is best’ for the child and to relinquish some of their power in order to
co-operate in a more consultative model. Colver (2006) is concerned that children’s
services do not provide children with enough information about treatment options to
enable them to make choices. Children remain for the most part, recipients of healthcare
and passive in decision-making. The continuing dominance of the medical model of
disability is inherent to this discussion. Power continues to preside, albeit often
unwittingly, with the healthcare professional. Parents also necessarily hold power to provide for and to protect children. However, such power can be misplaced and children prevented from participating as fully as possible. It is incumbent upon adults to find appropriate tools of communication and to be skilled in listening. These inadequacies of adults rather than the physical or cognitive impairments of the child are the barriers to the participation of the child in giving their views.

Interviewing children as young as three is unusual and is not reflected in the literature yet in this study the three-year-olds were able to make their views known. Standard techniques, as used with adults, may not be appropriate with young children and different methods therefore need to be sought. Irwin and Johnson (2005) report the difficulties experienced in engaging the attention of the six-year-olds in their study. Some of their participants were occupied in what they have termed ‘kinetic conversations’. These children were constantly moving around while actively answering questions. The four young children in this study did engage in the interviews, but it would have been interesting to see if the data would have been richer if this tactic had been employed even though two of the children had very limited mobility. The interviews would presumably have taken longer but that may have been beneficial and enabled the children to have more thinking time. Engaging the child in role play about bedtimes and sleep would also have been an interesting and potentially appropriate method of soliciting their views.

Techniques for including children with profound cognitive and communication difficulties in research have been described by Morris (2003) (see section 2.2.3.1); however, further research is needed to demonstrate the effectiveness of the techniques. Examples of the use of these techniques in practice, if successful, would demonstrate to carers and professionals that children with profound impairments are able to make their views known.

Using the Talking Mat to enable the children with little or no speech to indicate their views was successful but it also had limitations. Vocabulary had to be offered to the children and although the research team had made an effort to find out what the children may have wanted to say (refer to section 3.2.2.2) and to have those symbols ready, on
occasion the team were not entirely satisfied that the vocabulary was sufficient or represented what the child would have liked to say.

The questions had to be answered with a ‘yes/no’ or in some cases a ‘like/don’t like’. The closed questions restricted the richness of the data. Other researchers have found, however, that young children may lack the linguistic ability to be able to deal with the complexities of open-ended questions and recommend that interviews are at least started with closed questions (Irwin & Johnson 2005). It had been thought that the children might answer in the way they felt their parents or the research team might have wanted but there was no obvious evidence of that, in fact sometimes parents were surprised by what the child said. Houlihan et al (2004) has questioned the reliability of the responses of young children but if children are to be viewed as social actors in their own right then adults must learn to acknowledge children’s views as being meaningful.

5.1.5 Organisation of therapy services

The government agenda set out in Supporting People with Long Term Conditions (DH 2005) is for prepared and pro-active services in which patients and their families are both informed and empowered. These services should be evidence-based, using national and local guidelines and have committed and engaged leaders. Services working in this manner would use resources effectively and reduce the use of interventions of little therapeutic value. It is thought that there is currently too much variation in clinical practice with inequity of access to high standards of care across the country (DH/CMO 2007). Variation of practice was found in this study, with unequal access to sleep systems across the localities in the South-West of England represented in the study.

There is an interest in the Kaiser Permanente triangular model of healthcare as a means of achieving services that meet the government’s agenda (DH 2005, p10; Yarnall, personal communication January 4th 2010). This model meets the needs of postural management services as well as other services concerned with the needs of people with chronic conditions (refer to Fig. 2:2). At the base of the triangle families are empowered to increase their levels of self-management through training. In the middle layer of the triangle generalist paediatric therapists advise and support families. Competency levels could be used to guide these generalist therapists and to measure the gaining of
experience and expertise. At the apex of the triangle a specialist in postural management would lead the service, identify the training needs of the families and staff and provide specialist support for individual patients and their generalist therapist.

Families need information in order that they can self-manage to some extent and various models for training parents and carers are in use around the country. Nationally, under the banner of the Skills for Health programme a Train the Trainer pilot project is underway in which eight NHS Trusts are being funded, in the first instance, to train several staff as postural care trainers. The trainers then train families and other professionals in postural care in their locality. The intention is to set up a sustainable process for developing wide-spread carer involvement in postural management. The impact of this programme on postural management services for children in the future is yet to be seen, however, and funding of staff to undergo this posture care skills training may be an issue in the short-term in which NHS and social care budgets are very likely to be cut in the drive to reduce the UK financial deficit.

North Devon offers a rolling programme of training for all parents and carers of children identified as meeting the criteria for being on the 24-hour postural management care pathway. The training was initiated by the researcher as part of the development of the care pathway and is delivered jointly by a physiotherapist and occupational therapist in a two-hour session with an annual update. All those caring for the child are expected to attend including parents and other family carers, school and respite care staff. Participative sessions for siblings have also taken place to help them understand the rationale for and use of the equipment. No funding was sought for the training programme but it was incorporated into the therapy department’s timetable as it was seen as important for the client group.

The readiness of parents to persevere with using a sleep system and addressing sleep hygiene issues may relate to the information they have been given about how their child’s posture may change in the future. Formalised postural management training for parents may help by enabling them to understand the rationale for 24-hour postural management in the context of the evidence underpinning it and the life journey of their child. Formal training highlights this message and enables it to be delivered in a systematic rather than a reactive, ad-hoc manner in response to questions. Many staff
caring for children needing postural management equipment in mainstream primary schools report that they do not understand why it is needed (Hutton 2008). Some of the parents in this study had very ad-hoc information given to them. This advice often concerned the need for and use of a particular piece of equipment but did not necessarily include the broader case for 24-hour postural management or the evidence underpinning it. Without such information parents and all other carers are unable to make informed choices about how best to manage a child’s posture.

The generalist physiotherapists in the middle layer of the triangle are likely to lack competence unless this learning requirement is specifically addressed. The findings of this study raise the question of whether clinicians working limited hours and taking on few complex cases can have the required level of specialist knowledge and experience to recommend an appropriate sleep system or to choose an appropriate child. These clinicians will not have had the experiences commonly enough to allow their practice to develop sufficiently for them to acquire this level of specialism. Some of the physiotherapists participating in this study were working across a very large geographical area and had infrequent access to support from colleagues who may have greater experience and who could offer clinical supervision. The findings of this study suggest, therefore, that 24-hour postural management is beyond the scope of practice for general community paediatric therapists with a mixed caseload of children working without specialist support.

Competencies have been developed for practitioners in many areas of healthcare (http://www.skillsforhealth.org.uk/) linking in with the NHS Knowledge and Skills Framework (DH 2004). The special interest group for paediatric physiotherapists, the APCP, is also currently devising competencies for its members. These competency measures could be used with generalist paediatric physiotherapists to assess and develop their knowledge and skills when working with children requiring postural management.

If the Kaiser triangular model of healthcare is to operate successfully, a specialist post in postural management is required at the apex (refer to fig. 2:2). Community physiotherapy and occupational therapy teams are already likely to have specialists for different aspects of their services e.g. for children with neuromuscular disorders, for sensory processing disorders, for children with developmental co-ordination disorders,
for respiratory disease, for those with rheumatic disorders or musculo-skeletal problems etc. Some teams may already have a specialist for postural management in place. The findings of this study were, however, that even where there was a named person, their time may not have been ring-fenced for postural management and hence provision of committed and engaged leadership was not feasible. A trust or county-wide specialist post in postural management, possibly across children’s and adult’s services as pioneered in one locality in this study, may be a way forward for consideration by other children’s therapy services.

Findings from other areas of research suggest that specialist services are more effective in achieving desired outcomes than when services are delivered by generalist teams (Colver 2006); an example quoted is a service for young adults with additional needs which achieves greater participation for its service users than a similar-sized generalist service.

Pountney et al (2004) describe a three-track interactive process of clinical reasoning in postural management requiring investigation of all aspects of equipment provision: the child; the child in context of their family and other settings; and the therapist reflecting on and justifying the recommendations. This is similar to the findings of this study. Integrated care pathways can help in this process by signposting clinicians to consider all aspects of treatment and equipment provision. Integrated care pathways are a tool that can embed locally-agreed, evidence-based, patient-centred best practice into everyday use for the individual patient. Therapists, in an earlier study conducted by the researcher, reported that using a postural management care pathway made their practice proactive rather than reactive and that it was one area of intervention that was clearly evidence-based even if the evidence is limited (Humphreys and Pountney 2006).

The care pathway being followed in two of the localities in this study stipulates the process clinicians should follow when considering whether a child requires 24-hour postural management. Inclusion criteria offer clear guidelines as to which children this should apply to. This gives clinicians a clear basis for their clinical reasoning as to why one child needs a sleep system and another does not. The pathway also outlines the processes of discussions with families, training for parents and carers, assessment for equipment and follow-up and review procedures.
If a care pathway is in place and ratified by the clinical governance committee of the local primary care trust, clinicians are in a strong position to justify requests for equipment for children on that pathway. The use of care pathways may assist in the amelioration of unequal provision of sleep systems for children in different parts of the country.

It is unlikely that having a specialist post in postural management will be high on the priority list of essential resources if the children’s therapy lead does not have an interest in postural management and there is no other champion locally. Those physiotherapy managers in this study who expressed a strong interest in postural management also talked with passion about the desire to influence the posture of children in their care and to prevent the disastrous deformities they had witnessed. Those who come to the post through different clinical specialities have not necessarily had those experiences. Leaving children without timely access to postural management at night, however, runs counter to government recommendations (DES 2007; Franklin 2009), clinical interest groups (APCP, 2001, 2002) and an expert consensus of opinion (Gericke 2006). The local ethos of postural management and its priority will affect structures put in place to support the provision of that part of the community therapy service. It will affect the training that individual therapists receive, their competence, the existence of written care pathways, guidelines etc. and the organised training for parents (Humphreys and Pountney 2006). It will also influence the availability of sleep systems and the willingness of the manager to seek funding for them in a robust manner. Thus, postural management requires a local champion.

Children themselves should be encouraged to take an active part in decision-making as early as possible. Colver (2006) suggests that treatment options should be presented to children in terms of how different interventions might affect pain, self-care, participation and quality of life. Thinking in this way is also important for therapists in terms of therapy interventions. Functional outcomes from therapy intervention may be small but the effect on participation and quality of life may be smaller still or even have a negative effect in terms of pain, time taken and frustration on the part of the child. Therapists need to consider the effect of their intervention on participation and not simply on body functions and structures. The ICF framework model (see fig. 2:1) is a
useful tool to encourage therapists to focus on, and be led by, what the child wants to be able to do and hence what therapy interventions would be required.

When therapists are planning interventions it is important that they consider the effect on the family as a whole. Findings from a large study (Raina et al 2005) suggest that family functioning is a key factor in the health and well-being of parents of children with cerebral palsy. They advise that health-care providers should value family functioning as much as the technical aspects of the services they are offering. The issue of burden of care comes into consideration at this point. Positioning children at night in a sleep system could be seen as increasing the burden of care for parents (Gough 2009), however this could not be held true for those parents whose children sleep better and wake less when in their sleep system, as two out of seven did in this study.

The findings of this study provide therapists with a number of factors to consider before prescribing a sleep system. The factors could be considered within the ICF framework model (refer to Fig. 4:5) as suggested by Wright et al (2008) in their study on the outcomes from Botulinum toxin injections, and could include personal factors such as lifestyle, habits and coping strategies that are pertinent to the specific child and family as suggested by Morris (2009). Environmental factors could be considered further with issues that affect a child’s sleep hygiene, such as the sharing of a bedroom with siblings, poor bedtime routines and difficulty with settling etc., specified in some cases. If some of these factors are not optimal and would lead to an unsuccessful case, prescription of a sleep system would be likely to increase the burden of care. Therapists could, instead, highlight these sub-optimal factors to parents and professionals so they could be worked on prior to prescription. The provision of this process within postural management services would help to ensure that the burden of care is not increased for parents and that sleep systems are not commonly abandoned by families.
5.2 Trustworthiness of the findings

The debate concerning whether qualitative research should be judged in the same way as quantitative research, whether it should have its own rules or whether it is inappropriate to have any predetermined criteria of judging it at all, has been considered (Rolfe 2006; Yin 2003; Mays and Pope 1995; Green and Thorogood 2004). This study has used constructivist realism as its epistemological approach and therefore ‘truth’ is not the issue as there could be many ‘truths’. Trustworthiness is important, however, and that is how this study should be judged by the reader. The quality of this study will be considered in terms of its transparency, validity, reliability, comparison and reflexivity (Green and Thorogood 2004). The strategies put in place to promote trustworthiness are described under Issues of rigour, (section 3.4). The discussion here considers whether those strategies have been successful.

5.2.1 Issues of rigour

5.2.1.1 Transparency

It was intended that methods of data collection and analysis were made as explicit as possible. The steps and decisions made during that process were recorded to achieve this. During the analysis occasional leaps of imagination were made. If not recorded, they could have obscured the researcher’s path of reasoning and confuse the reader. The stages of analysis were, therefore, described in detail. Examples of each stage were provided in the text with further illustrations presented in the Appendix.

5.2.1.2 Validity

It was the intention to provide enough text and context to enable the reader to enter, to some extent, into the worlds of the participants.

It is necessary to convince the reader that the data was not selected to prove a point predetermined by the researcher but that all viewpoints were represented and supported by systematic and rigorous analysis. The reporting of deviant cases, in which the theory being tested is unsupported, assists this claim. In this study although there were cases which matched the indicators describing “the child continues to use the sleep system” and cases that matched the indicators describing “the child does not continue to use the sleep system” there were also deviant cases which matched some of each. Although this
finding is perhaps inconvenient, as it makes the evidence for supporting the theory less conclusive, it is reported and as such could be seen as increasing the validity of the study.

Recording the occurrence of similar views indicates to the reader the typicality of a response. In this study the use of numbers raised awareness of the commonality of issues. It was important, for example, that most of the children either communicated that they experienced pain or had it reported by proxy. Similarly, the significance that most of the children had sleeping difficulties highlights this common problem.

In a further attempt to increase validity, therapy managers were asked to verify that the transcripts were correct. In retrospect this was a weak form of respondent validation. It was not a request to verify the interpretation of their views, simply a request that they agreed the content of the transcript was correct. It appeared to be meaningless for the respondents because their replies to this request were either very brief or non-existent. Checking the interpretation of the data by participants was not considered appropriate because of the very individual nature of that process which is dependent on the analyst’s particular interests, knowledge, approach and epistemological framework.

5.2.1.3 Reliability

The audit trail of analysis of the data should enable readers to identify the rationale for the codes and themes and judge the credibility of the interpretation. The aim was to provide enough material for the reader to be able to repeat the analysis should they wish. It was not expected that all readers would agree with the decisions taken and the themes arrived at by the researcher. However, the process by which they were arrived at is explicit. Moreover, constant comparison between Children allowed regularities and exceptions to be found within the data sets. This in turn enabled the creation of typologies and testing of the theory.

5.2.1.4 Reflexivity and researcher bias

The interests and assumptions of the researcher decided the aims of the study and guided its direction. It is inevitable that these interests and assumptions contributed to
the data that was collected and were made explicit at the beginning of the thesis (see Fig. 1:1). Parents were aware of the researcher’s interest in postural management.

The relationship with the therapists was complex in some cases. In three instances the researcher was the manager of the therapists involved. This study was a topic of conversation within the workplace on occasions and as such was likely to have a positive effect on the recruitment of children by those therapists. Two of the three therapists managed by the researcher were senior colleagues while the third was a newly qualified physiotherapist. All three of these therapists spoke with confidence during their interviews but it can be imagined that they might have felt as though they were being examined on their practice. Every attempt was made to put them at their ease and to show that their answers to questions were interesting, relevant and appropriate.

The social settings of the research influenced the data that were gathered. In one instance an interview took place on a day the mother worked from home. It was clear she was very busy and the interview had a different resonance to other interviews as a result. Although she was welcoming, the experience was of being an intrusion into her working day. Another mother forgot she had agreed to be interviewed and declared that she was very tired and had hardly slept. The interview still took place but its tenor was more akin to a counselling session and an opportunity for her to disclose just how difficult the chronic sleep deprivation had become.

5.2.1.5 Generalisability and transferability

Generalisability in qualitative health research relates to the usefulness of the findings for clinical practice. The number of participants in this study is small and their circumstances are unique. However, concepts arising from the findings of the study can be generalised. Green and Thorogood (2004) suggest these concepts can provide a sensitising effect for readers and encourage new ways of thinking. The concepts arising from this study are:

a) Children with cerebral palsy and communication impairment can communicate their views from the age of three years if given the tools with which to do so.
b) The Talking Mat is an appropriate and effective tool with which children can express their views if they have a skilled interviewer and relevant vocabulary offered to them.
c) Very young children with cerebral palsy may experience pain regularly.
d) Many children with cerebral palsy have sleep difficulties.
e) Postural management should be led by therapists with specialist knowledge.
f) Factors have been found that influence a child’s use of a sleep system at night and can be considered within a conceptual framework as factors that moderate a child’s, parent’s or therapist’s role.
g) These factors can be placed within an ICF framework model along with factors that are personal to that particular child and family. A discussion of any sub-optimal factors may then take place with parents and other professionals prior to prescription of the sleep system in order that they may be remediated as far as possible to ensure the child continues to use the sleep system.

This study was located in the South-West of England. The concepts, however, are transferable to all settings.

5.2.2 Limitations of the study

The number of participants in the study was smaller than anticipated. The impression received from therapists in the region was that the inclusion criteria excluded many children who were being prescribed sleep systems at the time. These children did not have a diagnosis of cerebral palsy and were therefore correctly excluded. Including children with other diagnoses was considered by the researcher following the launch of the study to therapists who suggested the majority of sleep system prescriptions were made for children who did not have a diagnosis of cerebral palsy. Children included in previous research in the field of postural management, however, have been those with cerebral palsy and the decision was made to retain that inclusion criterion to enable comparisons to be made with published literature.

The initial interviews with the children using the Talking Mat were difficult and produced thin data. Questioning children about ideas and concepts in an explicit and simple form was complex and required practice. This was facilitated by the speech and language therapist on the research team who was skilled at putting the question simply, however, the researcher struggled with formulating appropriate questions.
The underlying ethos of the study was that all children have something to communicate and would be included regardless of their perceived levels of communication and cognitive abilities. It was therefore unfortunate that the research team excluded one child from having a ‘voice’ by the gate-keeping of another clinician. This child was denied an opportunity to be involved in research. The research team’s experience of gathering data from this child could also have been advantageous to the research community interested in researching children with profound disabilities. Different techniques would have been required, i.e. those described in section 2.2.3.1, and these were not anticipated by the researcher in the planning stage of the study and were therefore not included in the ethics application.

Another limitation was the incomplete entries in the sleep diaries. Two families were not issued with the diaries because they entered the study late, having already commenced or abandoned using a sleep system and of the remaining five only three sets of parents returned both sleep diaries. This poor response may suggest that keeping a sleep diary is an onerous task. The data provided in the sleep diaries was extremely valuable even though it was incomplete. An opportunity to convey information about the comparison between the child’s sleep before and after introduction of the sleep system was afforded, however, by the second interview with parents.

The data collected from the children and families provided a baseline of activity before intervention, with a further snapshot four to six months after beginning use of the sleep system. There was no further follow-up, however, and it is unknown if those families who were successfully using their sleep system at the second data collection point are currently continuing to do so. If they are not it could be presumed that other factors have come into play which could be identified by the therapist and parents reconsidering the ICF framework model.

As previously noted, a further limiting factor to the study is that the researcher was the manager of some of the participating therapists. Some of the participating children and parents were also known to the researcher and attended the school where the researcher is based and known as head of the therapy department. Although these factors should be acknowledged as limitations they can also be seen as advantageous. The results of this
study can be put to use in the workplace and as such therapists and parents were enthusiastic participants.
5.3 Conclusions

The voices of children with physical disabilities and communication and or cognitive impairment are largely absent in the world of research. Very young children are also rarely included. Some of the children in this study were younger than any that have been reported in the research literature previously. The findings establish that it is possible to include children with cerebral palsy with communication difficulties in research, from as young as three years old.

The Talking Mat was demonstrated to be an effective method for exploring the views of the participant children. A vital step in the research method, and one which should not be overlooked in future research employing the Talking Mat, was the gathering of appropriate vocabulary from similarly-aged children with cerebral palsy talking on the same topic. The Talking Mat can only be an effective means of communication if a child is offered vocabulary he or she might want. If relevant and appropriate symbols are unavailable, the child is likely to feel frustrated and will be denied the opportunity to express their view.

Findings from this study inform clinicians that they can and should consult routinely with young children about treatment options and to have the expectation that all children have something to communicate. Clinicians should raise awareness amongst all carers that children who practice expressing their opinions are more likely to be independent, to have higher self-esteem and to be able to ensure their basic needs are met. With raised self-esteem these children will be less vulnerable to abuse and more able to report instances of bullying and ill-treatment.

This is the first study to explore the in-depth experiences of children and their families when using a sleep system and it identified factors that influence whether the child and family are able to continue using the sleep system at night. Therapists could use these factors as a guide to ensuring the optimum outcomes when considering the prescription of a sleep system for a child for the first time. The conceptual framework (Fig. 4:4) and the ICF framework model (Fig. 4:5) will assist clinicians in focussing on those factors and in working to turn the factors into positive indicators that would predict the child and family are likely to continue to use the sleep system. Use of the ICF model to plan
therapy interventions is an important method for ensuring that participation is always a focus and that the child and family are involved in making those plans.

Children in this study reported pain. It surprised the researcher that children as young as three were experiencing pain on a regular daily basis. This is not reported in the literature on children with cerebral palsy and clinicians may routinely assume that pain is only present when there are obvious contractures and deformities. Pain as a cause of night-time waking was reported and needs to be taken very seriously because of the consequences of chronic sleep deprivation. These children need to be given the opportunity and the tools with which they can report pain. Professionals and parents need to be practiced in using the observational tools with which they can detect pain in children who are not able to self-report.

Some therapy techniques e.g. muscle stretching, may cause pain in the children they are intended to help. Therapists need to be aware of this, consider the evidence for the effectiveness of the technique and take children’s claims of pain during treatment seriously. Therapists should contemplate the potentially contradictory needs of the present child and the future adult.

This study was unusual in its in-depth exploration of parents’ concerns about sleep. The prevalence of sleep problems in this cohort of children was surprising to the researcher. The chronically sleep-deprived parents described immense difficulties with carrying out the necessary activities of daily living while feeling so fatigued. The findings suggest that all professionals working with children need to be proactive in asking parents and children about sleep. They can encourage parents to engage with services to help prevent the problems becoming chronic. In those localities where sleep intervention services are not yet available, professionals should consider raising awareness of the need by writing business plans and lobbying commissioners.

The findings of this study suggest that generalist paediatric therapists do not necessarily have the appropriate skills and experience to provide postural management programmes to children with moderate and severe cerebral palsy. This is a potentially risky situation which has not previously been identified. A recommendation from this study is that therapy services should include a specialist clinician to lead and organise local or
county-wide postural management services and to put in place the necessary training for generalist therapists. Use of a knowledge and skills competency framework would provide an auditable route for these generalist paediatric therapists to achieve greater awareness and experience in the field of postural management.

5.3.1 Significance for clinical practice

During the exploration of posture and sleep in children with cerebral palsy, key issues arose from the study which are novel. The dissemination and understanding of these findings will significantly contribute to improving clinical practice and the quality of life of children with cerebral palsy.

In the researcher’s own locality these findings have already made a difference to clinical practice with informal dissemination of findings on a regular basis to the local team both from the research findings and from the researcher’s reading around the subject. Therapists are aware that children’s voices are often not heard even when they can communicate verbally but especially when they cannot. Several instances of this new awareness of children not being listened to are reported in the following chapter.

There is also a new recognition locally that children are likely to be experiencing pain. The Paediatric Pain Profile observational tool has been introduced into daily practice. For some children it has been used to alert parents, who had previously dismissed the idea, that their child may be in pain and for other children to plot the presence of pain. The results are used in paediatric clinics to inform the paediatrician of the potential need for pain relief and to alert the multidisciplinary team of specific activities and positions that cause pain. An instance of an older child reporting pain for the first time is discussed in the following chapter. The finding from one local child in the study that he experienced pain from a possibly over-zealous muscle stretching regime at night, provoked discussion within the researcher’s therapy team and a change in focus from the concentration on body impairment to that of participation.

Use of the ICF framework model by therapists for any therapeutic intervention will assist them in identifying factors in all domains which need to be optimal in order that an intervention is most likely to be successful. It will be especially important to consider Environmental and Personal factors.
The raising of awareness of sleep problems in this client group with clinicians across the South-West region should result in changes to the clinical practice of a large number of clinicians. Locally, it has resulted in families having access to a sleep clinic with a trained sleep nurse from Cerebra once every six weeks. In the future there may be a fully funded sleep service across Devon with three trained sleep clinicians in post and the entire children’s workforce trained to take sleep histories and to deliver basic behavioural programmes around improving sleep hygiene. These innovations will have a significant impact on the quality of life for children and their families in the area, avoiding the debilitating consequences of poor sleep and reducing the burden of care for parents.

The findings of a lack of competence by some therapists and a wide variation in the provision of sleep systems within therapy services across the region are significant issues. Children are at risk of missing a vital opportunity to maintain symmetrical posture and reduce contractures and deformities and time and finances are wasted if prescription is inappropriate. Dissemination of the study findings to therapists through in-service training, conference presentations and publications will include advice to leaders of children’s therapy services that a triangular model of healthcare is a means to overcome these problems in practice. This model enables families to be empowered partners in care, generalist therapy clinicians to be trained and assessed for competency and the postural management service to be led by a clinical specialist.

This research study has generated practice knowledge that clinicians can draw on when working in the field of children with chronic disability.

5.3.2 The need for further research

This study has explored the experiences of children and families using sleep systems but although night-time support in a sleep system is recommended for children with moderate and severe cerebral palsy there is limited evidence of its effectiveness in the reduction or prevention of deformity. The Director of the Institute of Health Service Research at the Peninsula Medical School in Exeter became interested in night-time
postural management at an early presentation of this study. He noted the lack of strong evidence supporting its use and as a result a systematic review of the literature on sleep positioning for children with cerebral palsy has been funded. This has been lodged with the UK Cochrane Centre, with the researcher as a named author, and is currently in progress. Collaboration between research centres at Chailey Heritage, Oxford Brookes and Exeter has also been initiated with the aim of achieving funding for a large-population, randomised controlled trial to address this serious gap in knowledge.

Sleep systems are also prescribed to improve a child’s comfort at night and to enable better sleep but there is no evidence to date that children do sleep longer and more comfortably when positioned in a sleep system. Chailey Heritage Research Centre however, is currently conducting a study to investigate the effects of sleep systems on sleep quality and pain using the Chailey Sleep Questionnaire and the Paediatric Pain Profile as outcome measures. This researcher is involved in recruiting participants to the study in Devon.

Children with cerebral palsy have a higher incidence of sleep problems than the typically-developing child and this study found that sleep hygiene difficulties influence whether a child continues to use a sleep system. Current research studies being conducted by the Social Policy Research Unit in York are expected to provide evidence of the effectiveness of behavioural management programmes in improving sleep hygiene in children with learning disabilities. Those researchers have acknowledged the need for further studies that include children with physical disabilities.

The effects on children’s respiratory function when sleeping in a sleep system have been highlighted by Hill et al (2009) but their evidence is as yet inconclusive. Further research is needed to understand the risks for children with cerebral palsy sleeping in and out of a sleep system.

**5.3.3 Summary**

This study focussed on posture and sleep in a group of young children with cerebral palsy, who had been prescribed a sleep system, and their parents and therapists. This
population of children, as young as three years old and with communication difficulties, has not previously been included in research.

The clinical experience of the researcher enabled the identification of an important gap in the understanding of factors that influence the use of sleep systems by children and families. The practice knowledge that has been generated from the findings of the study can be used to direct clinical practice and enhance a child and family’s experience of the provision of postural management services. Therapists and other child health practitioners will be sensitised by these findings to the difficulties children have with making their voices heard, with pain and with sleep. Perhaps, importantly, families in the researcher’s home county of Devon may experience better sleep as a result of a sleep intervention service being funded following the presentation of results to local commissioners of children’s services.

The final chapter documents reflections on the immensely personal and satisfying journey taken by the researcher from the start of the doctoral programme to its conclusion.
CHAPTER 6: REFLECTION

This chapter records personal reflections on the research journey taken during the course of the Professional Doctorate programme. In contrast to the rest of the thesis and because of its intensely personal nature, it is written in the first person.

6.1 Beginnings

The first entry in my reflective diary, made immediately after the first cohort meeting at the university, records the discomforting experience of having my clinical practice challenged. We heard from the programme leader that all students at some point, usually in the second or third year, feel they know nothing. This happened to me on the first day and I reflected in my diary that I know I am very open to suggestion, an ‘early adopter’ in change management terms, and can therefore immediately assume that I am wrong and the challenger is right. My response to this feeling of unease is to find out more by reading and by discussing with colleagues until I can decide on a course of action which may include changing my ideas or practice. Although uncomfortable, this approach has, I think, stood me in good stead as a student researcher. That first challenge to my practice came from a casual remark by a fellow student. The second challenge arose from the unfamiliar literature in the field of sleep physiology.

On reading the classic paper by Kotagal et al (1994), I became aware of the breathing difficulties children with severe cerebral palsy may have during sleep. These difficulties, caused by obstructive sleep apnoea, central apnoea and epileptic episodes, were not being taken into account when a sleep system was being prescribed in my practice. Whereas typically-developing children with obstructive sleep apnoea change their position when they stop breathing, children with cerebral palsy in a sleep system cannot. Although many of these children are limited in their ability to move when lying without the support of the sleep system, the risks associated with sleeping in a sleep system need to be understood and assessed. In my practice, at that time, the decision to prescribe a sleep system was often made unilaterally with no reference to the child's paediatrician. My reading and later introduction to the Chailey Sleep Questionnaire changed practice in my workplace. The potential risks to a child sleeping in a sleep system are now fully discussed with the child's paediatrician prior to prescription.
I became increasingly tolerant of uncertainty as I read more and had my views challenged. An early note in my reflective diary states: "You don't know what you don't know until you start reading". In turn, I reminded colleagues that some of the evidence underpinning practice was based on inadequate research and encouraged a Pragmatist’s stance that, although this is what we think now, further evidence may change that thinking in the future.

### 6.2 Ontological and epistemological considerations

I had not discovered ontology and epistemology during my Master’s degree and consequently, when this new world with its incomprehensive terminology first arose in the doctoral programme it was utterly unknown to me but apparently familiar to most of the cohort. This was a concern and felt extremely uncomfortable for a period until, with further reading, philosophy became fascinating.

To understand the historical perspective to current ontological positions I read a little about the classical philosophers and how the history of thought developed. I began a journey of self-contemplation informed by ancient and modern philosophical writings which came alive and meaningful to me as an individual. Marx’s motto "question everything" described how I felt and it was exciting. The concept of "emancipation" took on a role not just for the proletariat but for my consideration of the barriers and boundaries that we put in place in our lives. The ideas of the Frankfurt Institute with their Critical Theory demanding that we challenge the status quo and seek change, that we open up new ways of understanding and search for freedom, resonated with me. Hegel wrote of reality not being static and that there will always come a force which destabilises stasis, the antithesis, which leads to a new way of being. The fourth century BC Stoics in Greece talked of inner solitude and that “Man is troubled not by events but by the meaning he gives them”. Marcus Aurelius in the first century spoke of having a steady mind and a peaceful repose and that “Virtue and happiness are entirely up to you”. I felt constantly surprised by the relevance to and resonance with modern everyday life. I had a feeling of wonder at the sense of continuity through the ages and that the human experience has probably not changed in essence since classical times.
Considerations of the study design made me first understand and then question my positivist assumptions. In clinical practice it seemed obvious that people had differing views of reality and that it is not always possible to distinguish causes from effects. It was also impossible for this study to be value-free because I held beliefs about the practice of postural management. Listening, in particular, to Gary Rolfe, Professor of Nursing, expanded my thinking from a narrow scientific view of the world to consider realms as different as Post-structuralism with its ‘Death of the author’ and ‘Birth of the reader’. These ideas were exciting and significantly challenged my original ontological and epistemological assumptions.

The direction of investigation changed considerably during the course of the first year of the doctoral programme from a quantitative study focussing on the effects of using a sleep system on hip migration, to the effects on oxygen saturation and finally to a qualitative study exploring the views of users. The reflective diary records reluctance to relinquish the intention of measuring hip migration percentage (refer to glossary), but documents that: “It’s no good knowing that postural management at night keeps hips in joint if parents and children won’t use it.”

At times I questioned the relevance of the study, thinking that the findings would simply corroborate what I already knew. Reading on the acquisition of practice knowledge, however, reassured me that even if the findings do not illuminate practice for expert clinicians, the findings will be an addition to the base of propositional knowledge that less expert clinicians could draw on when working in the field of postural management.

6.3 Influence on clinical practice

An increase in confidence and assertiveness was reflected back to me by senior colleagues as the doctoral programme progressed and it appeared that the combination of clinical expertise and research activity was respected. Paediatricians and fellow therapists listened to and acted on my suggestions for improvements to practice. The head of professional practice in the local NHS trust observed “you know so much”, a comment which greatly surprised my usually-modest self. Strong feelings of empowerment have arisen from meeting deadlines through hard work, of persevering when the journey seemed so long and from coping with disappointment when
supervisors came to different conclusions from me about the quality of writing submitted. This feeling of empowerment has transferred to other areas of life and bestowed an enhanced perception that, with effort, anything is possible.

In normal clinical, managerial and professional leadership practice there is little time to read, follow links, thoroughly explore the literature on a subject and then reflect on what it means for clinicians and service provision. This lack of time causes real difficulties with getting evidence into practice. The reading and reflection required for the professional doctorate programme, the close links with a multi-professional cohort of fellow students and the interaction with, and lectures from, stimulating professional researchers had an affect not only on me but also on my colleagues in the workplace. Often in a Monday morning staff meeting I posed questions about our current practice in the light of my reading over the weekend and sometimes these discussions would continue over several months as colleagues further reflected on the issues raised. They too have become more used to considering opposing views, to coping with uncertainty in the light of limited evidence that supports long-accepted elements of practice. They have expressed the view that they and the service we provide to children and families have benefited from my professional doctoral journey.

From my first presentation of the learning from the pilot studies, a professor at the Peninsular Medical School’s research department showed an interest in my work and has seen it as an opportunity to forge links with clinical service provision, as demanded by the Department of Health as a means of getting evidence into practice. This link between a research unit and a clinical partner was apparently instrumental in gaining funding from Cerebra, a charity that funds research into childhood disability, for a research base in Exeter. I am a member of the advisory group of the Cerebra Research Unit and currently involved with developing a study protocol for investigating the effectiveness of Lycra gloves for children with hemiplegia. This involvement in research has flowered from the very beginnings of my doctoral journey, has been interesting for me personally and has raised the profile of the organisation for whom I work.

The reading and reflection required for this study have made me consider identity and childhood in more depth than before. Having written a paragraph early one morning on
the identity of children as social actors in their own right, I heard a shocking news item about child slavery in Haiti while driving to work and considered how different the experience of childhood is between children. In a staff meeting we discussed the relative merits of our interventions for the child now and the future adult the child will become, a debate inspired by reading about pain from muscle stretching and the lack of evidence for the effectiveness of manual stretching.

In clinical practice I was sensitised to seeking and hearing the voice of the child, realising that sometimes we do not actively listen and at other times we lose the child’s voice in the clamour from parents. Several examples of this were startling at the time and were recorded in my diary. The first, a boy of 11 who had recently had multi-level surgery and was just out of plaster, shouted in pain and anxiety while his mother ignored his cries and continued to show the therapist how she had been moving his legs. When I asked him why he was upset he replied that his knees were extremely painful when allowed to roll inwards. Hearing that, his mother and the physiotherapist were able to move his legs while supporting the knees to prevent them rolling into the painful position. The physiotherapist reflected afterwards that we are sometimes drawn into colluding with parents because we assume they understand their child’s behaviour better than we do and always have their interests at heart. A second example arose recently as parents were agreeing with professionals about the necessity for their child to continue with toilet training, when the child spoke up and reported that his toilet chair was kept in the garage and was not available for use. A third example of the importance of listening to children and taking action where necessary was an incident in which a three-year-old described a scene of domestic violence within his household. This was taken seriously, recorded and reported to the appropriate services.

The finding that young children with cerebral palsy reported pain heightened my awareness of the potential for pain and I have instigated the routine use of the Paediatric Pain Profile for those children most at risk. One parent was surprised at the mention of the potential for pain in his child who was unable to report it verbally but on explaining the behaviours which might indicate pain, he recognised that his child had occasionally displayed these and on reflection, considered the presence of pain a distinct possibility. A teenager with a dislocated hip and spinal deformity recently presented with acute pain which was difficult to alleviate and which caused her very significant distress. She
disclosed that she had experienced regular pain since the age of nine, a fact of which her parents, paediatrician, orthopaedic surgeon and physiotherapist had been unaware and for which she had received no regular medication. One of the children in the study had been woken at night by pain caused by muscle stretching from use of his leg gaiters within a Chailey Lying Support. This was discussed with the child’s physiotherapist, one of my staff, and later in a staff meeting when we considered the weight of evidence for the effectiveness of passive muscle stretching versus the discomfort it caused and the requirement for quality of sleep.

A shift in thinking, where needed, has taken place from the medical to the social model of disability. Discussions about the use of the ICF framework model to help us focus on encouraging participation in life rather than on body impairment, have been an ongoing feature of clinical supervision sessions and staff discussions in recent months. Therapists have been encouraged to agree goals for intervention that are meaningful to the child and have long-lasting effects on quality of life rather than simply short term effects on impairment.

Significant concerns about the sleep difficulties experienced by families in the study caused me to take on the role of local champion for a sleep intervention service. I have alerted colleagues to the need to take a holistic view of the child and family and to heed advice, when considering interventions, that family functioning is a major factor in the emotional health of the child and the family. Reading studies exploring the role of gender and sleep caused me to consider my own position. I, in common with other women, was the one who woke quickly if a child was stirring and the parent to get up to deal with a child at night. The negotiated sleep with my partner causes me not to put the light on in the middle of the night to record a crucial thought that has occurred during a wakeful moment and to get out of bed the instant the alarm sounds, or preferably before it has sounded, in the early morning to allow my husband to continue undisturbed in a deep sleep. His perception is that he sleeps most deeply once I have got out of bed at 5.00 a.m. to write my thesis.
6.4 Conclusions

This thesis fittingly ends with a reflection on the journey taken during the course of the doctoral programme; a personal inner journey that has produced a more confident, assertive practitioner better able to tolerate uncertainty, assess evidence and question practice and one with a conviction that anything is possible with hard work and motivation. This journey has also produced changes to clinical practice and highlighted the need for closer attention to sleep difficulties and the potential for pain in children with cerebral palsy. My supervisors have enhanced the research experience with their consummate ability to encourage whilst being positively critical and their deep knowledge both of the process and clinical field. My cohort of fellow students has also enriched this adventure with their friendship, support and well-reasoned differing views.

Happily, the child and her mother who were the subjects of two of the pilot studies that so influenced and motivated me to champion the need for a sleep intervention service, do now usually sleep well; a satisfactory conclusion to this journey.
Glossary

**Ankle foot orthoses (AFOs) and night ankle foot orthoses (NAFOs)**

Splints, usually made out of polypropylene, designed to support the foot and ankle in a midline position. When needed for night-time use, the splints are designed slightly differently and are padded for comfort.

**Hip abduction**

Movement at the hip joint taking the leg out to the side.

**Hip adduction**

Movement at the hip joint taking the leg inwards across the body.

**Hip migration percentage**

Migration percentage is a measure of the femoral head’s containment within the acetabulum in the coronal plane (Reimers 1980).

**Hip subluxation and dislocation**

A hip is defined as subluxed if the hip migration percentage is between 33% and 80% and defined as dislocated if the hip migration percentage is over 80% (Cooperman et al 1987).
List of references


Chartered Society of Physiotherapy (2002) Integrated Care Pathways. PA46


College.


Royal College of Paediatrics and Child Health: Ethics Committee (2000) Guidelines for ethical conduct of medical research involving children. Archives of Disease in Childhood, 82, 177-182.


bilateral cerebral palsy. *Archives of Disease in Childhood*, 76, 381-384.


APPENDIX 1A

Examples of postural management equipment – seating

Junior seat, reproduced with kind permission from Jenx.

Symmetrikit Tiltrite chair, reproduced with kind permission from the Helping Hand Company.

Mygo chair, reproduced with kind permission from Leckey.

CAPS 2 seating system, reproduced with kind permission from Active Design.
APPENDIX 1B

Examples of postural management equipment – standing

Squiggles Stander, reproduced with kind permission from Leckey.

Prone Stander, reproduced with kind permission from Leckey.

Chailey Standing Support, reproduced with kind permission from Active Design.

Supine Stander, reproduced with kind permission from Jenx.
APPENDIX 1C

Examples of postural management equipment – lying

Lying Support, reproduced with kind permission from Active Design.

Symmetrisleep, reproduced with kind permission from the Helping Hand company.

Dreama sleep system, reproduced with kind permission from Jenx.

Sleepform, reproduced with kind permission from Leckey.

Original in Colour
APPENDIX 2

Talking Mat

The Talking Mat was developed by the Alternative and Augmentative Communication (AAC) research team at Stirling University in 1996 to provide adults using high tech communication aids with a means of thinking about and expressing their views on complex issues, giving them more time to consider the issue and vocabulary they may not have in their devices. Since then the technique has been used with children, people with learning disability, aphasia, and dementia for a variety of reasons such as transition planning, counselling, research and focus groups (Brewster 2004).

The Talking Mat consists of a Velcro mat and picture symbols (Picture Communication Symbols produced on Boardmaker software) with Velcro tabs on the back that stick to the board. The user can be offered three sets of symbols, those of issues, emotions and influences, appropriate to the discussion, which are placed on the mat and which they can move around and change until happy the final mat represents their views.

The technique was simplified in this study because the children were young. A question was posed and placed in the centre of the board, at the top. In the example shown below, the question is “How do you feel when you wake up in the morning?” Symbols representing differing feelings were then offered which the child could place, either physically or by indicating with their eyes, under a “yes” or “no” or in other instances a “like”, “don’t like” column. In this case the child indicated that she was happy in the mornings and that she did not have feelings of pain, tiredness or sadness.
APPENDIX 3

University of Brighton
Faculty of Health Research Ethics & Governance Committee
Date: 20.8.07

Title of project: What are the factors that influence the experience of using a sleep system at night for a child with cerebral palsy? A case study approach.

<table>
<thead>
<tr>
<th>Researcher’s name/s:</th>
<th>Ginny Humphrys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervisor/s name/s:</td>
<td>Anne Mandy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reviewer’s name/s:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1st reviewer: (Lead)</td>
<td>Raymond Lee</td>
</tr>
<tr>
<td>2nd reviewer</td>
<td>Vincent Cross</td>
</tr>
</tbody>
</table>

NOTE to Lead Reviewer:
Your role as lead will be to receive the comments of the 2nd reviewer and check against your own. If there is agreement between the comments both sets can be sent to the researcher unmodified. If there is conflict between the two sets of comments then you should discuss the issues with your fellow reviewer and agree one set of comments that can be returned to the researcher. Please ensure that the form clearly indicates any conditions you wish to impose or changes you require to be made.

Outcome:

- Approved: ☐
- Approved with minor changes, the chief investigator or the supervisor should confirm in writing to the administrator of FREGC that the changes have been undertaken: ☑
- Return to researcher for major changes and resubmission to FREGC: ☐
- Release sponsor letter to researcher for LREC: ☐
- Not approved: ☐

Comments:

This is generally a well-prepared application. Although there are no major ethical concerns, the applicant may wish to consider the following.

Question A24 of NRES form - the answer seems to be an explanation of why children are vulnerable subjects. This is not what the question asks. The direct answer to the question relates to page 2, paragraph 2 of the proposal, "There are also no studies as yet asking the children for their views on what it is like to sleep in a sleep system..." This explains why children are included (related to purpose of study). In particular justify the very young ones who are unable to communicate and comprehend (eg what additional info you will get from
A40-A41 of NRES form - Storing and analysing data at home is best avoided. But if this is necessary, some extra measures need to be taken eg setting password to have access to the device where data is stored, and this is known to the researchers only.
Dear Mrs Humphreys

Full title of study: What are the factors that influence the experience of using a sleep system at night for a child with cerebral palsy? A case study approach.

REC reference number: 07/H0202/121

The Research Ethics Committee reviewed the above application at the meeting held on 1 October 2007. Thank you for attending with Catherine Ward to discuss the study.

Ethical opinion
The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Ethical review of research sites
The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval
The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application</td>
<td>1</td>
<td>07 September 2007</td>
</tr>
<tr>
<td>Investigator CV</td>
<td>Ginny Humphreys</td>
<td>07 August 2007</td>
</tr>
<tr>
<td>Protocol</td>
<td>3</td>
<td>06 August 2007</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td></td>
<td>06 September 2007</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>4</td>
<td>22 January 2007</td>
</tr>
<tr>
<td>Participant Information Sheet: For children</td>
<td>4</td>
<td>03 September 2007</td>
</tr>
<tr>
<td>Participant Information Sheet: For therapists</td>
<td>4</td>
<td>03 September 2007</td>
</tr>
<tr>
<td>Participant Information Sheet: For children 1</td>
<td>4</td>
<td>03 September 2007</td>
</tr>
<tr>
<td>Participant Information Sheet: For parents</td>
<td>4</td>
<td>03 September 2007</td>
</tr>
</tbody>
</table>

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NHS Research Ethics Committees in England.
APPENDIX 4

Participant Consent Form: Parents 4 03 September 2007
Participant Consent Form: Therapists 4 03 September 2007
Appendix 2: Badge Design 1 03 September 2007
Appendix 1: Talking Matt 1 03 September 2007
10 Day Diary 2nd 3 06 August 2007
10 Day Diary 1st 3 06 August 2007
Parent contact details 3 06 August 2007
Indemnity confirmation
Letter to GP/Paediatrician 3 06 August 2007
CV Terry Pountney 07 August 2007
CV Catherine Ward 09 July 2007
Supervisor CV Dr Anne Mandy 18 July 2007

R&D approval
You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final approval from the R&D office before commencing any research procedures.

Membership of the Committee
The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/H0202/121 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Miss Kate Caldwell
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
Standard approval conditions SL-AC2

Copy to: Dr Anne Mandy, Clinical Research Centre, University of Brighton, 49 Darley Road, Eastbourne
Ms Pam de Clive Lowe, R&D Manager, RM&G Unit, Peninsula Primary Care,
Dean Clarke House

An advisory committee to South West Peninsula Strategic Health Authority
Therapist uses the Chailey Sleep Questionnaire to assess risk factors prior to prescription of sleep system

Contact Ginny who will send you an information pack for parents and an information sheet for therapists

Therapist gives information pack to parents
  
  this includes
  
  • Parent information leaflet
  • Child information leaflet
  • Contact details form and SAE

if parents and child interested, parent (or therapist on behalf of parent) sends contact details in SAE → Ginny

Ginny rings parents to give more information and if they are still interested sends consent form and SAE → parents

Parents send back consent form → Ginny
  (Therapist may need to remind or help)
This includes consent for Cat to contact child’s SLT for info on child’s level of communication
APPENDIX 5

Ginny interviews therapist
Ginny interviews parent(s).
Ginny and Cat interview child – gaining consent before and during

Parents keep sleep diary for 10 consecutive days

Sleep system acquired (Ginny probably has funds for one sleep system per geographic area but all need to be ordered with the study mentioned because there may be quick delivery and possibly a good price)

4-6 months later, Ginny interviews parent(s)
Ginny and Cat interview child

Parents keep sleep diary for 10 consecutive days

September 08 – September 09
Analysis of data and write up of thesis

Feedback of findings to parents
Feedback of findings – best practice guidelines to therapists

Conferences!
Publications!

Ginny Humphreys
01392 463812/468558
ginny.humphreys@vranchhouse.org
Child's Name: 

Date of Birth: 

Sex of Child: Male / Female 

Home Address: 

Home Telephone Number: 

Name of School: 

G.P Name & Address: 

Paediatrician Name & Address: 

Medical History: 

Primary Diagnosis: 

Current Medication: 

Postural Management Equipment Used: 

Who is completing questionnaire with child: 

APPENDIX 6

Child's Name: 

Today's Date: ........./....../200...

Part 1 – Sleep Information

1. What time does your child usually go to bed on:
   - Schooldays: ____________
   - Weekends/school holidays: ____________

2. What time does your child usually get out of bed on:
   - Schooldays: ____________
   - Weekends/school holidays: ____________

3. What is your child’s favourite sleeping position? ________________________________

4. Does your child regularly spend nights away from home? Yes / No
   If so, please detail: ________________________________

For EACH of the following questions please circle one option

<table>
<thead>
<tr>
<th>Bedtime Routine</th>
<th>Usually = 5-7 times per week</th>
<th>Sometimes = 2-4 times per week</th>
<th>Rarely = 1 or 0 times per week</th>
<th>Office Use Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Does your child go to bed at the same time each night?</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Does your child fall asleep within 20 minutes after going to bed?</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6a. If not, how long is it before s/he falls asleep?</td>
<td>20-30 mins/30-45 mins/45 mins+</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Does your child fall asleep alone in their own bed?</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Does your child fall asleep alone in their parent's bed?</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Does your child fall asleep alone in other places? E.g. sofa</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. How many children sleep in the same bedroom as your child?</td>
<td>1 / 2 / 3 / 4+</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Does your child need a parent with them to be able to fall asleep?</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Does your child need medication to help them fall asleep/stay asleep?</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Does your child struggle at bedtime? E.g. refuses to stay in bed, cries etc.</td>
<td>Usually / Sometimes / Rarely</td>
<td>1 2 3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total: ________________________________

## APPENDIX 6

<table>
<thead>
<tr>
<th>Night-Time Behaviour</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Office Use Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Does your child wake during the night?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>If so:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14a. How many times a night does your child wake?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>14b. How long are the waking periods?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>15. Does your child move, or are they moved, to someone else’s bed during the night?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>16. Does your child wake during the night crying?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>17. Does your child wake during the night sweating and screaming?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>18. Does your child wake during the night and is inconsolable?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>19. Is your child restless and do they move around a lot during the night?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>20. Does your child talk or vocalise whilst asleep?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>21. Does your child grind their teeth whilst asleep?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>22. Does your child bang their head or rock back and forth whilst falling asleep or whilst asleep?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>23. Does your child wet the bed during the night?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>24. Does your child wake during the night in pain?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>25. Does your child need a change of position during the night?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>26. Can your child change his/her position at night?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>27. Does your child sleep too little?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>28. Does your child sleep too much?</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
**Night-Time Behaviour cont...**

<table>
<thead>
<tr>
<th>Question</th>
<th>Usually = 5-7 times per week</th>
<th>Sometimes = 2-4 times per week</th>
<th>Rarely = 1 or 0 times per week</th>
<th>Office Use Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. Does your child take a lot of time to become alert in the morning?</td>
<td>Usually / Sometimes / Rarely</td>
<td></td>
<td></td>
<td>3 2 1</td>
</tr>
<tr>
<td>30. Does your child seem tired to you in the morning?</td>
<td>Usually / Sometimes / Rarely</td>
<td></td>
<td></td>
<td>3 2 1</td>
</tr>
<tr>
<td>31. Does your child take daytime naps?</td>
<td>Usually / Sometimes / Rarely</td>
<td></td>
<td></td>
<td>If over 3 yrs: 3 2 1</td>
</tr>
<tr>
<td>If so:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31a. How many naps a day does your child take?</td>
<td>1 / 2 / 3+</td>
<td></td>
<td></td>
<td>1 2 3</td>
</tr>
<tr>
<td>31b. How long (approximately) does your child nap for?</td>
<td>0-30mins / 30-60mins / 1 hour+</td>
<td></td>
<td></td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

**Total:**
Child's Name: 

Today's Date: ..........................

<table>
<thead>
<tr>
<th>Breathing Quality at Night</th>
<th>Usually = 5-7 times per week</th>
<th>Sometimes = 2-4 times per week</th>
<th>Rarely = 1 or 0 times per week</th>
<th>Office Use Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. Is your child's breathing disturbed during sleep?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Does your child snore loudly?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. Does your child's breathing stop and start during sleep?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Does your child have shallow breathing during sleep?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Does your child struggle for breaths during the night?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Is your child's breathing interrupted by snorts and gasps?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Does your child gag or choke during the night?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. Does your child sweat during the night?</td>
<td>Usually / Sometimes / Rarely</td>
<td>3 2 1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**APPENDIX 6**

**Child’s Name:**

**Today’s Date:**

---

## Part 2 – Medical Information

For EACH of the following questions please circle one option.

<table>
<thead>
<tr>
<th>ORTHOPAEDIC PROBLEMS:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does your child have any orthopaedic problems?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes:</td>
<td></td>
</tr>
<tr>
<td>1a. Do these problems cause pain during the night?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SPINAL CURVATURE (Scoliosis/Kyphosis):</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Does your child have Scoliosis/Kyphosis?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes:</td>
<td></td>
</tr>
<tr>
<td>2a. Grade the degree of Scoliosis/Kyphosis?</td>
<td>Mild / Moderate / Severe</td>
</tr>
<tr>
<td>2b. Is the Scoliosis getting worse?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>2c. Is spinal surgery planned / or has it occurred?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so, when:</td>
<td></td>
</tr>
<tr>
<td>2d. Does your child wear a spinal jacket?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>2e. Does your child sleep in a spinal jacket?</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CEREBRAL SHUNT:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Does your child have a cerebral shunt?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes,</td>
<td></td>
</tr>
<tr>
<td>3a. Has your child experienced any problems with the shunt in the last 6 months?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so please detail:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FACE/HEAD/NECK:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Does your child have an unusual face shape/deformity?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>5. Has your child had surgery to: The Face?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>The Head?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>The neck?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so, please detail:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TONSILS AND ADENOIDs:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Does your child have recurrent ear/throat infections?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>7. Have the tonsils/adenoids been removed?</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

### APPENDIX 6

<table>
<thead>
<tr>
<th>FEEDING:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Does your child have difficulties with chewing/swallowing?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so, please detail:</td>
<td></td>
</tr>
<tr>
<td>9. Does your child have problems with feeding?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes:</td>
<td></td>
</tr>
<tr>
<td>9a. Is your child fed by nasogastric/gastrostomy feeds alone?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>9b. Is your child fed by combination of tube and oral?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so, please detail:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GASTRO-oesophageal reflux:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Does your child experience vomiting/regurgitation during:</td>
<td>Yes / No</td>
</tr>
<tr>
<td>- The day</td>
<td>Yes / No</td>
</tr>
<tr>
<td>- The night</td>
<td></td>
</tr>
<tr>
<td>11. Does your child have a problem with retching at night?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes, does your child require any drugs to control this?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so, please detail:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Constipation / diarrhoea:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Does your child experience periods of constipation lasting more than 5 days?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>13. Does your child experience periods of diarrhoea lasting more than 5 days?</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sensory impairments:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Does your child have problems with his/her vision?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If so, please detail:</td>
<td></td>
</tr>
<tr>
<td>15. Does your child have a hearing problem?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes, does your child use a hearing aid?</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Learning:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>17. Does your child have learning difficulties?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes, please grade the level of learning difficulty.</td>
<td>Mild / Moderate / Severe / Profound</td>
</tr>
</tbody>
</table>
**CONVULSIONS / FITS:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. Has your child ever had a convulsion or fit?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes:</td>
<td>None / less than 5 / 5+</td>
</tr>
<tr>
<td>18a. How many convulsions/fits has your child had in the last 6 months?</td>
<td>Early morning / afternoon / evening / night time</td>
</tr>
<tr>
<td>18b. What time of the day/night do the convulsions/fits usually occur?</td>
<td>Seconds / less than 15 minutes / 15 minutes +</td>
</tr>
<tr>
<td>Please detail:</td>
<td>None / 1 drug / 2 drugs / 3 drugs / more than 3 drugs</td>
</tr>
<tr>
<td>18c. How long do the convulsions/fits last?</td>
<td></td>
</tr>
<tr>
<td>18d. How many different drugs are needed to control the convulsions/fits?</td>
<td></td>
</tr>
</tbody>
</table>

**HEADACHES:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Does your child indicate that they suffer from headaches?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>20. Does your child seem to have headaches in the mornings?</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

**CHEST INFECTIONS AND Colds:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. Has your child had a chest infection in the last 6 months?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes:</td>
<td>1 / 2-5 / 5+</td>
</tr>
<tr>
<td>21a. How many chest infections has your child had in the last 6 months?</td>
<td>None / Some / All of them</td>
</tr>
<tr>
<td>21b. How many of these required antibiotics?</td>
<td>None / Some / All of them</td>
</tr>
<tr>
<td>21c. How many required hospitalisation?</td>
<td></td>
</tr>
<tr>
<td>22. Does your child find it difficult to recover from a cold?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>23. Can your child cough easily?</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

**FACIAL COLOUR:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Does the colour of your child’s face change during sleep?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes, describe the colour change:</td>
<td>Red / Mottled / Pale white / Blue</td>
</tr>
<tr>
<td>25. Is your child’s face a different colour in the morning after being asleep?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>Child's Name:</td>
<td>Version 4, 22/01/2007</td>
</tr>
<tr>
<td>--------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Today's Date:</td>
<td>………/……/200…</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GENERAL:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>26. In the last 6 months has your child had any surgery?</td>
<td></td>
</tr>
<tr>
<td>If Yes, please detail:</td>
<td>Yes / No</td>
</tr>
<tr>
<td>27. In the last 6 months has your child’s medication changed?</td>
<td></td>
</tr>
<tr>
<td>If Yes, please detail:</td>
<td>Yes / No</td>
</tr>
<tr>
<td>28. In the last 6 months has your child been hospitalised for any reason?</td>
<td></td>
</tr>
<tr>
<td>If Yes, please detail:</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

| Notes:                                                                 |       |
Glossary for Medical and Sleep Related Terms.

Cerebral palsy – a persistent disorder of posture/movement due to trauma to the developing brain.

Orthopaedic - problems involving bones.

Kyphosis – excessive outer curvature of the back causing hunching of the back.

Scoliosis – excessive sideways curvature of the back.

Spinal Jacket – polypropylene jacket used to maintain position of the spine.

Cerebral Shunt – an artificial shunt used to drain excess fluid from the brain.

Nasogastric - feeding via a tube put down through the nose and mouth into the stomach.

Gastrostomy - feeding through a tube in the stomach.

Gastro-oesophageal reflux – the passage of stomach contents and secretions into the food pipe.

Sensory Impairment – disorder of the senses, most commonly vision or hearing.

Epilepsy/fits/convulsions/seizures – a disorder of brain activity.

Sleep behaviour – behaviour around sleep times.

Parasomnias – movements or behaviours occurring in and around sleep.

REM – rapid eye movement or ‘dreaming’ sleep.

Obstructive sleep apnoea – the complete or partial cessation of breathing during sleep due to an obstruction in the upper airways.
APPENDIX 6

Child's Name: 

Today's Date: ....../....../200...

Sleep Information

Bedtime Routine:
Score Range 0 - 30.

Problem Categories
8 - 11 = Low
12 - 16 = Medium
17 - 30 = High

Night-Time Behaviour:
Score Range 18 - 66

Problem Categories
18 - 24 = Low
25 - 37 = Medium
38 - 66 = High

Breathing Quality at Night:
Score Range 8-24

Problem Categories
8 - 12 = Low
13 - 16 = Medium
17 - 24 = High

Scoring

Categorisation

Low = No Problem.

Medium = A problem that may need further investigation.

High = A high level problem in need of attention.

Sleep diary

Name of child

Sleeping and sleep for research into 10 day diary

University of Brighton

Please add further comments here.
<table>
<thead>
<tr>
<th>Day</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

**Comments**: (PTO, sick, more)

- How many times did your child sleep in the night?
- How many times did you get up to attend them?
- How many times did your child fall asleep? Please comment.
- Did your child go to sleep on their own?
- Did your child go to sleep on their own?

**Length of time (in minutes)**

What are the factors that influence the experience of sleep in a child with cerebral palsy? A case study approach.
Sleep diary

Name of child:

Systems
Sleeping and Sleep
For Research Into
10 Day Diary

University of Brighton

Please add further comments here
<table>
<thead>
<tr>
<th>Comments (10/10 for more)</th>
<th>Day</th>
<th>Day</th>
<th>Day</th>
<th>Day</th>
<th>Day</th>
<th>Day</th>
<th>Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often does your child sleep?</td>
<td>10</td>
<td>9</td>
<td>8</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>What are the factors that influence the amount of sleep your child gets each night? (Please consider emotional, physical, external factors)</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Length of time (in minutes) you child took to get to sleep?</td>
<td>10</td>
<td>9</td>
<td>8</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Did your child go to sleep in their own bed?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Sleep system works?</td>
<td>Yes / No</td>
<td>10</td>
<td>9</td>
<td>8</td>
<td>7</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>How many times did you get up to check?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Who does the room things for the night?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>How many times did your child wet the bed?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Can you comment on your child’s sleep pattern?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>How long did your child sleep in the system?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>The sleep system works?</td>
<td>Yes / No</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>How many times did your child wake up during the night?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>What are the factors that influence the amount of sleep your child gets each night? (Please consider emotional, physical, external factors)</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Length of time (in minutes) you child took to get to sleep?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Did your child go to sleep in their own bed?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Sleep system works?</td>
<td>Yes / No</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>How many times did you get up to check?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Who does the room things for the night?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>How many times did your child wet the bed?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>Can you comment on your child’s sleep pattern?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
<tr>
<td>How long did your child sleep in the system?</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
<td>Day</td>
</tr>
</tbody>
</table>
**ANTICIPATION OF PROBLEMS**

<table>
<thead>
<tr>
<th>AP</th>
<th>Hard explaining concept to child beforehand</th>
<th>AP-CON</th>
</tr>
</thead>
<tbody>
<tr>
<td>AP</td>
<td>Anticipation child may find it difficult</td>
<td>AP-DIFF</td>
</tr>
<tr>
<td>AP</td>
<td>Prepared to give it a go</td>
<td>AP-DIFF</td>
</tr>
<tr>
<td>AP</td>
<td>Child’s sleep is very poor</td>
<td>AP-PS</td>
</tr>
<tr>
<td>AP</td>
<td>Cannot settle or sleep alone</td>
<td>AP-SD</td>
</tr>
<tr>
<td>AP</td>
<td>Tonic seizures may cause discomfort in SS</td>
<td>AP-FITS</td>
</tr>
<tr>
<td>AP</td>
<td>Child mobile</td>
<td>AP-MOB</td>
</tr>
<tr>
<td>AP</td>
<td>Hours when possible to use SS</td>
<td>AP-HRS</td>
</tr>
<tr>
<td>AP</td>
<td>Threat to independence</td>
<td>AP-IND</td>
</tr>
</tbody>
</table>

**PARENTS’ VIEWS ON WHY A SS HAS BEEN PRESCRIBED**

<table>
<thead>
<tr>
<th>PU</th>
<th>Postural management training / lack of</th>
<th>PU-PMT</th>
</tr>
</thead>
<tbody>
<tr>
<td>PU</td>
<td>Because child/carers are not getting enough sleep</td>
<td>PU-FS</td>
</tr>
<tr>
<td>PU</td>
<td>To improve comfort</td>
<td>PU-FC</td>
</tr>
<tr>
<td>PU</td>
<td>For posture</td>
<td>PU-FP</td>
</tr>
<tr>
<td>PU</td>
<td>Training one to one for specific equipment</td>
<td>PU-OE</td>
</tr>
<tr>
<td>PU</td>
<td>No training as such</td>
<td>PU-NT</td>
</tr>
<tr>
<td>PU</td>
<td>For relaxed side lying</td>
<td>PU-FSL</td>
</tr>
<tr>
<td>PU</td>
<td>To have choices of supported positions</td>
<td>PU-FCh</td>
</tr>
<tr>
<td>PU</td>
<td>Child able to sleep anywhere with SS</td>
<td>PU-FI</td>
</tr>
<tr>
<td>PU</td>
<td>Child feeling safe</td>
<td>PU-FS</td>
</tr>
<tr>
<td>PU</td>
<td>Needed new bed</td>
<td>PU-NB</td>
</tr>
<tr>
<td>PU</td>
<td>Easier moving and handling because no need for cot sides</td>
<td>PU-MH</td>
</tr>
<tr>
<td>PU</td>
<td>Movement / lack of in bed</td>
<td>PU-MOV</td>
</tr>
<tr>
<td>PU</td>
<td>Hip X-Rays as part of clinical reasoning</td>
<td>PU-XR</td>
</tr>
</tbody>
</table>

**SLEEP HYGIENE (BEHAVIOUR, PATTERN AND ENVIRONMENT)**

<table>
<thead>
<tr>
<th>SH</th>
<th>Sleeping in own / parents’ bed</th>
<th>SH-OB</th>
</tr>
</thead>
<tbody>
<tr>
<td>SH</td>
<td>Bedtime routine</td>
<td>SH-R</td>
</tr>
<tr>
<td>SH</td>
<td>Number of hours asleep</td>
<td>SH-HA</td>
</tr>
<tr>
<td>SH</td>
<td>Cried because didn’t like night splints</td>
<td>SH-C</td>
</tr>
<tr>
<td>SH</td>
<td>Pain</td>
<td>SH-PN</td>
</tr>
<tr>
<td>SH</td>
<td>Number of awakenings</td>
<td>SH-NA</td>
</tr>
<tr>
<td>SH</td>
<td>Cause of awakenings</td>
<td>SH-CA</td>
</tr>
<tr>
<td>SH</td>
<td>Length of time awake</td>
<td>SH-TA</td>
</tr>
<tr>
<td>SH</td>
<td>What happens when child wakes in night</td>
<td>SH-A</td>
</tr>
<tr>
<td>SH</td>
<td>Discipline</td>
<td>SH-D</td>
</tr>
</tbody>
</table>
### SH
- Settling for sleep (SH-S)
- Position for sleeping pre-SS (SH-P)
- Behaviour (SH-B)
- Deep sleep from epilepsy medication (SH-MED)
- Fits causing awakenings (SH-FITS)
- Sensory issues (SH-SEN)
- Parental sleep deprivation (SH-PSD)
- Environment / siblings (SH-E)
- Child’s mood in morning (SH-MOO)
- Physical feelings in morning (SH-PHY)
- Advice and support (SH-AS)

### ORTHOSES AND POSTURAL MANAGEMENT EQUIPMENT

<table>
<thead>
<tr>
<th>O/PM</th>
<th>Description</th>
<th>O/PM-L</th>
</tr>
</thead>
<tbody>
<tr>
<td>O/PM</td>
<td>Use of lycra</td>
<td>O/PM-L</td>
</tr>
<tr>
<td>O/PM</td>
<td>Orthoses at night</td>
<td>O/PM-N</td>
</tr>
<tr>
<td>O/PM</td>
<td>Use of AFOs</td>
<td>O/PM-Afo</td>
</tr>
<tr>
<td>O/PM</td>
<td>Powered mobility</td>
<td>O/PM-M</td>
</tr>
<tr>
<td>O/PM</td>
<td>Standing frames</td>
<td>O/PM-ST</td>
</tr>
<tr>
<td>O/PM</td>
<td>Walker</td>
<td>O/PM-W</td>
</tr>
<tr>
<td>O/PM</td>
<td>Daytime lying support</td>
<td>O/PM-D</td>
</tr>
<tr>
<td>O/PM</td>
<td>Gaiters</td>
<td>O/PM-G</td>
</tr>
<tr>
<td>O/PM</td>
<td>Parental upset</td>
<td>O/PM-PU</td>
</tr>
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</table>

### PROCESS OF INTRODUCTION OF SS

<table>
<thead>
<tr>
<th>PRO</th>
<th>Description</th>
<th>PRO-PT</th>
</tr>
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<tbody>
<tr>
<td>PRO</td>
<td>Therapist demonstrated</td>
<td>PRO-PT</td>
</tr>
<tr>
<td>PRO</td>
<td>Demonstration by company rep</td>
<td>PRO-CO</td>
</tr>
<tr>
<td>PRO</td>
<td>Laid in it only briefly</td>
<td>PRO-BT</td>
</tr>
<tr>
<td>PRO</td>
<td>Wait between trial period and getting own SS</td>
<td>PRO-W</td>
</tr>
<tr>
<td>PRO</td>
<td>Anticipation of confidence about using SS</td>
<td>PRO–C</td>
</tr>
<tr>
<td>PRO</td>
<td>Opportunistic because rep was in building</td>
<td>PRO-O</td>
</tr>
<tr>
<td>PRO</td>
<td>Child’s first impressions</td>
<td>PRO-IM</td>
</tr>
<tr>
<td>PRO</td>
<td>Trial of SS</td>
<td>PRO-TR</td>
</tr>
<tr>
<td>PRO</td>
<td>Parents’ message to child</td>
<td>PRO-ME</td>
</tr>
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### CHILD’S PAIN

<table>
<thead>
<tr>
<th>PN</th>
<th>Description</th>
<th>PN-S</th>
</tr>
</thead>
<tbody>
<tr>
<td>PN</td>
<td>Site and type of pain</td>
<td>PN-S</td>
</tr>
<tr>
<td>PN</td>
<td>Causes need for change of position at night</td>
<td>PN-POS</td>
</tr>
<tr>
<td>PN</td>
<td>Tiredness / activity and pain</td>
<td>PN-T/A</td>
</tr>
<tr>
<td>PN</td>
<td>Pain or behaviour?</td>
<td>PN-B</td>
</tr>
<tr>
<td>PN</td>
<td>Pain as possible cause of waking</td>
<td>PN-W</td>
</tr>
<tr>
<td>PN</td>
<td>Pain during the day</td>
<td>PN-D</td>
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### CHILD’S HEALTH PROBLEMS

<table>
<thead>
<tr>
<th>H</th>
<th>Description</th>
<th>H-REF</th>
</tr>
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<tbody>
<tr>
<td>H</td>
<td>Reflux</td>
<td>H-REF</td>
</tr>
<tr>
<td>H</td>
<td>Asthma</td>
<td>H-A</td>
</tr>
<tr>
<td></td>
<td>Chest infections</td>
<td>H-CI</td>
</tr>
<tr>
<td>---</td>
<td>------------------</td>
<td>------</td>
</tr>
<tr>
<td>H</td>
<td>Fits</td>
<td>H-FITS</td>
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**SUPPORT FOR PARENTS**

<table>
<thead>
<tr>
<th>SUP</th>
<th>From therapists</th>
<th>SUP-TH</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUP</td>
<td>From Paediatricians</td>
<td>SUP-P</td>
</tr>
<tr>
<td>SUP</td>
<td>From social worker</td>
<td>SUP-SW</td>
</tr>
<tr>
<td>SUP</td>
<td>Relationship between parents and therapists</td>
<td>SUP-REL</td>
</tr>
<tr>
<td>SUP</td>
<td>Trust in therapist</td>
<td>SUP-TT</td>
</tr>
<tr>
<td>SUP</td>
<td>For sleep</td>
<td>SUP-FS</td>
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**CHILD’S EXPERIENCE OF SS**

<table>
<thead>
<tr>
<th>CE</th>
<th>Independence / loss of</th>
<th>CE-IND</th>
</tr>
</thead>
<tbody>
<tr>
<td>CE</td>
<td>Mood / reaction to SS</td>
<td>CE-M</td>
</tr>
<tr>
<td>CE</td>
<td>Comfort</td>
<td>CE-COM</td>
</tr>
<tr>
<td>CE</td>
<td>Daytime concentration</td>
<td>CE-DTC</td>
</tr>
<tr>
<td>CE</td>
<td>Position</td>
<td>CE-POS</td>
</tr>
<tr>
<td>CE</td>
<td>Use of SS</td>
<td>CE-USE</td>
</tr>
<tr>
<td>CE</td>
<td>Trail of SS</td>
<td>CE-TR</td>
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</table>

**PARENTS’ EXPERIENCES / OUTCOMES FOLLOWING SS**

<table>
<thead>
<tr>
<th>PE/O</th>
<th>Lack of / achievement of goals</th>
<th>PE/O-AG</th>
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</thead>
<tbody>
<tr>
<td>PE/O</td>
<td>Perseverance</td>
<td>PE/O-P</td>
</tr>
<tr>
<td>PE/O</td>
<td>Timing of SS</td>
<td>PE/O-T</td>
</tr>
<tr>
<td>PE/O</td>
<td>Concerns re inhibition of movement</td>
<td>PE/O-M</td>
</tr>
<tr>
<td>PE/O</td>
<td>Message to child</td>
<td>PE/O-MES</td>
</tr>
<tr>
<td>PE/O</td>
<td>Accidents</td>
<td>PE/O-A</td>
</tr>
<tr>
<td>PE/O</td>
<td>Confidence in positioning in SS</td>
<td>PE/O-CON</td>
</tr>
<tr>
<td>PE/O</td>
<td>Position</td>
<td>PE/O-POS</td>
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**PRACTICALITIES OF SS ONCE ARRIVED**

<table>
<thead>
<tr>
<th>P</th>
<th>Nappy changing within SS</th>
<th>P-NC</th>
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<tr>
<td>P</td>
<td>Re-setting SS</td>
<td>P-RSET</td>
</tr>
<tr>
<td>P</td>
<td>Setting up process</td>
<td>P-SUP</td>
</tr>
<tr>
<td>P</td>
<td>SS design, drawbacks and attributes</td>
<td>P-DES</td>
</tr>
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</table>
### Thematic framework for views of therapists

- SS = sleep system
- PM = postural management
- OT = occupational therapist

#### CLINICAL REASONING

<table>
<thead>
<tr>
<th>CR</th>
<th>Gradual increase in PM</th>
<th>CR-INC</th>
</tr>
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<tbody>
<tr>
<td>CR</td>
<td>Which SS</td>
<td>CR-WHSS</td>
</tr>
<tr>
<td>CR</td>
<td>Which position</td>
<td>CR-WHPO</td>
</tr>
<tr>
<td>CR</td>
<td>Hip X-rays</td>
<td>CR-XRYS</td>
</tr>
<tr>
<td>CR</td>
<td>Outcomes for SS</td>
<td>CR-OUT</td>
</tr>
<tr>
<td>CR</td>
<td>Timing of SS</td>
<td>CR-TIM</td>
</tr>
<tr>
<td>CR</td>
<td>Assessment</td>
<td>CR-AX</td>
</tr>
<tr>
<td>CR</td>
<td>Risks</td>
<td>CR-RSK</td>
</tr>
<tr>
<td>CR</td>
<td>Evidence base for decision-making</td>
<td>CR-EVB</td>
</tr>
<tr>
<td>CR</td>
<td>History taking of sleep problems</td>
<td>CR-HIST</td>
</tr>
<tr>
<td>CR</td>
<td>Sensory issues</td>
<td>CR-SENS</td>
</tr>
<tr>
<td>CR</td>
<td>Processes/Pathways/Protocols</td>
<td>CR-PATH</td>
</tr>
<tr>
<td>CR</td>
<td>Which child</td>
<td>CR-WCH</td>
</tr>
<tr>
<td>CR</td>
<td>Knowledge of complex cases</td>
<td>CR-KNCC</td>
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<tr>
<td>CR</td>
<td>Ethos of PM in therapy team</td>
<td>CR-ETH</td>
</tr>
<tr>
<td>CR</td>
<td>Child motivated</td>
<td>CR-CM</td>
</tr>
<tr>
<td>CR</td>
<td>Postural management</td>
<td>CR-PMAN</td>
</tr>
<tr>
<td>CR</td>
<td>Parents motivated</td>
<td>CR-PM</td>
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#### TRAINING FOR PARENTS / PARENTAL MOTIVATION

<table>
<thead>
<tr>
<th>TR/PM</th>
<th>Knowledge/training</th>
<th>TR/PM-KN</th>
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</thead>
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<tr>
<td>TR/PM</td>
<td>Home environment/space</td>
<td>TR/PM-HE</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Family strengths</td>
<td>TR/PM-FS</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Follow up contact</td>
<td>TR/PM-FU</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Discipline and sleep hygiene</td>
<td>TR/PM-DIS</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Function and independence</td>
<td>TR/PM-F</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Therapist concerns of parental acceptance of SS</td>
<td>TR/PM-ACC</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Information-giving to parents</td>
<td>TR/PM-INFO</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Therapist's motivation</td>
<td>TR/PM-MOT</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Joint working</td>
<td>TR/PM-JW</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Partnership with parents</td>
<td>TR/PM-PP</td>
</tr>
<tr>
<td>TR/PM</td>
<td>Parental dependence on therapists’ decision making</td>
<td>TR/PM-ThDM</td>
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</table>

#### SLEEP HYGIENE

<table>
<thead>
<tr>
<th>SH</th>
<th>Parental discipline</th>
<th>SH-PD</th>
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<tr>
<td>SH</td>
<td>Team approach</td>
<td>SH-TA</td>
</tr>
<tr>
<td>SH</td>
<td>Therapists wanting to know more</td>
<td>SH-TMOT</td>
</tr>
<tr>
<td>SH</td>
<td>Continence</td>
<td>SH-CONT</td>
</tr>
<tr>
<td>-----</td>
<td>------------------</td>
<td>---------</td>
</tr>
<tr>
<td>SH</td>
<td>Sleep settling</td>
<td>SH-SS</td>
</tr>
<tr>
<td>SH</td>
<td>History taking</td>
<td>SH-HIST</td>
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</table>

**COMFORT**

<table>
<thead>
<tr>
<th>COM</th>
<th>Discomfort with use of other orthotics for sleeping</th>
<th>COM-ORTH</th>
</tr>
</thead>
<tbody>
<tr>
<td>COM</td>
<td>Comfort important</td>
<td>COM-IMP</td>
</tr>
<tr>
<td>COM</td>
<td>Comfort in SS</td>
<td>COM-SS</td>
</tr>
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</table>

**KNOWLEDGE AND EXPERIENCE OF THERAPIST**

<table>
<thead>
<tr>
<th>KN/EX</th>
<th>Very part-time</th>
<th>KN/EX-PT</th>
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</thead>
<tbody>
<tr>
<td>KN/EX</td>
<td>Few complex cases</td>
<td>KN/EX-CC</td>
</tr>
<tr>
<td>KN/EX</td>
<td>Lack of success with SSs</td>
<td>KN/EX-SUC</td>
</tr>
<tr>
<td>KN/EX</td>
<td>Of postural management</td>
<td>KN/EX-PM</td>
</tr>
<tr>
<td>KN/EX</td>
<td>Experience of SSs</td>
<td>KN/EX-SS</td>
</tr>
<tr>
<td>KN/EX</td>
<td>Ethos of PM in team</td>
<td>KN/EX-ETHOS</td>
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**MULTI-DISCIPLINARY TEAM APPROACH**

<table>
<thead>
<tr>
<th>MDT</th>
<th>With OTs</th>
<th>MDT-OT</th>
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</thead>
<tbody>
<tr>
<td>MDT</td>
<td>With paediatricians</td>
<td>MDT-P</td>
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</table>
**Chailey Sleep Questionnaire scores**

<table>
<thead>
<tr>
<th>Child number</th>
<th>Bedtime Routine</th>
<th>Night-time Behaviour</th>
<th>Breathing Quality at Night</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>2</td>
<td>High</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>3</td>
<td>High</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>5</td>
<td>Low</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>6</td>
<td>Low</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>7</td>
<td>Low</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>8</td>
<td>Medium</td>
<td>Medium</td>
<td>High</td>
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N/A = not available
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<tr>
<th>Question</th>
<th>YES</th>
<th>NO</th>
<th>YES</th>
<th>NO</th>
<th>YES</th>
<th>NO</th>
<th>YES</th>
<th>NO</th>
<th>YES</th>
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**APPENDIX 12A**

Chart 1: Process of Introduction to SS
<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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</thead>
<tbody>
<tr>
<td>What month is here?</td>
<td>January</td>
<td>January</td>
<td>January</td>
<td>January</td>
<td>January</td>
</tr>
<tr>
<td>What year is it?</td>
<td>2023</td>
<td>2023</td>
<td>2023</td>
<td>2023</td>
<td>2023</td>
</tr>
<tr>
<td>What day is it?</td>
<td>Monday</td>
<td>Monday</td>
<td>Monday</td>
<td>Monday</td>
<td>Monday</td>
</tr>
<tr>
<td>What time is it?</td>
<td>12:00 PM</td>
<td>12:00 PM</td>
<td>12:00 PM</td>
<td>12:00 PM</td>
<td>12:00 PM</td>
</tr>
<tr>
<td>What is the weather like?</td>
<td>Sunny</td>
<td>Sunny</td>
<td>Sunny</td>
<td>Sunny</td>
<td>Sunny</td>
</tr>
<tr>
<td>What is the forecast for today?</td>
<td>Sunny</td>
<td>Sunny</td>
<td>Sunny</td>
<td>Sunny</td>
<td>Sunny</td>
</tr>
<tr>
<td>What is the temperature?</td>
<td>70°F</td>
<td>70°F</td>
<td>70°F</td>
<td>70°F</td>
<td>70°F</td>
</tr>
<tr>
<td>What is the humidity?</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>What is the wind speed?</td>
<td>10 mph</td>
<td>10 mph</td>
<td>10 mph</td>
<td>10 mph</td>
<td>10 mph</td>
</tr>
<tr>
<td>What is the pressure?</td>
<td>30.02 in</td>
<td>30.02 in</td>
<td>30.02 in</td>
<td>30.02 in</td>
<td>30.02 in</td>
</tr>
<tr>
<td>What is the dew point?</td>
<td>60°F</td>
<td>60°F</td>
<td>60°F</td>
<td>60°F</td>
<td>60°F</td>
</tr>
<tr>
<td>What is the relative humidity?</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>What is the precipitation?</td>
<td>0.00 in</td>
<td>0.00 in</td>
<td>0.00 in</td>
<td>0.00 in</td>
<td>0.00 in</td>
</tr>
<tr>
<td>What is the sunrise time?</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
</tr>
<tr>
<td>What is the sunset time?</td>
<td>6:00 PM</td>
<td>6:00 PM</td>
<td>6:00 PM</td>
<td>6:00 PM</td>
<td>6:00 PM</td>
</tr>
<tr>
<td>What is the moon phase?</td>
<td>New Moon</td>
<td>New Moon</td>
<td>New Moon</td>
<td>New Moon</td>
<td>New Moon</td>
</tr>
<tr>
<td>What is the moon age?</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>What is the moon illumination?</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>What is the moon position?</td>
<td>West</td>
<td>West</td>
<td>West</td>
<td>West</td>
<td>West</td>
</tr>
<tr>
<td>What is the moon transit?</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
</tr>
<tr>
<td>What is the moon light?</td>
<td>Left</td>
<td>Left</td>
<td>Left</td>
<td>Left</td>
<td>Left</td>
</tr>
<tr>
<td>What is the moon phase?</td>
<td>New Moon</td>
<td>New Moon</td>
<td>New Moon</td>
<td>New Moon</td>
<td>New Moon</td>
</tr>
<tr>
<td>What is the moon age?</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>What is the moon illumination?</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.00%</td>
</tr>
<tr>
<td>What is the moon transit?</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
<td>6:00 AM</td>
</tr>
<tr>
<td>What is the moon light?</td>
<td>Left</td>
<td>Left</td>
<td>Left</td>
<td>Left</td>
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</tbody>
</table>

**Appendix B**

**Chapter 2: Sleep Hygiene**
<table>
<thead>
<tr>
<th>V/N</th>
<th>V/N</th>
<th>V/N</th>
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<tbody>
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<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
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<td>No</td>
<td>No</td>
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</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
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<tr>
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<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Where & out of SS

If yes, did you

Chart 4: Child’s willingness to adapt
<table>
<thead>
<tr>
<th>Chart 5: Parents' Readiness to Persevere</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
<td><strong>Definition</strong></td>
</tr>
<tr>
<td>Parental Engagement</td>
<td>The degree to which parents actively involve themselves in their child's education and development.</td>
</tr>
<tr>
<td>Parental Support</td>
<td>The extent to which parents provide emotional and practical support to their children.</td>
</tr>
<tr>
<td>Parental Involvement</td>
<td>The level of involvement parents have in their child's daily activities and responsibilities.</td>
</tr>
<tr>
<td>Parental Commitment</td>
<td>The degree to which parents are committed to their child's education and well-being.</td>
</tr>
<tr>
<td>Parental Communication</td>
<td>The effectiveness of communication between parents and their children.</td>
</tr>
<tr>
<td>Parental Influence</td>
<td>The influence parents have on their child's behavior and choices.</td>
</tr>
<tr>
<td>Parental Role</td>
<td>The roles and responsibilities parents assume in their child's life.</td>
</tr>
<tr>
<td>Parental Influence</td>
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<tr>
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</tr>
<tr>
<td>Parental Influence</td>
<td>The influence parents have on their child's behavior and choices.</td>
</tr>
</tbody>
</table>

**Note:** The chart highlights the importance of parental engagement and involvement in a child's education and development, which are critical factors in a child's readiness to persevere in challenging situations.
<table>
<thead>
<tr>
<th>Event</th>
<th>Description</th>
<th>Action</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child is hurting himself.</td>
<td>From perspective: The child is doing something.</td>
<td>Needing comfort and guidance</td>
<td>Child feels safe and cared for.</td>
</tr>
<tr>
<td>The child is hitting others.</td>
<td>From perspective: The child is causing harm.</td>
<td>Needing boundaries and redirection</td>
<td>Child respects others and learns limits</td>
</tr>
<tr>
<td>The child is kicking and screaming.</td>
<td>From perspective: The child is in distress.</td>
<td>Needing support and validation</td>
<td>Child feels understood and supported</td>
</tr>
<tr>
<td>The child is refusing to eat.</td>
<td>From perspective: The child is not willing.</td>
<td>Needing encouragement and alternatives</td>
<td>Child develops healthy eating habits</td>
</tr>
<tr>
<td>The child is hitting self.</td>
<td>From perspective: The child is expressing anger.</td>
<td>Needing guidance and emotional support</td>
<td>Child learns healthy ways to express emotions</td>
</tr>
</tbody>
</table>

**APPENDIX D**

**VAM** = vertical muscle contract

**SS** = static position

**OO** = object of the action
<table>
<thead>
<tr>
<th>Action</th>
<th>Supportive Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor hygiene</td>
<td>Good hygiene, proper clothing, frequent handwashing</td>
</tr>
<tr>
<td>Lack of knowledge</td>
<td>Good knowledge provided, frequent reminders</td>
</tr>
<tr>
<td>Overcrowding</td>
<td>Good space allocation, time management</td>
</tr>
<tr>
<td>No designated caregiver</td>
<td>Good caregiver assigned, supportive environment</td>
</tr>
<tr>
<td>No designated area</td>
<td>Good location provided, supportive environment</td>
</tr>
<tr>
<td>Inadequate follow-up</td>
<td>Good follow-up, supportive environment</td>
</tr>
<tr>
<td>No designated number</td>
<td>Good number provided, supportive environment</td>
</tr>
</tbody>
</table>

**APPENDIX 12E**
<table>
<thead>
<tr>
<th>Rich 10</th>
<th>Desired outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>IMP. M. 15</td>
<td></td>
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<tr>
<td>IMP. M. 14</td>
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<td>IMP. M. 13</td>
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<td>IMP. M. 12</td>
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<td>IMP. M. 11</td>
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<td>IMP. M. 10</td>
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<td>IMP. M. 7</td>
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<td>IMP. M. 4</td>
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<td>IMP. M. 2</td>
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</tr>
<tr>
<td>IMP. M. 1</td>
<td></td>
</tr>
</tbody>
</table>

To improve sleep:  
- Establish a bedtime routine
- Create a sleep-friendly environment
- Avoid stimulating activities before bedtime
- Limit screen time before bed
- Practice relaxation techniques

To improve diet:  
- Increase intake of fruits and vegetables
- Reduce consumption of sugary and fatty foods
- Stay hydrated
- Limit alcohol and caffeine intake
- Eat regular meals

To improve exercise:  
- Engage in regular physical activity
- Incorporate stretching and yoga
- Set achievable fitness goals
- Monitor progress and adjust as needed
- Stay motivated

To improve work-life balance:  
- Set clear boundaries between work and personal life
- Schedule time for hobbies and leisure activities
- Allocate time for relaxation and self-care
- Prioritize tasks and deadlines
- Seek support when needed

To improve social connections:  
- Foster meaningful relationships
- Engage in social activities
- Communicate effectively
- Offer support to others
- Accept help when needed

To improve emotional well-being:  
- Practice mindfulness and meditation
- Seek professional help if needed
- Cultivate positive thinking
- Express gratitude
- Engage in creative activities

To improve financial stability:  
- Create a budget
- Save for emergencies
- Reduce unnecessary expenses
- Invest wisely
- Seek financial advice when needed

To improve educational and professional development:  
- Set professional goals
- Seek opportunities for growth
- Continuously learn and develop new skills
- Network with peers and professionals
- Stay informed about industry trends

To improve personal health:  
- Practice good hygiene
- Engage in regular check-ups
- Follow healthy habits
- Manage stress effectively
- Seek medical advice when needed

To improve environmental sustainability:  
- Reduce waste
- Conserve resources
- Support sustainable practices
- Advocate for environmental causes
- Participate in community initiatives
<table>
<thead>
<tr>
<th>Problem</th>
<th>Description</th>
<th>Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Image]</td>
<td>[Image]</td>
<td>[Image]</td>
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<td>4</td>
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<tr>
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<td>N/A</td>
<td>N/A</td>
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<tr>
<td>Chart 12: Children's self-reported experiences of sleep before and after the introduction of a sleep system</td>
<td></td>
<td></td>
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</tbody>
</table>